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Survivorship Care Planning in Colorectal Cancer: Feedback from Survivors & Providers

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Abstract

The IOM recommended that all patients receive survivorship care plans (SCPs) post-treatment to improve quality of follow-up care. However, little is known regarding how survivors utilize SCPs and the congruency between providers' and survivors' perspectives. Feedback from colorectal cancer survivors (in receipt of a personalized/individualized SCP) and oncology providers was obtained via interviews. Survivors noted SCPs benefits of reduced duplicative procedures and cancer worry with the synthesized treatment information. Providers noted billing/reimbursement and time investiture (for form completion) as potential barriers. Further investigation of survivorship care plans is warranted regarding utility prior to widespread adoption in follow-up care.

Introduction

Adult cancer survivorship has been relatively neglected in advocacy, education, clinical practice, and research (Hewitt, Greenfield, & Stovall, 2006). This of particular importance, given there are currently more than 12 million people in the United States (U.S.) who are considered cancer survivors (CDC, 2004a; CDC & LAF, 2004b; Jemal, Siegel, Xu, & Ward, 2010; Reuben & Leffall, 2006). By 2030, it is estimated this burgeoning cohort will surge to 22 million cancer survivors (ACS, 2010; CDC, 2004a) due to the aging of the population and ongoing advances in detection and treatment. The transition from active treatment to survivorship is a critical period within the cancer trajectory. It is during this transition when many survivors realize the medical and psychological effects of cancer and its treatment. The survivorship phase is dynamic and provides opportunities to improve the health and quality of life of cancer survivors. However, many survivors are unaware of the exact treatment they received, much less their heightened health risks, leaving them ill-equipped to effectively manage the late and long-term effects of cancer treatment (Hewitt et al., 2006).

Based on recent trends, it is estimated 1 in 20 adults will be diagnosed with colorectal cancer during their lifetime, making it the third most common cancer in the U.S. (143,000 new cases in 2010) (ACS, 2010; CDC, 2004a; Jemal et al., 2010). With an estimated 84%

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survival rate (12-mos post-treatment), most adults diagnosed with colorectal cancer will become long-term survivors, yet up to 40% will later go on to develop recurrent disease (Evans et al., 2002; Green et al., 2002). Commensurate to the increased risk for recurrence and new primary tumors, nearly 25% of colorectal cancer survivors report worry and/or fear of disease recurrence. Adverse sequelae are also common among colorectal cancer survivors, inclusive of depression (37%), chronic fatigue (23%), body image concerns (14%), bowel dysfunction (diarrhea 13%, constipation 7%), and sexual dysfunction (vaginal dryness, erectile dysfunction 25-45%) (Ramsey, Berry, Moynour, Giedzinska, & Andersen, 2002; Rauch, Miny, Conroy, Neyton, & Guillemin, 2004; Sprangers, Taal, Aaronson, & te Velde, 1995). Given these medical/physiological and psychosocial sequelae, there is a significant need for ongoing quality follow-up care to optimize long-term outcomes (survival, quality of life, and symptom management) of colorectal cancer survivors.

Consensus-based recommendations for surveillance of colorectal cancer have been developed by the American Society of Clinical Oncology (ASCO) (Desch et al., 2005) and the National Comprehensive Cancer Network (NCCN) (Engstrom et al., 2009a, 2009b; NCCN, 2011). However, up to 40% of colorectal cancer survivors do not receive the recommended surveillance (Hewitt et al., 2006). Many cancer survivors are lost to systematic follow-up, resulting in fragmented, uncoordinated care after the completion of treatment (Hewitt et al., 2006). Studies have indicated discordant expectations and confusion regarding cancer survivorship care, e.g., disagreement among survivors, oncologists, and primary care physicians regarding which health care provider is responsible for screening non-index cancers and managing ongoing symptoms stemming from cancer treatment (Cheung, Neville, Cameron, Cook, & Earle, 2009; Grunfeld & Earle, 2010; Snyder et al., 2008). In contrast to their increasing involvement, primary care physicians indicate significant barriers to providing quality care for survivors such as inadequate, ill-defined follow-up guidelines (82%) and a lack of formal preparation/training in cancer survivorship (50%) (Bober et al., 2009).

