Cancer Survivorship Care Plans: What Can Be Learned From Hospital Discharge Summaries?

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Abstract

The Institute of Medicine panel on cancer survivorship recommended that all patients with cancer and their primary care providers receive a written survivorship care plan that summarizes their initial treatment and provides guidance on post-treatment management. Cancer survivorship care plans aim to improve coordination of care and communication between providers as their patients transition from oncology to primary care settings. As such, survivorship care plans share similarities with hospital discharge summaries, focusing on improving the transition from inpatient to outpatient settings. In this article, we explore potential lessons that may be learned from hospital discharge summaries, which may be used to facilitate the development, implementation, and testing of survivorship care plans.

Introduction

Survivorship care plans (SCPs) aim to improve the transition of care from oncology to primary care settings[1] and share similarities with transitions from inpatient to outpatient settings, the latter facilitated through discharge summaries. Yet, although cancer survivorship care planning is in its infancy stages, hospital discharge summaries have benefitted from years of implementation, research, and more recently attempts at standardization. In this article, we describe the similarities and differences between hospital discharge summaries and SCPs (Table 1) and provide insights into potential lessons that may be learned. We focus on SCPs targeting providers; a discussion of SCPs tailored for patients is beyond the scope of this article.

Development

Although hospital discharge summaries are now required by The Joint Commission (TJC; formerly the Joint Commission on the Accreditation of Healthcare Organizations),[2] they were in existence for years before the requirement. The use and expansion of hospital discharge summaries were likely promulgated by a number of factors, including Medicare reimbursement and accreditation requirements,[3] focus on health care quality,[4] efforts to reduce errors,[5] and emergence of hospitalists.[6] Likewise, although communication between providers caring for patients with cancer has occurred for years via use of consultation letters, SCPs were proposed by the Institute of Medicine (IOM) as a means of providing a standardized summary of patients' cancer treatment and follow-up plans. The recommendation to develop SCPs was adopted by the American Society of Clinical Oncology (ASCO), also motivated by national quality initiatives and the contemporaneous 2005 hurricanes, which resulted in fragmentation of care when displaced cancer survivors sought care elsewhere.[7]

Standards

Hospital Discharge Summaries

The current TJC requirement specifies that hospital discharge summaries be completed within 30 days after discharge and that they include several key elements summarizing the reason for hospitalization, significant findings, treatment provided, and patient condition at the time of discharge. Guidance on the recommended elements have come from several sources, including surveys of primary care providers (PCPs), observational studies of discharge documentation and how deficits in the included elements may affect care, and regulatory requirements and consensus statements of professional organizations.[8,9] Currently, the recommended standard for hospital discharge summaries is the Care Transitions Performance Measurement Set, developed by consensus by the American Board of Internal Medicine Foundation, American College of Physicians, Society of Hospital Medicine, and Physician Consortium for Performance Improvement.[10] Table 2 presents elements for the recommended transition record and analogous elements that may be incorporated into SCPs.

Although mandated and now developed by multistakeholder consensus, empiric evidence to support each data element recommended for inclusion in the hospital discharge summary is mostly lacking. Some elements are deemed important for inclusion based on informational needs reported by PCPs,[8] whereas others are based on malpractice literature.[11,12] One study found a six-fold increase in readmissions at 3 months if workup errors occurred (ie, failure to perform recommended outpatient test or procedure), suggesting the importance of clearly documenting this information in discharge summaries.[13] Similarly, other studies have shown that pending tests at discharge is a common event with clear potential for patient harm,[14] although interventional studies to correct this problem are currently lacking. Lastly, several studies have demonstrated the potential harm of postdischarge medication discrepancies[15,16]; a few medication reconciliation interventions have resulted in decreased hospital readmissions.[17-19]

SCPs

Although the development of standards for hospital discharge summaries may have benefited from input from PCPs at the receiving end of the transition, to our knowledge, the process

Table 1. Similarities and Differences Between Hospital Discharges and Transitions of Care Among Cancer Survivors

