Evaluating Primary Care Providers' Views on Survivorship Care Plans Generated by an Electronic Health Record System

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Abstract

Purpose: Survivorship care plans for cancer survivors may facilitate provider-to-provider communication. Primary care provider (PCP) perspectives on care plan provision and use are limited, especially when care plans are generated by an electronic health record (EHR) system. We sought to examine PCPs' perspectives regarding EHR-generated care plans.

Methods: PCPs (N = 160) who were members of the Wisconsin Research and Education Network listserv received a sample 10-page plan (WREN cohort). PCPs (n = 81) who had or were currently seeing survivors enrolled onto one of our survivorship clinical trials received a copy of the survivor's personalized care plan (University of Wisconsin [UW] cohort). Both cohorts received a survey after reviewing the plan. All plans were generated within an EHR.

Results: Forty-six and 26 PCPs participated in the WREN and UW cohorts, respectively. PCPs regarded EHR-generated plans as useful in coordinating care (88%), understanding treatments (94%), understanding treatment adverse effects (89%), and supporting clinical decisions (82%). Few felt using EHR-generated plans would disrupt clinic workflow (14%) or take too much time (11%). Most (89%) preferred receiving the plan via EHR. PCPs reported consistent provision (81%) and standard location in the medical record (89%) as key factors facilitating their use of survivorship care plans. Important facilitators of care plan use included a more abbreviated plan, ideally one to three pages (32%), and/or a plan specifically tailored to PCP use (57%).

Conclusion: Plans were viewed as useful for coordinating care and making clinical decisions. However, PCPs desired shorter, clinician-oriented plans, accessible within an EHR and delivered and located in a standardized manner.

Introduction

There are more than 14 million cancer survivors in the United States. This number is projected to increase substantially over the next decade.¹⁻³ The increasing number of long-term survivors places new demands on oncology and primary care providers (PCPs) and requires increased attention to chronic cancer-specific health needs. Suboptimal communication and coordination of care for cancer survivors remain as public health challenges that need to be addressed as efforts are made to transition survivorship care to primary care settings.^{4,5} PCPs express a desire for additional information with sufficient detail and guidance in order to provide sufficient care to cancer survivors.⁶⁻⁸ Efforts to improve the transition from oncology to primary care, as survivors move from acute cancer care to ongoing preventative care, have focused on survivorship care plans.⁹ The Institute of Medicine advises that each cancer survivor receive a survivorship care plan summarizing his or her cancer diagnosis, treatment, and recommendations about follow-up care. This personalized care plan is also provided to the survivor's PCP.¹⁰⁻¹² Research has demonstrated that PCPs desire care plans that address their survivorship information needs.⁶ However, a recent ASCO statement notes that care plan provision is low and cites the significant time and resources required to create care plans as key factors.¹³ ASCO advocates using electronic health records (EHRs) to create and provide care plans,¹³ as EHR generation might reduce the barriers to

preparation and use.^{13,14} The Commission on Cancer's guidelines requiring care plans may increase diffusion into clinical practice.¹⁵ However, barriers to effective use will remain. These may include the static nature of current care plans^{14,16} and difficulty accessing current templates within an EHR.

Previous studies have focused on care plan content, length, impact on patient management, and perceived usefulness of non-EHR-based care plans, sometimes using sample care plans.^{6,8,9,17-21} However, PCPs' attitudes might vary when reviewing sample plans versus personalized plans prepared for their own patients. Limited data are available with regard to personalized care plans, EHR-generated care plans, and how PCPs would like updates incorporated.^{17,19,22,23} Timing and content of updates are important areas of research,²⁴ as studies suggest that PCPs¹⁸ and survivors¹⁴ desire updates to care plans. Perception is critical to use: if care plans are perceived as awkward, time consuming to review or use, or of limited utility, PCPs and survivors are unlikely to continue using them.

Our objective was to assess PCP perceptions of the length, understandability, ease of use, and accuracy of both sample and personalized EHR-generated care plans and the perceived impact of care plans on clinical workflow and behavior. We also asked about preference for the method and timing of delivery of care plans, as well as need for and frequency of updates.

Methods

Setting and Participants

We conducted this work in two settings, a practice-based research network, the Wisconsin Research and Education Network (WREN), and within the University of Wisconsin (UW) Health Hospitals and Clinics. WREN is one of the oldest primary care–based practice networks in the country, with 160 practicing clinicians in 86 practices. WREN includes both rural and urban PCPs working within 24 health care organizations and 47 communities. We surveyed PCPs within WREN regarding their perceptions of a sample care plan (WREN cohort). We surveyed PCPs who were monitoring survivors seen at the UW regarding their perceptions of a personalized care plan, developed for one of their patients with breast cancer (UW cohort).^{14,20,21} The UW Institutional Review Board approved all study activities.