Institute of Medicine's (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006), highlighted gaps between the needs of survivors and current practice. Four essential components of survivorship care were delineated: prevention, surveillance, intervention, and coordination of care. Specifically, the IOM noted that cancer survivors need support in order to prevent/detect cancer recurrence, address treatment-induced effects, and coordinate necessary follow-up care between oncology providers, non-oncology specialists, and primary care providers (Hewitt et al., 2006). To address these supportive needs, IOM recommended that all patients receive treatment summaries and survivorship care plans (hereafter collectively referred to as "TS/SCPs") after completion of primary treatment (Hewitt et al., 2006; Institute of Medicine, 2007). The TS/SCP comprises a comprehensive, synthesized cancer care record (treatment summary denoting diagnosis, stage, primary treatments, and toxicities or side effects) accompanied by Oncology Provider recommendations for: surveillance testing, management of long-term treatment effects, monitoring for potential late effects, prevention and health promotion, and designation of physician(s) responsible for monitoring each health domain (Earle, 2006; Faul, Shibata, Townsend, & Jacobsen, 2010; Ganz, Casillas, & Hahn, 2008; Institute of Medicine, 2007). TS/SCPs aim to facilitate a seamless transition from cancer patient to survivor by 1) improving patient knowledge of their cancer care history, and awareness of necessary follow-up care; 2) increasing patient confidence in obtaining appropriate care post-treatment; and 3) aid communication with and among providers (Earle, 2006; Faul et al., 2010; Ganz & Hahn, 2008; Hewitt et al., 2006). Other benefits from care plans may include decreased symptom burden (physical and emotional), prevention/reduction of treatment side effects, increased adherence to surveillance, and increased survival (Hewitt et al., 2006). Since the IOM report, many organizations have created survivorship care plans and

survivorship resources such as the American Society of Clinical Oncology, National Comprehensive Cancer Network, American Cancer Society, National Cancer Institute, LIVESTRONG, Center for Disease Control, Oncology Nursing Society, National Coalition for Cancer Survivorship, and WellPoint/Journey Forward.

Care plans and treatment summaries are becoming a standard of survivorship care (ACoS, 2011; Stricker et al., 2011; Hahn & Ganz, 2011). Recently, the American College of Surgeons' (ACoS) Commission on Cancer announced intentions to mandate survivorship care plans among its accredited cancer programs by 2015 (ACoS, 2011). Yet, despite recommendations by the IOM, ASCO, and ACoS and available/accessible templates, these forms (TS/SCPs) are not widely adopted in oncology settings (Casillas et al., 2011; Eshelman-Kent et al., 2011). Stricker and colleagues (2011) assessed delivery of care plans to breast cancer survivors within 13 dedicated survivorship care centers, 7 NCI-designated comprehensive cancer centers and 6 community-based centers participating in the LIVESTRONG Survivorship Centers of Excellence (COE) network. Fewer than 10% of eligible breast cancer survivors were receiving care plans across these COE sites. Of the sites providing the forms, it was noted that the care plans routinely lacked IOM-recommended content. Absent/omitted from the forms was: a) designation of the provider responsible for coordinating follow-up cancer care, b) contact information for the follow-up care provider(s), c) signs of recurrence and secondary cancer, d) psychosocial effects, and e) prevention and health promotion recommendations (Stricker et al., 2011).

Care plans and treatment summaries are increasingly being implemented despite a paucity of evidence on their utility and efficacy on patient-level outcomes. In order to meaningfully improve survivorship care via these documents, it is important first to determine the impact of treatment summaries and survivorship care plans in order to maximize benefits to survivors. IOM called for research (qualitative and quantitative methodologies) and implementation of survivorship care plans to be conducted concurrently (IOM, 2007; Ayanian & Jacobsen, 2006; Earle, 2007).

Research on TS/SCPs to date has been largely theoretical. The majority of studies have assessed the hypothetical use and utility of care plans after respondents (key stakeholders such as survivors, providers) are presented with a blank template/form. Hewitt and colleagues conducted a study comprising focus groups and interviews with 30 cancer survivors, several primary care physicians, and 54 oncology providers (34 nurses and 20 oncology specialists) (Hewitt, Bamundo, Day, & Harvey, 2007). Oncology providers noted barriers to the implementation of TS/SCPs (i.e., time investiture/constraints and reimbursement issues) (Hewitt et al., 2007). In similar studies, there was some overlap in the perspectives from primary care providers and oncology physicians regarding the potential utility of the TS/SCPs; 100% of primary care physicians felt these documents would enhance survivors' quality of care (Baravelli et al., 2009; Del Giudice, Grunfeld, Harvey, Pilotis, & Verma, 2009), while only half of oncology providers shared this perspective (Brennan, Butow, Spillane, & Boyle, 2010). Conversely, the survivors interviewed reported unanimous support for the implementation of TS/SCPs despite having never received one (Baravelli et al., 2009; Brennan, Butow, Marven, Spillane, & Boyle, 2011; Brennan et al., 2010; Burg, Lopez, Dailey, Keller, & Prendergast, 2009; Miller, 2008; Hewitt et al., 2007; Jefford et al., 2011).