Element	Hospital Discharge	Cancer Care Transition
Timing	Each discharge is a one-time event	Transition point may be less clearly defined; may be ongoing process over time
Transfer of responsibility	Essentially complete from inpatient to outpatient providers	May be incomplete and dynamic
Intended audience for transition summary	PCP and other responsible outpatient providers, although often used to guide care in subsequent hospitalizations	PCP and other responsible outpatient providers, including possible future oncology providers
Information needs	What next provider(s) should know to care for patient after transition, including recent condition of patient, care received, response to treatment, ongoing issues, tasks to be completed, and contingency planning	What next provider(s) should know to care for patient after transition, including recent condition of patient, care received, response to treatment, ongoing issues, tasks to be completed, and contingency planning
Reimbursement for summary	Indirect only through higher charges and fees for discharge day, likely undercompensated; may benefit from efforts to reform health care payment and organization	Creation of survivorship care plan is uncompensated, but visit with clinician is reimbursed; may benefit from efforts to reform health care payment and organization

Abbreviation: PCP, primary care provider.

for developing SCPs has not received sufficient scrutiny by this target audience, and SCPs had not been subjected to empiric research before the IOM recommendation. PCPs have noted that the transition from oncology has been fair or poor[20] and have been in favor of patient-specific standardized care plans or letters that may be completed in oncology settings.[7] Their reported information needs included type, frequency, and duration of surveillance tests, followed by information about possible adverse effects of treatment.[20] To what extent this research has influenced the inclusion of elements in SCPs is not clear.

Although the IOM did not mandate the specific elements to be included in the SCPs, the following were proposed: diagnostic tests performed and results; tumor characteristics; dates of treatment initiation and completion; types of treatment used, including agents, dosage, indicators of treatment response, and toxicities during treatment; psychosocial, nutritional, and other supportive services provided; contact information; and identification of a key point of contact and coordinator of continuing care. The IOM further recommended information about follow-up needs, including the likely course of disease; recommended screening and other testing; information about possible late and long-term effects of treatment; information about psychosocial implications, such as relationships, insurance, and employment; recommendations for healthy behaviors; genetic counseling; possible chemoprevention strategies; referrals for additional follow-up; and a listing of cancer-related resources.

Implications for SCPs

To our knowledge, whether the proposed information in cancer SCPs meets the needs of PCPs and/or other provider recipients has not been adequately evaluated. Furthermore, the effect of individual items on outcomes is not known. It is likely that the extent of information proposed by the IOM may be unnecessarily complicated and lengthy for a PCP,[21] who cares for a large panel of patients with chronic conditions and aims to coordinate care with numerous specialists.[22] However, oncologists may feel the need to write the plans not just for PCPs but also for future oncologists (in the same way that inpatient physicians may write discharge summaries in anticipation of the next hospitalization). Further complicating the task to create SCPs is the need to share them with patients, where the content, style, and presentation must be appropriately tailored. Hospital discharge materials now include specific instructions for patients, distinct from the summaries prepared for providers. It is important to determine the designated audience of the SCP and create it accordingly.

Table 2. Recommended Data Elements in Discharge Summaries and Applicability to Survivorship Care Plans

Discharge Summary Data Element	Survivorship Care Plan Equivalent
Key findings on discharge physical examination	Key findings from oncology specialist's physical examination, including mental status
Results of key tests, procedures, and studies	Results of key cancer-related tests, procedures, and studies (biopsy, staging studies, and so on)
Primary diagnosis	Cancer diagnosis (type, grade, stage)
Treatment received	Treatment received, planned, current and potential complications
Tests pending at discharge, who is responsible, how to obtain results	Tests to be done at time of plan, who is responsible, how to obtain results
Follow-up care needed, scheduled, who is responsible	Follow-up care needed or scheduled, when, who is responsible
Medication changes made and reason for changes	Medication changes made and reason for changes, what medications may interact with cancer treatment
Advance directives, content of discussion, reason for not having discussion	Advance directives, content of discussion, reason for not having discussion
Patient instructions	Patient instructions
24-hour contact information to call with emergencies related to hospitalization	Contact information of oncology provider(s)

Numerous templates for cancer SCPs have been (and continue to be) developed by ASCO, cancer centers, and other organizations and institutions. Testing with PCPs and/or other audience members for acceptability and use is needed. As may be gleaned from the hospital discharge experience, consensus and standardization of SCPs will ultimately need to be achieved.

