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Risk-Based Health Care, the Cancer Survivor, the Oncologist and the Primary Care Physician

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Abstract

Cancer survivors face substantial risks for morbidity, reduced quality of life, and premature mortality related to the cancer itself and/or the interventions undertaken to control cancer. Risk-based care that involves a personalized systematic plan of periodic screening, surveillance, and prevention relevant to the cancer experience is recommended to address the comprehensive health needs of the growing population of cancer survivors. Risk-based care and coordination between oncology and primary care providers have been identified as important metrics of quality cancer survivorship care. Various models of survivorship care, treatment summaries and survivorship care plans have been promoted as methods to facilitate communication among providers across care transitions and improve survivor access to quality survivorship care. However, research supporting the feasibility of implementing these practices and their effectiveness in enhancing health outcomes is limited. This article reviews key concepts underpinning clinical and research initiatives endeavoring to improve access to quality care among long-term survivors and summarizes results of intervention studies implementing these elements in transitioning survivors from oncology to primary care providers for long-term follow-up care.

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INTRODUCTION

Contemporary therapy produces long-term survival for almost 65% of individuals diagnosed with cancer in the United States. This growing population of survivors, estimated to reach 20 million by 2020,¹ faces substantial risks for morbidity, reduced quality of life, and premature mortality related to the cancer itself and/or the interventions undertaken to control cancer. Follow-up of cancer survivors after therapy continues to be important, not only to accurately characterize cancer-related morbidity, but also to facilitate timely diagnosis of cancer-/treatment-related complications and implement remedial or preventive interventions to preserve health.^{2,3} Considering the heterogeneity of cancer and ongoing evolution of therapeutic approaches, risk-based health care has become one of the benchmarks for quality survivorship care recommended by the Institute of Medicine (IOM).² Risk-based care involves a systematic plan of periodic screening, surveillance, and prevention that considers a survivor's personal health risks predisposed by the previous cancer and its treatment, genetic and familial factors, comorbid health conditions and lifestyle behaviors.^{2,3} As such, implementing risk-based care requires knowledge about specific cancer histology, therapies received, and potential treatment effects to guide surveillance, screening and counseling. Ideally this information is organized in a cancer treatment summary that is a component of a broader survivorship care plan delineating the roles of oncology and primary care providers sharing responsibility for survivor care.

Because diagnostic and treatment details and their associated health risks may not be known or understood by survivors or their providers, applying the tenets of risk-based care is often challenging for providers. Inadequate reimbursement, suboptimal education, and poor communication contribute to these deficiencies, as well as limitations in published research evaluating late health outcomes following cancer treatment.⁴ What is known is that extended survival following diagnosis of cancer has resulted in increasing numbers of individuals who may benefit from, but are not routinely receiving risk-based assessment, preventive services and counseling regarding risk reduction measures pertinent to their cancer experience.⁵⁻⁸ Moreover, coordination of care among oncology and primary care providers is lacking for many survivors, which may lead to inefficiencies in care, increased health care costs, and missed opportunities for health promotion. Herein, we review key concepts underpinning clinical and research initiatives endeavoring to improve access to quality care among long-term survivors and discuss research results of intervention studies implementing these elements to improve survivor care transitions between oncology and primary care providers.

THE EVOLUTION OF MODELS OF CARE

Beginning with the publication of the 2005 Institute of Medicine report, there has been an increasing focus on the development of formal programs and services - models of care - designed to address the comprehensive health care needs of cancer survivors.² Recent reports and publications have put forth recommendations for a variety of configurations for the delivery of post-treatment follow-up.^{9,10} This acknowledgment that survivors are in need of care that goes beyond surveillance for recurrence has resulted in formal services that are based on evidence about the incidence of long-term and late effects and the resulting need for interventions in specific survivor populations. Initially, these programs were limited to

academic medical centers, such as the seven institutions designated as LIVESTRONG Survivorship Centers of Excellence, but there is now rapid growth in survivorship services in community hospitals and practices as well.^{11,12} In 2007, the National Cancer Institute (NCI) initiated the NCI Community Cancer Center Program and included the development of survivorship services as an evaluation metric for the 21 community cancer centers in 16 states.¹³ For the last decade, the Centers for Disease Control and Prevention has promoted the development of survivorship as part of the state comprehensive cancer control plans. Currently all fifty states have plans and 88% of these states include survivorship services as a focus with the goal of encouraging action among health provider and patient groups.¹⁴