Oeffinger and colleagues (2010) examined the effect of a mailed one-page surveillance plan on surveillance adherence in high-risk survivors of childhood Hodgkin Lymphoma (HL). HL survivors (enrolled in the Childhood Cancer Survivor Study, Robison et al., 2002, 2009) were eligible if they were at high risk of serious sequelae stemming from their lymphoma treatment regimen, i.e., cardiomyopathy or breast cancer from exposure to mantle radiation

and/or anthracycline chemotherapy regimens. Eligibility was further restricted; only those adults *not* meeting surveillance guidelines for mammograms and echocardiograms (Oeffinger et al., 2010). Breast cancer and cardiac surveillance was increased after receiving a mailed one-page surveillance plan, compared to those who did not receive a plan (Oeffinger et al., 2010).

Grunfeld and colleagues (2011) examined whether patient outcomes during the transition from oncologist to primary care physician were enhanced by receipt of a survivorship care plan. Outcomes assessed were cancer-related distress, quality of life, patient satisfaction, and coordination of care among women 3 or more months post-treatment for breast cancer. Compared to participants assigned to usual care condition (transition visit with oncologist), women who also received SCPs at the transition visit were better able to correctly identify their primary follow-up cancer care provider ($p < .05$; Grunfeld et al., 2011). Modest (non-significant) reductions in cancer distress were associated with receipt of an SCP (Grunfeld et al., 2011). However, participation rates were low (40% refusal rate). Additionally, 38% of the 408 women were diagnosed with breast cancer more than 6 years prior (range= 3.5 months - 375 months). 330 participants were 2 or more years post-diagnosis(81%). While group assignment was stratified by time since diagnosis, participants were typically 3+ years post-diagnosis, which may have attenuated the effects of the intervention (Grunfeld et al., 2011).

To date, there is a paucity of studies examining cancer survivors in receipt of an individualized/tailored TS/SCPs (reflecting their personal cancer history, diagnosis, treatment, and ongoing follow-up care). This qualitative study aimed to explore the role and usage of TS/SCPs via perspectives of colorectal cancer survivors who had received a personalized/individually tailored TS/SCPs compared to the views of colorectal oncology providers not currently using/providing these forms.

Method

Design

The study had a qualitative design, using in-depth individual semi-structured interviews. Grounded theory was the qualitative theoretical framework used to systematically obtain perspectives on content domains to assess the benefits of TS/SCPs and to identify any emergent domains not previously identified. Grounded theory is purposed to develop theory about phenomena of interest, in our case the benefits of TS/SCPs, based on observation. This qualitative study was part of a larger ongoing study that is developing and piloting a measure assessing the benefits of survivorship care plans (NCI R03 CA138077-02, LAF and BR).

Participants

Colorectal oncology providers—Oncology health care providers (OPs) within the Gastrointestinal Oncology Clinic from an NCI-designated comprehensive cancer center were interviewed. Respondents across multiple disciplines providing care for colorectal cancer patients were approached for interviews. None of the providers interviewed were currently using treatment summaries and survivorship care plans in their follow-up care with colorectal cancer survivors. Colorectal oncology providers in the study comprised two medical oncologists, two radiation oncologists, one registered nurse, one physician's assistant, and one social worker (100% participation rate). Average weekly patient volume (colorectal cancer patients/survivors) was 26-50 for 6 of the 7 providers; the social worker saw, on average, 11-25 colorectal cancer patients per week.

Colorectal cancer survivors—Eligible patients: a) were at least 18 years old, b) had completed active treatment for non-metastatic colon or rectal cancer (stage I-III) within the past year, and c) had received a treatment summary and survivorship care plan from their oncology medical team at their 12-month post-treatment visit. Patients were ineligible if they had other cancer diagnoses (except non-melanoma skin cancer) and/or could not speak/read English. Participants were identified by their oncologist and were recruited during a regularly scheduled, follow-up care clinic visit after they were screened for eligibility. Eligible survivors were asked if they would like to take part in an interview about cancer survivorship and follow-up care.