WREN listserv members were invited via an e-mail to participate in evaluating sample care plans. The e-mail contained the sample care plan and a hyperlink to the survey. Only physicians (MD, DO) or advanced practice practitioners (nurse practitioner, physician assistant) caring for patients in full- or part-time clinical practice were to respond, with approximately 160 providers on the listserv meeting these criteria. At the UW, there were 81 PCPs eligible to participate in the study of personalized care plans; all were invited to participate. Eligibility was based on being listed as the PCP for at least one of the 105 survivors who participated in our survivorship care plan trials, either at the time of survey or at some point since care plan creation. UW-affiliated PCPs received the personalized EHR-generated care plan and a hyperlink to the survey via UW e-mail. All other PCPs received the plan and survey via US mail to preserve patient privacy. PCPs did not receive any compensation for participating. Each cohort was sent one reminder 3 weeks after first contact.

EHR-Generated Survivorship Care Plan

We used the same template for both sample and personalized plans. It can be quickly generated within our EHR.¹⁴ For our sample plan, we created a 10-page document for a fictitious breast cancer survivor, consisting of a cover letter (one page), treatment summary (two pages), follow-up recommendations and resources (five pages), and a glossary of terms (two pages). Personalized care plans (median length, eight pages; range, four to 11 pages) were prepared between 2011 and 2014 by one of the four treating oncologists responsible for the 105 survivors included in the original two trials. The format of each personalized plan followed that of the sample plan (letter, summary, follow-up and glossary). [Table 1](#) describes the care plan content in further detail, and the Data Supplement includes the sample plan provided along with the UW Cancer Survivorship Survey for Primary Care.

Survey Questions

Oncology specialists, PCPs, and health systems engineers developed an 18-item survey (the UW Cancer Survivorship Sur-

vey for Primary Care) to gather information on (1) PCP demographics; (2) PCP views on optimal timing of care plan delivery, need for plan updates, and preferred method of plan delivery; and (3) PCP assessment of plan accuracy, content and length, and impact on clinical workflow and behavior. The survey included 15 multiple-choice questions with three open-ended questions (Data Supplement). Although we asked about EHR use, we did not ask participants to provide details about their access to the UW EHR system. However, all UW providers would have access, and other providers likely had access via the UW electronic health information exchange.

Statistical Analysis

Response rates were summarized using an estimated denominator (N = 160) for eligible practitioners from the WREN cohort and actual denominator of PCPs contacted for the UW cohort. Survey answers were summarized using counts and percentages out of those completing the survey.

Results

PCP Characteristics

Data were collected June to August 2014 for both cohorts. Forty-six of the estimated 160 eligible WREN PCPs completed the survey (29% response rate). Most were physicians (87%) specializing in family medicine (98%). More women than men responded (62%); most had been in practice for more than 10 years (69%). Of the eligible PCPs from the UW cohort, 26 completed the survey (32% response rate). Most were physicians (88%) specializing in family medicine (58%). More women than men responded (69%); most had been in practice for more than 10 years (58%). All participants in both cohorts reported that their practice used an EHR.

Usefulness

Whether viewing a sample or personalized plan, most PCPs agreed that EHR-generated care plans were accurate, clearly written, understandable to them, and easy to use ([Table 2](#)). Few felt that using the plan would disrupt clinic workflow or take too much time. The majority agreed plans would improve understanding of treatments given and treatment adverse effects, improve coordination of care, and facilitate better decision-making and clinical care.

Provision and Updates

PCPs favored receiving the plan via EHR, although a few expressed concern about the interoperability of EHR systems and desired delivery via both paper and EHR ([Table 2](#)). Most strongly preferred to avoid accessing external Web sites or mobile apps to access plans. As one provider stated, “If I have to look in one more location to find important clinical data about my patients, I will scream!”

Views were mixed on when care plans should be provided ([Table 3](#)). Combining both cohorts (n = 72), half (50%) wanted care plans provided immediately after a survivor completed primary treatment. In regard to updates, a majority

Table 1. Elements of the EHR-Generated Care Plan: UWCaSP

Section Title	Subsection Title	Description of Content
Cover letter on letterhead	Introduction	Brief description of UWCaSP, reason for providing; discussion of other documents survivor might need and information for obtaining
Treatment summary	General information	Name, date of birth, medical record number
	Care team	Treating providers, phone numbers, including primary care provider
	Background information	Genetic testing (recommendation, results if done), menstrual status at cancer diagnosis, comorbidities
	Oncologic history	Cancer presentation, screening and diagnostic mammogram, ultrasound, MRI, with date and findings (if applicable)
	Treatment plan and information	Biopsy date, receptors, histology, lymphovascular invasion, Ki-67, margins, grade
		Surgery: surgeon, type/date, pathologic findings including TNM stage
		Chemotherapy: medical oncologist; regimen name, drugs, dates; complications/toxicities experienced
		Radiation: radiation oncologist, total dose and type, dates
		Endocrine therapy: medical oncologist; drugs used and date started; date if discontinued, with reason
		Reconstruction (if applicable): surgeon, type and date
		Trials (if applicable): trial participation and name, brief description
	Ancillary studies	Staging studies (eg, labs, CT, bone scan), left ventricular ejection fraction study if done, and any repeated assessments
	Current treatment	Any treatment survivor still receiving, with anticipated end date
Follow-up or survivorship care plan	Symptoms to watch for	List of symptoms to contact clinic about: recurrence and second tumors
	What happens after treatment for breast cancer?	Recommended screening and schedule for breast cancer follow-up; last mammogram and MRI, along with future recommendations; hyperlinks to national guidelines
	Lifestyle changes to consider	Diet and exercise recommendations; other preventative health care: vaccinations, colonoscopies, pelvic and Pap, bone densitometry testing, vitamin D levels, including dates last done; smoking cessation resources, including hyperlinks
	Possible side effects of treatments	Recovery from toxicities, late and chronic adverse effects of treatments survivor received (information was not provided for treatments not given: eg, if no chemotherapy given, chemotherapy adverse effects not included), lifetime dosage of anthracycline
	Life after cancer treatment	Referrals information for patient navigator, support groups, and cancer psychology and social work; includes hyperlinks to resources
	Concerns and resources	Hyperlinks to resources about marital/partner relationship, sexual functioning, work, and parenting, and potential future need for psychosocial support; insurance, employment, financial concerns
Glossary	Understanding words and concepts used by your cancer team	List of definitions and abbreviations commonly encountered, hyperlinks to general information resources