Implementation

Hospital Discharge Summaries

A recent review assessed the quality of information transfer between inpatient and outpatient settings among 55 studies conducted between 1970 and 2005 (before the TJC requirement).[8] Most of the studies evaluated care delivered in medical inpatient services. The review found that direct communication between inpatient and outpatient physicians occurred only 3% to 20% of the time and often lacked information about diagnostic test results, treatment or hospital course, and test results pending at discharge. Follow-up plans were noted only 2% to 43% of the time. Although medical literature shows that discharge summaries are most useful when available by the time of the first postdischarge visit, the review found that in only 12% to 34% of patient cases was the discharge summary available at this time,[8] and in one study, outpatient physicians estimated that their management was adversely affected by delayed or incomplete discharge communication in 24% of patient cases.[23] Another study found that when the discharge summary was available, there was a 26% reduction in readmission rates.[24] Given these findings, the current TJC requirement that hospital discharge summaries be available within 30 days of discharge is inadequate. A more appropriate consensus was reached by the Care Transitions Performance Measurement Set, requiring that discharge summaries be transmitted to the designated follow-up provider within 24 hours of discharge.

Implications for SCPs

When should a cancer SCP be available to the PCP? This question has yet to be resolved. Although clearly this summary is needed at the time of a transition of care from active treatment, often patients continue to undergo active surveillance by their oncology providers (eg, patients with low-grade prostate cancer or those with indolent lymphoma). In such cases, a transition point is less clearly defined. Recently, a study conducted in the Surveillance, Epidemiology, and End Results–Medicare population showed that patients with advanced cancer are receiving unnecessary screening for other cancers and conditions.[25] This raises a question of whether SCPs are indicated for all patients with cancer at all stages of disease and phases of care. Developing SCPs for patients with advanced cancers (even if still undergoing active treatment or surveillance by an oncologist) may help their PCPs understand the severity of disease, estimated prognosis, and benefits of additional screening and/or treatment.

Personnel and Compensation Issues

Hospital Discharge Summaries

To our knowledge, hospital discharge literature has not addressed the issues of the clinician responsible for completing the discharge summary and compensation for the effort. Ideally, whoever knows the patient best and has the needed skills for this task should be responsible for generating discharge summaries; in most academic centers, this task usually falls on first-year interns. This may be problematic because they are the least-experienced clinicians on the inpatient team, do not have sufficient ambulatory care experience, and may not have the perspective to determine what information is required by postdischarge providers. Having interns write discharge summaries may also send the implicit message that this is an unimportant task. In one study, community hospitals performed better at including important data elements in discharge summaries, possibly because they were written by attending-level physicians and not interns.[9]

Whether the task of discharge documentation can be delegated to other clinical personnel is an ongoing question. To a first pass, discharge documentation has always been a multidisciplinary effort including input from care coordinators, nurses, and medical providers (the latter responsible for discharge summary and orders). More recently, interventions designed to expedite the discharge process and/or reduce readmissions have involved the use of dedicated personnel (eg, nurses or nurse practitioners) to play additional roles such as arranging follow-up appointments, educating patients and families, and writing discharge summaries and patient instructions. This approach has advantages and disadvantages, because it provides dedicated personnel with time to perform this process well, but it could lead to information loss and inefficiencies created by an additional handoff, delegation of responsibility, and differences in the skill sets of different clinical personnel.

Regarding compensation, hospitals and professionals do charge more on the discharge day, an acknowledgment of the additional time required for discharge planning. However, these tasks remain largely undercompensated, and this may at least partly explain the lack of attention to discharge summary quality and the delegation of tasks to lower-paid personnel. Under payment reform, including incentives for lower readmission rates or global payment systems such as those proposed by the Accountable Care Organizations initiative, incentives would be aligned to invest more resources in the discharge process.

Implications for SCPs

In oncology practice, much discussion has focused on having midlevel clinicians complete SCPs. It may be reasonable to argue that this is appropriate, because they likely have sufficient clinical experience to summarize the patients' care, may know the patients well (particularly their psychosocial issues), may not be as time-pressured as oncologists, and thus may be better able to pass on relevant aspects of their follow-up care. As with the use of additional providers in discharge planning, issues of delegation of responsibility, inefficiencies inherent in handoffs in care, and different skill sets of different personnel may offset some of the potential gains of this approach. Although current compensation models seem to be feasible for a survivorship-based office visit, as with hospitals, ongoing efforts in health care reform may lead to better alignment of financial incentives for the development of SCPs. Lastly, like hospital discharge summaries, SCPs

may in fact be mandated in the future, with or without specific compensation or changes in reimbursement models.