Treatment Summary and Survivorship Care Plan—The treatment summary and survivorship care plan (TS/SCP) was modeled after templates for colon cancer developed by the American Society of Clinical Oncology (ASCO), specifically the Colon Cancer Adjuvant Treatment Plan and Summary (ASCO, 2009a) and the Colon Cancer Survivorship Plan (ASCO, 2009b). Survivors had been provided a modified form prior to participating in our study. These ASCO forms were combined into a single document and then reformatted (i.e., larger font, and space was added to allow information to be filled in by hand). Modifications to the ASCO forms comprised the following: inclusion of radiation treatment; the inclusion of health promotion and prevention recommendations (weight management, smoking cessation); the inclusion of screening recommendations for non-index cancers (mammograms or PSA tests). The individualized treatment summary and survivorship care plan was prepared and reviewed with them individually by one advanced practice nurse at the survivor's 12-month post-treatment visit. Per the eligibility criteria, all of the survivors had been given a completed written care plan containing their cancer care history at their 12-month post-treatment follow-up visit.

Procedure

Interviews with colorectal cancer providers and survivors—A semi-structured interview guide was developed through a review of the IOM reports and existing literature. Semi-structured, in-depth qualitative interviews (interview guide comprising open-ended probes) were conducted to assess respondents' perceptions of the TS/SCP. The general purpose of the interviews was to explore key stakeholders' perspectives on the use, utility, and benefits (to survivors) of TS/SCPs as well as novel domains (not suggested by the IOM) (Hewitt et al., 2006; Institute of Medicine, 2007). Content of the interview guide (query excerpts displayed in Tables I and II) was based on current literature, and the IOM reports, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006) and *Implementing Cancer Survivorship Care Planning* (Institute of Medicine, 2007). All participants had the opportunity to suggest additional content to assess patient benefits (suggested by IOM) as well as to identify novel or alternative domains of patient benefits (and corresponding content) of the provision of treatment summaries and survivorship care plans (Hewitt et al., 2006; Institute of Medicine, 2007). All interviews were conducted by the PI of this study (LAF) in a clinic consultation room at the cancer center. All participants provided informed consent prior to the interview. In our study we discovered no new themes were identified after individual interviews with seven survivors and seven oncology providers (saturation). We stopped recruitment after reaching saturation. This study was approved by the university institutional review board, and participants received a \$20 cash stipend.

Qualitative Data Coding and Analysis

Interviews were digitally recorded, transcribed verbatim, manually coded, and reviewed by members of the research team. Data were analyzed using a combination of content analysis and the constant comparison method. The study codebook consisted of a priori codes,

derived from existing literature and emergent codes, identified as data analysis progressed. The coding procedures followed a series of steps which included: (1) developing a preliminary set of codes (themes) corresponding to each item in the interview protocol, (2) creating additional codes that emerged and were of special interest to the research goals, (3) developing non-substantive codes, and (4) producing detailed codes to use for analyses of specific topics. ATLAS.ti (Muhr & Friese, 2004), a computer-assisted qualitative data analysis software program, was used to facilitate the coding process. This software aids in the electronic organization of segments of interview text into meaningful units for additional analysis. Two members of the study team coded each transcript independently, and codings were compared to ensure reliability (Strauss & Corbin, 1998). Agreement between coders was evaluated using a Kappa statistic and codes were redefined until an 85% agreement was reached (Kappa= .97). Sociodemographic information of participants was summarized using descriptive statistics, including means, standard deviations, and frequencies.

Results

Sample Characteristics

All survivors and oncology providers approached to participate in the study agreed, thus the response rate was 100%. Interim analysis revealed that saturation had been reached (no new content) after interviews with seven colorectal cancer survivors and seven oncology providers. As such, no additional interviews were attempted.

Survivors were on average 71 years old (ages ranged from 54-84 years, SD= 9.2 years) and male (n=4). Most survivors were married (71%; 5 survivors), high school graduates (100%), college graduates (57%; 4 survivors), Caucasian (100%), and retired (71%). Two of the seven survivors reported current full-time employment. A diagnosis of early stage colorectal cancer was an eligibility criterion. Three participants were diagnosed with stage I, and two participants had stage II or III disease. Average time off-treatment (time since treatment completion) was 18 months (range, 13 - 36 months).