Since formal, multidisciplinary follow-up programs have long existed for survivors of pediatric cancers, this model was initially replicated in cancer centers for the follow-up care of survivors of adult-onset cancers. This model is resource intensive and is most effective in caring for small groups of survivors with complex health care needs.¹⁵ Thus, in the United States (US), Europe, Australia and Canada a number of new models for adult survivors are being implemented and evaluated.^{10,16-19} Each has a different approach based on the patient population, type of follow-up and type of provider. In some institutions and practices, the clinic is disease-specific, such as a breast cancer survivor clinic. Or a clinic may be intervention-specific and focus on the unique needs of a group treated with a particular intervention, such as a clinic for the follow-up care of bone marrow transplant patients.^{10,20,21} Both of these models offer specific expertise in the identification and management of long-term and late effects and are established for the follow-up of complicated patients or specific disease groups that have a large number of survivors. Other clinics provide follow-up for survivors of different cancers and use either a consultative or longitudinal model. The consultative model allows for ongoing care by the oncologist or primary care physician (PCP), but provides a one-time consultation that includes: the provision of a treatment summary and care plan for both the patient and PCP, a comprehensive health assessment with recommendations for specialized services, if needed, and tailored surveillance information. In the longitudinal model, the patient is transitioned from the oncologist at a point when the risk of recurrence is decreased and the immediate effects of therapy have resolved, usually one to five years after treatment. During this initial period, ongoing oncology care is provided with a focus on the identification and management of late effects, appropriate screening for second cancers, health promotion counseling and the provision of a treatment summary and care plan. The care in each of these models is provided by a physician (primary care or oncologist) or, increasingly, by non-physician providers (nurse practitioners or physician assistants).^{10,20-23}

To date, there have been limited evaluations of these models to determine which type of care model is most effective for a particular survivor population.⁹ This current paucity of data presents an important challenge to the community of health services researchers since the development of best practices for the structuring of post-treatment services across health care systems is increasingly important because of the burgeoning number of survivors and because of the changes in health care delivery under the Affordable Care Act.²⁴⁻²⁶

RISK-STRATIFIED SURVIVORSHIP CARE

Regardless of the type of survivorship care model, a risk-stratified approach to care is a critical component in assuring that follow-up services are based on the risk of long-term and late effects, cancer recurrence and second primaries.²⁷ (See Figure 1) This risk stratification addresses the important questions of – who needs to be followed, by whom and for what duration, and by what modalities and frequency? Such an approach optimizes the provision of health care resources by identifying services and specialty provider by need. For example, a portion of survivors have mild or no persistent toxicity of therapy, are at low risk of recurrence and are at minimal risk of late effects. In contrast, there are other survivor groups that are at high risk of recurrence and/or who have severe organ dysfunction persisting after treatment ends or who are at high risk of serious late effects, such as cardiovascular and pulmonary disease, causing premature mortality. In the center of this continuum of risk are most cancer survivors who are at moderate risk of recurrence and who may have moderate toxicity from cancer treatment. A survivor's position in the continuum may also be influenced by the presence of comorbid health conditions, health care access, psychosocial support, and availability of rehabilitative health services. The anticipated health care needs of each of these survivors across this continuum differ markedly. However, until recently, oncologists have followed all survivors in the same way with little attention to the distinctions among these three groups. Continuing such a generic approach to care is fiscally untenable and makes inefficient use of resources. On an individual level, it likely results in under-treatment of some individuals and encourages others to be unnecessarily reliant on their oncologists.⁶ Thus, an important component of establishing new models of survivorship care is the incorporation of a risk-based approach that will guide the intensity of services provided during the post-treatment period, focus referrals to the medical and psychosocial issues of importance, and determine the type of health care professional best suited to provide the needed care.