Evaluation and Efforts to Improve Quality

Hospital Discharge Summaries

Ongoing studies are using a variety of outcomes to evaluate the effectiveness of hospital discharge summaries via explicit measures of quality, such as inclusion of various data elements, measures of timeliness, patient-centered measures of the quality of transition (eg, using Care Transition Measure-3),[26] and receiving provider satisfaction. Tools to improve hospital discharge communication generally include templates, either on paper or dictation cards to solicit required data fields, or the use of health information technology. Health information technology tools often have the ability to actively solicit information through templated headings but can also auto-import administrative and/or clinical data from existing electronic sources. Other approaches include provider education and use of additional personnel, as described.

Kripalani et al[8] cited 18 intervention studies aimed to improve communication at discharge, including three randomized controlled trials. Almost all interventions to improve timeliness succeeded, including hand delivery of a discharge letter by the patient to the PCP,[27] generation of the discharge summary from information manually entered into a database,[28] and telephone calls to PCPs and educational booklets to patients and their PCPs.[29] Interventions to improve the quality of discharge communication, primarily through the use of computer-generated summaries, standardized dictation formats, or discharge templates, were also mostly successful. Recently, two studies of fairly sophisticated systems to create electronic discharge summaries were published,[30,31] but only one reported improvement in explicit measures of quality, timeliness, and provider satisfaction. Another multifaceted intervention composed of physician and nurse education, hospitalist training, physician feedback, and case manager review improved the inclusion of recommended elements.[32]

Implications for SCPs

Similar to hospital discharge summaries, in which evaluation and quality improvement occurred after implementation in clinical practice, SCPs are being put into practice before rigorous testing. As with hospital discharge summaries, the methods described here may improve the quality and timeliness of SCPs. SCPs may benefit from information already available in electronic medical records that may be pulled into a standardized tool. Although the transition of chemotherapy and even surgical treatment from inpatient to outpatient settings may have negatively affected communication, outpatient medical records may now serve as the optimal source of comprehensive oncology information. However, because most cancer care is provided in community-based practices that may not yet have electronic records, practices may still have to go through the cumbersome task of extracting information from paper medical records. Yet, as practices shift to electronic records, it is critical that the ease of generating SCPs be included in the planning.

As interventions to improve SCPs are being implemented, use of standardized forms and/or electronic templates with automated input of information from existing records should be strongly considered. Implementation efforts would also benefit from multidisciplinary provider education, feedback, and continuous quality improvement efforts designed to enhance the rates of completion and inclusion of key elements. Interventions need to be developed, tested, refined, and tested again. Outcomes to be studied should include process measures that are most sensitive to change, patient and receiving provider satisfaction measures, and measures of downstream outcomes and processes of care.

Conclusion

Discharge summaries grew from historical precedent. Standards developed organically over time and were later codified into regulatory requirements. Perhaps as a result of that history, standards remained inadequately specified for years. It is only recently that attempts have been made to reach consensus among stakeholders and specify requirements to the degree necessary to ensure a seamless transition in care. Another problem has been a lack of detailed measurement and reporting on the quality of discharge documentation. This has remained in the realm of research studies rather than an integral component of hospital processes. As a result, most hospitals have been able to meet minimum regulatory requirements, complying with the letter of the law while continuing to provide discharge documentation, with the multiple deficiencies noted here.

More recently, attempts have been made to develop standards with the input of PCPs, conduct more rigorous measurement of quality and outcomes, and develop interventions to improve discharge documentation. These interventions have led to better timeliness, increased inclusion of important data elements, and improved provider satisfaction. Few other outcomes (such as health care utilization) have been improved as a result of these efforts, but there is at least an association between successful completion of postdischarge follow-up plans and decreased readmission rates and a few interventions that have directly reduced readmissions (although mostly because of medication reconciliation efforts).