Seven oncology providers were interviewed, comprising two medical oncologists, two radiation oncologists, a registered nurse, a physician's assistant, and a licensed clinical social worker. Most of the oncology providers (6 of the 7) had an average weekly volume of 26-50 colorectal cancer patients while one provider (social worker) saw between 11-25 colorectal cancer patients per week.

Qualitative Analysis

In the following sections, key perspectives are summarized and discussed in the context of colorectal cancer survivors and oncology providers.

Perspectives of Colorectal Cancer Survivors

Colorectal cancer survivors were initially queried about their general survivorship care and colorectal cancer history. After viewing a blank care plan template, survivors were asked if they recalled receiving the identical survivorship care plan detailing their personal cancer history and recommendations for follow-up care. Survivors were then asked about the use, utility, and benefits from TS/SCPs. Table I contains interview queries, response themes, and quotes from seven survivors of colorectal cancer.

Knowledge and Survivorship Care Plans—All cancer survivors reported receipt of a written TS/SCP at their annual post-treatment follow-up visit (100% accurate recall). All survivors noted benefits and value of having their cancer care history, surveillance schedule, and health promotion recommendations in a condensed, written format, although they also

noted that their oncology provider (OP) had verbally explained all aspects of cancer treatment and follow-up care. Additionally, all survivors were satisfied with the clinical aspects of their care and pleased with the idea of having a comprehensive summary of their treatment and a “roadmap” for what they could expect in terms of follow-up care. All of the survivors noted that TS/SCPs enhanced their knowledge of their cancer, treatment history, and awareness of recommended follow-up care guidelines (Table I). Many survivors (71%, 5 out of the 7) commented on the value of the summary of written information, in comparison to relying on their ability to recall specific information about their treatment and follow-up appointments. Five of the seven survivors (71%) also noted that the TS/SCP encouraged them to raise lingering questions/issues about their treatment and surveillance with their oncology medical team.

Self-Efficacy/Intentions and Use of Survivorship Care Plans—Responses were mixed from survivors about how they currently used (or intended to use) their TS/SCPs. Many survivors brought their TS/SCP to each follow-up oncology appointment for updating (5 of 7, 71%). Four of the seven survivors (57%) had already shared this plan with other health care providers outside the cancer center (e.g., primary care physicians or cardiologists). The other three survivors noted that it had not occurred to them to share their TS/SCPs with their non-oncology health care providers, believing their cancer care records were readily available to those physicians (e.g., had been faxed from cancer center directly to their primary care physician). These three survivors reported that they intended to share the TS/SCP with their non-oncology physicians at a future medical visit. This same group also expressed they were not having any additional health problems at the time of this interview and thus were not regularly using the services of other health care providers (community physicians in primary or specialty care).

Five out of seven survivors (71%) mentioned keeping large files of records about their cancer care services; the TS/SCP was typically stored within these larger files. Additionally, two survivors (29%) were unsure about how to utilize the TS/SCP in relation to other cancer care records they had received. Many survivors noted the value of the TS/SCP “if I need it in the future” (5 out of 7, 71%).

Fear of Recurrence and Survivorship Care Plans—Six of the seven survivors discussed the psychological impact of their worry and fears regarding cancer recurrence (Table I). TS/SCPs were noted to bring “peace of mind,” via the facilitation of survivors' efforts to reduce cancer worry via coping and obtaining surveillance to monitor for potential recurrence. Four of the seven participants discussed the benefit of the TS/SCPs in the context of genetic education and counseling among family members, i.e., addressing and conveying the potential increased familial risk (of developing colorectal cancer). One survivor reported using the TS/SCP to encourage his siblings to get recommended cancer screening (colonoscopies). Two other survivors reported using the TS/SCP to share their cancer history with family members in order to enhance the collective knowledge of familial medical history, and inform possible risk profiles for disease.

Five of the seven colorectal cancer survivors mentioned that their treatment summary and survivorship care plan encouraged them to ask questions about their treatment and provided an opportunity to fully understand the ongoing monitoring and surveillance care they were to receive during survivorship (71%). Four survivors (57%) reported using the TS/SCP to monitor their own biological indicators such as blood levels from CEA testing. This enhanced ability for self-monitoring was also reported as providing “peace of mind” about their ongoing recovery and cancer status during survivorship.