Another important element of these new delivery models is the application of evidence-based guidance for surveillance and the management of long-term and late effects. To date, this information has been lacking except for a few cancers and specific medical problems. Fortunately, the American Society of Clinical Oncology (ASCO), the American Cancer Society and the National Comprehensive Cancer Network are working to develop surveillance guidelines and clinical guidance for the identification and management of survivorship issues using a symptom-based approach.

THE ROLE OF THE PRIMARY CARE PHYSICIAN

Critical to the success of any model of care is the coordination and sharing of care between the oncology specialist and the PCP.²⁸ Yet, there are real and perceived barriers to actualizing this approach and published surveys have identified concerns about PCP lack of knowledge and disagreement about management preferences among oncologists, survivors and primary care physicians.²⁹⁻³² In contrast to oncology, there are well-established examples in the US where specialists and PCPs share the care of patients with chronic disease, such as diabetes and hypertension.^{33,34} And recent studies have found that cancer and non-cancer preventive services are more likely to be provided when the survivor is

followed by both an oncologist and PCP rather than a single provider.^{5,6,8} In Europe plans have been developed for the PCP to share care beginning at diagnosis so that once treatment is complete, a risk-based plan of care can be implemented with the PCP assuming survivorship care as part of a comprehensive rehabilitation program.^{18,35} Combining a risk-stratified approach with the shared-care of survivors provides clear direction for the ideal co-management between the oncologist and PCP, with the goal of optimizing the long-term health of the cancer survivor, but implementation poses significant challenges considering the burden imposed by the declining numbers of primary care providers.

RESEARCH EVALUATING MODELS OF SURVIVORSHIP CARE

The multi-faceted aspects of survivorship care described in this paper should ideally be tested through rigorous high quality intervention studies. However, currently there are few studies that involve randomized comparisons of different approaches to providing survivorship care, and none that explicitly test a multi-faceted risk-stratified approach based on survivor risk for adverse outcomes like recurrence or late effects. A recent systematic review identified 11 randomized controlled trials testing different models of survivorship care.³⁶ These trials provide us with some understanding of the issues related to transitioning survivors from traditional oncology care to another provider for long-term follow-up care.

Comparison of oncologist to primary care physician-led care

There are five trials that compared usual oncologist care to primary care led care of cancer survivors. Three of these trials studied breast cancer patients,³⁷⁻³⁹ one studied patients with melanoma,⁴⁰ and one studied patients with colon cancer.⁴¹ These trials, all of which involved patients discharged from the formal cancer system to the PCP in the community, measured a range of outcomes including clinical outcomes such as the rate of serious recurrence-related clinical events, time to detection of recurrence, adherence to guidelines, as well several domains of health-related quality of life and satisfaction.³⁶ Collectively, study results found no important differences among any of the outcomes measured, but did support the feasibility, acceptability, and safety of transitioning these survivor groups to primary care in the community. Of note, in each of these studies the PCPs received relevant guidelines on follow-up. This points to the importance of ensuring that PCPs are provided with the necessary knowledge and tools to assume the role of principal provider of follow-up. For most cancer types and for several aspects of survivorship care, however, there is a limited knowledge base on the multi-faceted aspects of survivorship care such as the optimum elements of follow-up (e.g., frequency of visits, frequency and types of surveillance tests) management of long-term effects, and identification and management of late-effects. This deficit makes it difficult to develop truly evidence-based guidelines upon which to build the interventions. It is important to correct this limitation through further research.

Comparison of oncologist to nurse led care

The systematic review³⁶ identified six trials evaluating nurse-led follow-up care.⁴²⁻⁴⁷ Each of these trials was institution-based, as they included patients who were not formally transitioned to the community.³⁶ Rather, a trained nurse based within an institutional setting

provided on-demand or telephone follow-up. The outcomes studied included quality of life domains, satisfaction, and resource utilization. These studies also support the feasibility, acceptability and safety of an alternative to oncologist-led follow-up.^{48,49}

Cancer types studied

As summarized above, the majority of trials involved breast cancer patients. Prostate, colon, esophageal, and melanoma were each the subject of one trial. It is clear from this review that it is imperative to broaden the focus of research to include patients with cancer types that are understudied but have specific and complex needs such as, for example, gynecological cancers and head and neck cancers.