The IOM panel on cancer survivorship has issued guidelines on SCPs, and it is likely that cancer practice quality measures will soon include the completion of such care plans. Therefore, this is an opportunity to learn from years of development, implementation, and research on discharge summaries (Table 3). As standards for SCPs are developed, it is critical to include the input of the receiving clinician, generally the PCPs, who will have important feedback about the information desired and how it should be presented and when. As with discharge summaries, consensus building with respective professional organizations is needed. Furthermore, measurement of quality (as opposed to pro forma compliance) needs to be part of the evaluation process.

Compensation for SCP development will likely continue to be an issue. As with discharge planning, changes in health care organization and payment may favor efforts to develop

Table 3. Opportunities for Survivorship Care Plans Based on Lessons Learned From Hospital Discharge Summaries

Category	Hospital Discharge Summaries	Opportunities for SCPs
Development	Developed over years, eventually required by TJC	Not used in past, now being developed by individual hospitals/programs/practices
Standards	Standards originally inadequately specified, now becoming more specified with input of professional societies	Use being recommended by Institute of Medicine panel of cancer survivorship; standardization early on, with high degree of specificity, would likely simplify and streamline development of SCPs and maximize clinical impact
	Development of standards has taken into account views of PCPs on receiving end of summaries	Development led by oncology practices and organizations, with no or limited input by PCPs (key recipients of care plans); primary care and general internal medicine professional organizations need to play active role in development of SCPs
Implementation	To be most effective, summaries must be available within 24 hours, be brief, and provide key elements of information	Summaries may be initiated during treatment and forwarded to PCPs during that time; can be updated at end of treatment; should be available to primary care providers before upcoming patient visits
	Templates on paper forms or in EMRs can solicit input of certain data elements and increase reliability of inclusion of required information	Templates on paper forms or in EMRs should be capable of soliciting input of certain data elements and increasing reliability of inclusion of required information
	EMRs with standardized items that can be captured directly in discharge summary can make process easier	EMRs with standardized items that can be captured directly in discharge summary can make process easier
	Often completed by housestaff and/or physician assistants/nurse practitioners, but not clear if best suited	Whether SCPs may be delegated to other clinical personnel is ongoing question; if standardized items may be captured directly, then likely may be readily completed by nonphysicians
	Compensation for hospital discharge summaries not directly provided; may be affecting quality, delegation to housestaff and/or nonphysician clinicians	Compensation is area of ongoing concern; may be compensated in future, particularly if shown beneficial, but ultimately may be mandated without specific compensation
Evaluation and quality improvement	Mostly in the realm of research studies; individual hospitals generally report only what is required by TJC	Would benefit from measurement that is clinically relevant, comprehensive, built into care delivery, ongoing, and designed to lead to continuous improvement
	In studies, quality measures shown to correlate with reduced readmissions, and improvements in quality measures shown to increase completeness and timeliness of documentation and improve provider satisfaction; other outcomes being studied or under consideration	Need to define measurable outcomes, such as timeliness of both completion and receipt; services utilization (including appropriate follow-up testing successfully completed), patient and PCP satisfaction/knowledge

Abbreviations: EMR, electronic medical record; PCP, primary care provider; SCP, survivorship care plan; TJC, The Joint Committee.

and improve SCPs. But at some point, survivorship care planning may be simply considered to be part of quality care, just like hospital discharge summaries, and not be specifically compensated.

Although many similarities exist between hospital discharge summaries and SCPs, there are differences (Table 1). For example, each hospital discharge is a one-time event, where transfer of responsibility is essentially complete. In contrast, SCPs are part of a dynamic process. Patients may require more or less involvement from their oncologist and/or PCP over time; for some, care responsibility may never be completely transferred to the PCP. As such, SCPs may require continued updating and must be designed in a way that allows for this evolving process of care.

The oncology community is appropriately concerned about improving the quality and safety of patient care during clinical transitions, in this case from oncologists to PCPs. It would do well to take advantage of the work that has been done in improving patient care during other transitions, such as hospital discharges. If applied, the lessons learned from this body of work have the potential to inform the design and implementation of SCPs and improve cancer care quality, including coordination of care and communication between cancer and noncancer providers.

Accepted for publication on June 28, 2011.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

Author Contributions

Conception and design: All authors

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

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DOI: 10.1200/JOP.2011.000273; published online ahead of print at jop.ascopubs.org on November 22, 2011.

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