Coordination of Follow-up Care and Survivorship Care Plans—All survivors noted TS/SCPs seemed to reduce duplicative testing and/or screening for other cancers (Table I). Four survivors recalled specific situations where a primary care provider attempted to order blood work/tests or screening while the TS/SCP showed that these diagnostic tests had already taken place (57%). Five survivors (71%) also reported the value of TS/SCPs in enhancing communication with medical staff (both oncology and non-oncology providers). Three respondents reported using the TS/SCP when they traveled as it provided a comprehensive summary of their cancer and cancer treatment, believing the TS/SCP would be of use should they become ill or symptomatic while away from home (43%). Two survivors reported perceiving their medical records and updates were already sent to any healthcare provider they were seen by and did not feel the TS/SCP was for use with other non-oncology providers (such as primary care physicians or specialists, cardiologists, etc.,) but rather was for their personal use only.

Additional domains about treatment summaries and survivorship care plans raised by colorectal cancer survivors are noted in Table I.

Perspectives of Oncology Providers

To begin the interview, oncology providers were asked to describe follow-up care they provided to colorectal cancer survivors. Oncology providers were shown a blank TS/SCP template (identical to the forms received by survivors). OPs were then asked about the potential use, utility, and benefits of TS/SCPs to patients completing treatment for colorectal cancer. Table II contains interview queries, response themes, and quotes from multi-disciplinary oncology providers. Five of the seven colorectal oncology providers endorsed implementation/use of treatment summaries and survivorship care plans while two providers were unsure of the value added to quality of follow-up care.

Coordination of Follow-up Care and Survivorship Care Plans—All of the oncology providers discussed how TS/SCPs could increase coordination of care of cancer survivors, particularly given the multiple providers from whom patients receive medical care (cardiologists, primary care physicians) (Table II). Oncology providers (86%, 6 out of 7) also reported TS/SCPs could assist with the long-term, cancer-related follow-up care that increasingly will be provided outside of the larger cancer centers, i.e., via non-oncology community-based providers (primary care physicians). TS/SCPs were noted by all seven oncology providers to have the capability of augmenting both continuity and quality of cancer care.

Patient Knowledge and Self-Efficacy and Survivorship Care Plans—Six of the seven providers approved of the concept, format, and structure of TS/SCPs, especially its primary goal of decreasing patient burden by synthesizing complex tumor and treatment details with recommendations for ongoing cancer follow-up care (surveillance and health promotion) into a single document (Table II). It was stated having this information in one document was superior to a disorganized collection of myriad notes from oncology disciplines (reports from radiation, medical, and surgical oncologists). Five providers also noted that TS/SCPs would be an even greater asset for patients whose cancer treatment courses were very involved or prolonged, such as complex multimodal regimens, and/or marked by tumor progression, recurrence, or the development of a second primary tumor. All oncology providers noted that the need for easily comprehensible, specific recommendations regarding ongoing monitoring/follow-up is heightened among patients with a difficult disease course and those who are at risk for recurrence, as is the reality for many survivors of colorectal cancer.

Integration of Survivorship Care Plans into Current Practice: Concerns and Caveats—Though generally in favor of integration of treatment summaries and survivorship care plans into routine follow-up, a few concerns were raised by OPs in regards to their implementation/roll-out. Specifically, one provider discussed TS/SCPs were a duplication of current practice. This provider relayed the belief that TS/SCPs were more appropriate for clinical usage (i.e., between oncology providers and primary care physicians or non-oncology specialists), expressing reservations about their implementation with patients centering on comprehensibility. Another oncology provider stated integrating care plans into their follow-up care practices may be burdensome. Specifically, this provider felt that it would add to the complexities involved in following patients unless the task of preparing and maintaining care plans was assumed by a specified/designated clinic staff member (e.g., as is done within a survivorship clinic model, or nurse-led follow-up care models). Other issues noted by two OPs included time investiture and billing/reimbursement as well as the long-term sustainability of TS/SCPs (availability and transportability of electronic versus paper formats, ease of access across care settings, and the capability of the forms to be easily updated and/or maintained over time).

Additional domains about treatment summaries and survivorship care plans raised by oncology providers are noted in Table II.