Risk-stratified approaches

Although tailoring follow-up survivorship care based on risk for adverse outcomes is widely considered to be the way forward,²⁷ rigorous evaluations of this risk-stratified approach have not yet been published. Of the trials reviewed above, only one explicitly stated disease recurrence risk as an inclusion criteria (low to moderate risk of recurrence⁴²) and none considered other aspects of risk such as psychosocial adjustment and risk of long-term or late-effects of treatment. In the United Kingdom, the National Cancer Survivorship Initiative is predicated on a risk-stratified approach¹⁸ and the assessment tools that have been developed to underpin it will facilitate further research. Rigorous research is the key to determining the effectiveness of survivorship care that is tailored to the specific risk profile of the individual patient, the cost implications, and the feasibility of widespread implementation of such an approach. Such evaluations are of interest at the National Institutes of Health where the conduct of comparative effectiveness research within integrated health care delivery systems is a focus.⁵⁰

A framework for cancer survivorship research that explicates elements that are common to all cancer survivors and elements that are unique as determined by the type of cancer, the specific treatments, and the complexity of individual patient factors can facilitate development of a research program predicated on a risk-based approach.⁵¹ Integral to such a research program is the need to develop: 1) valid and reliable tools to stratify patients into risk categories (considering risk of recurrence, psychosocial risk, risk of long-term and late-effects) that are practical to use both in the clinical and research settings; and 2) valid and reliable outcome measures that assess the range of domains of interest that are sufficiently sensitive to detect clinically important differences.

TREATMENT SUMMARIES AND SURVIVORSHIP CARE PLANS

One of the major recommendations from the IOM was for every cancer survivor to receive a care plan which contains a personal treatment summary, possible late and long-term effects, signs of recurrence, guidelines for follow-up care, identification of providers, lifestyle recommendations and supportive resources.² This recommendation was made based on the high face validity that provision and sharing of such information among providers, patients, and caregivers would improve the quality of cancer survivorship care and the assumption that harms were minimal. Given the generally widespread support of the concept, a number

of versions of treatment summaries and survivorship care plans have been developed. Some care plans have been developed for specific health care systems and others have been developed for more widespread adoption with many in the public domain. Professional oncology associations as well as philanthropic organizations have been particularly instrumental in creating care plans that either a patient or provider can complete and utilize as a resource, record, and communication tool.

In general, available survivorship care plans cover the issues that were specifically recommended in the IOM report although they vary substantially with regard to their design, length and detail, as well as the primary audience for whom they are intended. (See Table 1 for the IOM-recommended ideal elements to include in a survivorship care plan.) For example, ASCO has developed a generic care plan template as well as certain disease specific templates (e.g., breast and colon) that consist of a concise 3 page grid-like design focused on conveying specific details including treatments received, recommendations for follow-up and identification of providers. These downloadable templates are designed to be populated by providers and serve as a communication tool between providers and patients. In contrast, the LiveStrong Care Plan, which is powered by Penn Medicine's OncoLink, is a web application with associated database for storing of information for potential analyses. The application is designed for patients to develop their own care plan, to be reviewed by their healthcare team. When completed, the LiveStrong Care Plan is approximately 14 pages in length and includes relevant educational text with embedded links to additional informational and supportive care resources. The Journey Forward is another comprehensive care plan designed based on the ASCO template and guidelines to be a more patient-oriented communication tool and resource repository that is designed to be populated by a health care provider for patients. The Journey Forward provides a reader friendly treatment summary and recommendations for follow-up as well as further details regarding risks of long-term and late effects that patients may face in light of their cancer and treatment history. This care plan developed through a public-private collaborative group also provides numerous links to relevant educational and supportive care resources for patients.