Discussion

In this exploratory study, we assessed the role and utility of TS/SCPs among colorectal cancer survivors and their oncology providers. The current study contributes to the emerging science on survivorship care planning via its inclusion of colorectal cancer survivors who have received an individualized TS/SCP. Specifically, we examined the attitudes, barriers, and potential benefits of TS/SCPs among survivors and oncology providers from multiple disciplines.

Overall, the perspectives of the colorectal cancer survivors regarding TS/SCPs were consistent with the current body of science. Colorectal cancer survivors expressed peace of mind with TS/SCPs as a written synopsis of their cancer diagnosis, treatment(s), and future follow-up care. Survivors reported using these documents in various ways. While some used it to share information with family members for historical records and to recognize genetic risk, other survivors did not share their summary and care plan with anyone. There was uncertainty among a few survivors about the ability of the TS/SCPs to convey needed information for other non-oncology providers; some survivors perceived their medical records were already available to current and future health care providers. Most oncology providers noted the value of TS/SCPs, specifically the possibility that receipt of these forms might enhance quality of follow-up care of colorectal cancer survivors. Oncology providers suggested, however, that current practice would have to undergo significant change in order to successfully integrate TS/SCPs into routine follow-up care.

Although oncology providers acknowledged the value of creating survivorship care plans and treatment summaries, a few noted reluctance regarding the surmised/presumed time investiture, and lack of specific procedural code for medical billing and reimbursement. Ganz and Hahn (2008) and the Institute of Medicine (2007) recommended that completion and administration/delivery of the TS/SCP be coded and billed similarly to activities supporting completion of hospital discharge forms and/or rehabilitative services. With patient/survivor advocacy groups calling for change that is now echoed by national efforts to modernize U.S. health care (i.e., standardized electronic medical/health records), implementation of treatment summaries/survivorship care plans will be increasingly feasible.

Results of the current study indicate a fair amount of uncertainty and ambiguity for colorectal cancer survivors surrounding the consequences of cancer treatment and aspects of recommended surveillance as they completed treatment. Survivors reported experiencing significant worry during and after treatment about cancer-related symptoms and concerns/fear of recurrence. It is essential to inform cancer survivors of potential late and long-term effects of treatment they may experience and clearly designate a key provider for follow-up cancer care (responsible for monitoring and managing these symptoms). The qualitative work presented here is a first step toward development and evaluation efforts outlined by the IOM (Hewitt et al., 2006; IOM, 2007).

Study Limitations

Participants and providers were recruited from a single clinic which may have introduced selection bias. However, the current findings echo previous qualitative results with survivors novel to treatment summaries and survivorship care plans (Hewitt et al., 2007; Baravelli et al., 2009; DelGuidice et al., 2009; Brennan et al., 2010, 2011). The perspectives and attitudes reported here are not necessarily representative of survivors or oncology providers as a whole. As is the case of all qualitative work, results are not generalizable to other populations or institutions.

Clinical Implications

The oncology community is currently involved in efforts to include survivorship care plans based on the IOM and American College of Surgeon's Commission on Cancer accreditation standards. However, several questions remain regarding the use and utility of treatment summaries and survivorship care plans. Chief among these is the extent to which TS/SCPs improve/enhance factors (knowledge, satisfaction with care, adherence) that influence survivors' short- and long-term outcomes (quality of life, survival). Currently this is unknown, in part, due to a lack of metrics and measures that evaluate the benefits of treatment summaries and survivorship care plans (Hewitt et al., 2006; Faul et al., 2010). Future research is needed to develop evidence-based recommendations regarding the implementation and integration of TS/SCPs into standard oncology care, specifically their dissemination (format, delivery/administration) and methods to promote efficacy balanced against cost-effectiveness. For example, should TS/SCPs be implemented for all cancer survivors or only those requiring extended follow-up? Who should deliver the plans to patients? What is the optimal time to complete and administer a TS/SCP to cancer survivor? Should two formats be developed, a patient/survivor form and a separate one for medical providers? How best to integrate the use of treatment summary and survivorship care plan with other tools (EMRs, eHealth efforts) that too are aim to improve coordination of care and communication among multiple providers? Resolving these lingering questions will help inform current practice in the integration of survivorship care plans, thus maximizing their benefits to patients and survivors.

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Table I
Perspectives from Colorectal Cancer Survivors

Benefits Theme	Interview Query	Survivors' Feedback
Patient Knowledge	Understanding more about your cancer diagnosis, or the exact treatment you received? Learning more about how often you should see your oncologist for follow-up tests/scans?	“The TS/SCP...helps me remember all the treatment I had and know what's going on in my cancer care” “Encourages patients to be more involved, ask more questions because if you don't have it, you don't know or remember much of anything later on”
Patient Self-Efficacy and Intentions regarding Adherence to Follow-up Care	Knowledge/awareness of components of comprehensive follow-up care, e.g., surveillance, prevention (skin cancer screening), and health promotion (smoking cessation)Intentions to do what my oncologist recommends (CEA)	“A TS/SCP is a great tool...reminder of what I need to do every three months”“It would have been hard to keep track of it all (myself)...(on the TS/SCP) you've got it all right there in front of you if there's ever a question from you, your family, another doctor...you know what tests you need and what you've had done already”
Coordination of Care and Communication with Non-Oncology Health Care Providers	Coordination of care between the oncology team and my primary care physician? Communication between the oncology team and my community providers (PCPs, non-cancer specialists)?	“Good to have (an SCP) if you change doctors or are referred to a different doctor for a consult” “Your primary care doctor needs to have everything that you have (diagnosis and cancer treatment) because how are they going to know if they don't ”
Satisfaction with Care	Information I received about my treatment and follow-up care? Ease of transition from active treatment to survivorship?	100% of colorectal cancer survivors were happy/pleased with their cancer care (during active treatment and follow-up) and information they received from their oncology team. Survivors spoke of how the oncology team prepared them for survivorship with an end-of-treatment visit, and that the survivorship care plan was first presented and reviewed at their 1-year anniversary (post-treatment).
Fear of Recurrence and “Peace of Mind” [Novel theme, i.e., no query/interview probe]		“It's good because you have a comparison from this (time) to that, to see whether something has changed or hasn't” (e.g., CEA test results) “There's a possibility that it's (colon cancer) genetic so the SCP is good for historical purposes...if one of the kids or grandkids develops something, I would be able to say 'here's what happened to me'...that's important” “My mother died at a young age from gastric problems. But I was 60 when my first colonoscopy discovered my cancer. I discussed it (my experience) with my brother, sister, and our children (using the TS/SCP). I told my brother and way. They both got screened because we sister to get colonoscopies right a may all be at greater risk for cancer”

Note: TS/SCP and/or SCP: treatment summary and survivorship care plan; CEA: carcinoembryonic antigen; PSA: prostate-specific antigen.

Table II
Perspectives from Oncology Providers Caring for Colorectal Cancer Survivors

Benefits Theme	Interview Query	Oncology Providers' Feedback
Patient Knowledge	Might a survivorship care plan aid a patient's understanding of their diagnosis and treatment?	"Maybe 10-25% of patients know the specifics of their treatment...many (patients) are unaware of their risk of second cancers and/or recurrence" "Patients probably love it because the SCP lays it out for them...'this is where I am; this is what I'm supposed to be getting now'...especially for older patients...they know this is the way my cancer life is scheduled out for me"
Confidence/Self-Efficacy in Receiving Appropriate Follow-up Care	Might a survivorship care plan boost patient confidence in meeting demands of follow-up and surveillance adherence?	"It's (the TS/SCP) a tool for survivors to learn more, to know more, and to be proactive in their ongoing care"
Intentions re: Adherence with Follow-up Care Guidelines	Might a survivorship care plan increase survivor's intentions to follow recommendations?	57% of providers (4 of 7) felt the TS/SCP would increase patient intentions to adhere to recommended follow-up guidelines "SCPs help patient adherence because they become more accountable...'I have this here (TS/SCP); I know what I need to get done when, let me go get it done'"
Satisfaction with Care	Would satisfaction with treatment and follow-up care be via receipt of a survivorship care plan?	"The TS/SCP gives the patients the sense of this is our goal.. " (and patients respond to that how...?) "favorably because it gives them a timeline...'when this is going to be behind me?' ...and the full expectations of what we hope to see in the next few months" (during the follow-up period)
Coordination of Care and Communication Team and Primary Care Community Providers	Optimal/best time for survivorship care plan How might a patient finishing active treatment best utilize a survivorship care plan?	"There's a need for better communication between physicians...Often primary care providers don't get the forwarded cancer treatment notes" "TS/SCPs list which oncology provider to call to get the appropriate management of side effects...who is responsible for doing the required tests (surveillance)"

Note: TS/SCP and/or SCP: treatment summary and survivorship care plan.