The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers (COG Guidelines) include comprehensive and abbreviated electronic treatment summary templates for providers and survivors that include all of the data elements currently necessary for generation of patient-specific health screening recommendations.⁵² The abbreviated template meets the minimum data requirements to interface with the web-based application Passport for Care (PFC). PFC is designed to provide childhood cancer survivors and their providers with a summary of their cancer history and treatment which then drives algorithms to produce individualized monitoring and management recommendations derived from the *COG Guidelines*.⁵³ The computer interface includes both patient friendly printout options, efficient lists for providers, as well as levels of expert consensus for each recommendation and associated references. The PFC tool is only accessible to COG members and accessed via a HIPAA compliant password protected website. In the coming years, the plan is for the PFC to be available to all COG clinics and the hope is that future research using this tool will

determine whether its routine use improves health behaviors and outcomes in this population.

VALUE AND USE OF CARE PLANS

Available evidence suggests care plans are well received by patients and providers both at beginning and end of care.⁵⁴⁻⁵⁶ However, to date, there has been only limited uptake of care plans in routine clinical practice. In a survey of all 53 NCI-designated cancer centers that treat adult cancer patients, Salz and colleagues found that only 43% delivered care plans to survivors of colon and breast cancer. Further, among those that were able to estimate the proportion of eligible patients who received care plans at their institutions, 52% reported that fewer than half received them.⁵⁶

The lack of routine uptake is undoubtedly due in part to a lack of consensus on the optimal content, timing, and mode of sharing care plans for cancer survivors. However, the greatest barriers to routine implementation are practical issues: lack of time and manpower, lack of a system in most settings to complete a care plan for each cancer survivor and the fact that there is no financial model or reimbursement source that supports such a model at this time. Further, there is virtually no level one evidence to date that care plans improve important patient outcomes. In fact, one large randomized controlled trial evaluating the effects of a care plan compared with a standard discharge visit prior to transferring breast cancer survivors to primarily PCP care showed no difference in patient-reported outcomes.³⁷ In light of these findings and the barriers to routine implementation of the IOM-recommended care plan model, there have been calls to “not let the perfect be the enemy of the good” with regard to improving the delivery of survivorship care.^{4,57} Efforts are currently underway in many systems to connect cancer survivors and their providers with the information and resources they need in a manageable way and to determine the true costs and benefits of such systems. Future research to implement and evaluate the routine use of care plans in diverse disease and treatment settings is clearly warranted.

SUMMARY AND FUTURE DIRECTIONS

Great progress has been made over the last decade in increasing awareness about the unique health issues related to cancer survivorship and the need for quality survivorship care. However, this awareness has not positively impacted health care quality or health outcomes among large numbers of survivors.⁵⁷ The IOM and other groups have proposed metrics for quality care that address the medical and psychosocial consequences of cancer, but implementation of the recommended practices on a broad scale has not been feasible due to clinician workload burden and lack of equitable reimbursement for survivorship services. Moreover, data is lacking to support that such care indeed enhances quality and length of survival. Because the evidence base defining optimal survivorship care is limited, research is required to address knowledge gaps in multiple areas. Characterization of long-term and late health outcomes after cancer is essential to improve the quality of survivorship care evidence and guide surveillance and screening measures that should be performed by providers caring for long-term survivors. Well-designed and conducted studies that directly compare follow-up models are needed to provide the evidence for the optimal care for

particular groups of survivors, understanding that there is not likely to be one model for all adult cancer survivors. The development of valid and reliable assessment tools that are easy to use in both the clinical and research settings is also important to facilitate systematic evaluation of the needs of patients and identify unmet needs. Research is also needed to assess the effectiveness and feasibility of methods to facilitate education and communication across survivorship care transitions. Importantly, all avenues of research should consider the diversity of cancer types, patient populations, and health care environments to optimize dissemination and implementation of quality survivorship care.

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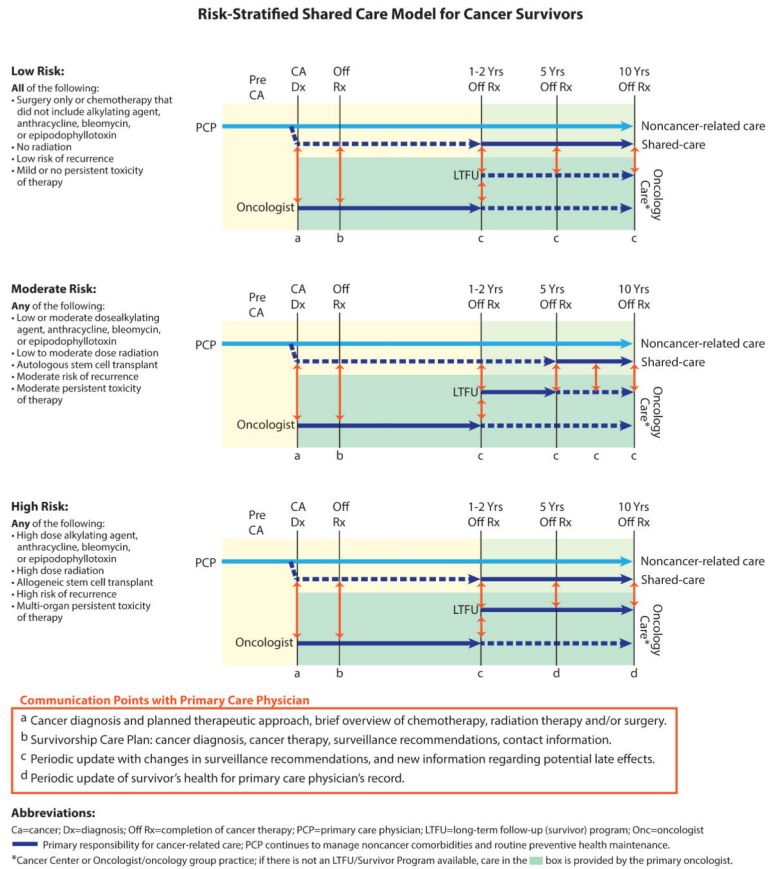


Figure 1. A risk-stratified shared care model for cancer survivors assigns follow-up services based on the risk of long-term and late effects, cancer recurrence and second primaries. Roles and responsibilities of the oncology and primary care provider are defined across the survivorship spectrum from diagnosis to long-term follow-up. Such an approach optimizes the provision of health care resources by identifying services and specialty provider by need. Modified and adapted, with permission, from Oeffinger KC and McCabe MS, *J Clin Oncol*, 2006.

Table 1

Ideal Elements to Include in a Survivorship Care Plan*

Main Element	Specific details
Record of Care	Diagnostic tests performed and results
	Tumor/disease characteristics
	Dates of treatment initiation and completion
	All treatments received (e.g., surgery, chemotherapy, radiotherapy, transplant, hormonal therapy) including agents used, regimen including total dosage and specifics of clinical trials, if enrolled
	Indicators of treatment response and toxicities experienced with treatment
	Psychosocial, nutritional, and other supportive services provided
	Full contact information for key providers and treating institutions; Identification of key point of contact and coordinator of continuing care
Follow-up care plan incorporating evidence-based standards of care	Likely course of recovery from toxicities of treatment/disease
	Recommended periodic testing and examinations including cancer screening and schedule as well as who should provide them
	Referrals to specific follow-up care providers, support groups, and/or patient's primary care provider
Information addressing:	Possible late and long-term effects and symptoms of such effects
	Possible signs of recurrence and second cancers
	Possible effects of cancer on relationships, sexual functioning, work, parenting and potential future need for psychosocial support
	Potential insurance, employment, and financial consequences and counseling, legal aid and financial assistance resources
	Genetic counseling and testing when appropriate and recommendations for family members re: genetics and screening when appropriate
	Recommendations regarding optimal health behaviors, secondary prevention options (e.g. chemoprevention)
	Cancer related resources and information (e.g. web-based sources and telephone listings for support organizations)

* adapted from Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press; 2006.