Abbreviations: CT, computed tomography; EHR, electronic health record; MRI, magnetic resonance imaging; UWCaSP, University of Wisconsin Cancer Summary and Plan.

(57%) felt updates should be based on information changes, with changes to screening guidelines (53%), or changes to follow-up recommendations (56%) being most commonly selected.

Barriers and Facilitators

PCPs in both cohorts reported the main barriers to plan use as not knowing a plan existed (83%), not knowing how to find the plan (75%), not being able to locate the plan in the patient chart (71%), and not knowing to look for the plan (72%). PCPs identified potential facilitators to use as increased awareness of plan existence (85%), standardized location within medical records (89%), and consistent provision of care plans for all patients (81%). Notably, many PCPs (57%) indicated that providing a care plan specific to primary care rather than a document designed for both clinicians and survivors would also facilitate use. As one stated, “plans [should be] targeted for the primary care provider. We need to know... more clearly what... to do for specific follow-up testing that the oncologist

or surgeon won't be doing... putting everything I need to know on one page... would be best.”

As this comment indicates, a number of PCPs (32%) also felt that shorter plans would facilitate use. Ideal length was reported as one to three pages.

Personalized Plan Impact

The UW cohort was asked whether they knew the plan existed before our survey, and whether the care plan had or would change care. The majority reported being unaware that their patient had a care plan ($n = 19$; 73%); four (15%) indicated they knew the plan existed but had not accessed it. Only three (12%) indicated previously accessing the plan. More than half of PCPs ($n = 14$; 54%) indicated that the care plan did not or would not result in a change of care, citing reasons such as, “Patient continues to follow with heme/onc.” Among clinicians who indicated that the care plan had or would change care, cited examples included “more frequent bone density scans given

Table 2. Provider Perceptions of and Preference for EHR-Generated Breast Cancer Survivorship Care Plans (sample or personalized)

Perception	WREN Cohort: Sample Plan (n = 46)*			UW Cohort: Personalized Plans (n = 26)*		
	Strongly Agree or Agree (%)	Neutral (%)	Strongly Disagree or Disagree (%)	Strongly Agree or Agree (%)	Neutral (%)	Strongly Disagree or Disagree (%)
PCP perception of plan						
Care plan information regarded as accurate	93	5	2	96	4	0
Care plan clearly written	78	13	9	96	4	0
Care plan content understandable by PCP	89	7	4	100	0	0
Care plan easy to use	69	18	13	92	8	0
Care plan disrupts clinic workflow	13	18	69	17	12	71
Care plan too time consuming	13	24	62	8	16	76
Helpfulness of plan for patient care						
Care plan increases understanding of treatment	93	7	0	96	4	0
Care plan increases understanding of side effects	84	13	2	96	4	0
Care plan improves coordination of care	89	11	0	85	8	8
Care plans helps make decisions	80	20	0	84	12	4
Care plans helps provide better care	91	9	0	77	19	4
Preferred methods of providing care plan						
Paper care plan	44	27	29	12	29	58
Care plan via EHR	87	7	7	92	8	0
Patient provides care plan (eg, paper or mobile app)	27	16	58	12	38	50
Access plan via external Web site	9	20	71	8	0	92

Abbreviations: EHR, electronic health record; PCP, primary care provider; UW, University of Wisconsin; WREN, Wisconsin Research and Education Network.

* Denominators for individual questions vary, based on whether participants answered.

anastrozole therapy” and “make sure that patient follows up with recommended exams after cancer treatment.”

Discussion

We found that PCPs endorsed the use of care plans for understanding breast cancer diagnosis, treatment, and recommended follow-up. Our data suggest that PCPs may prefer a shorter plan (one to three pages), oriented to clinicians, with a uniform location in the medical record. Most PCPs (89%) preferred to receive care plans via the EHR; all PCPs reported use of an EHR within their practice, not surprising given that Wisconsin has a 71% EHR adoption rate.²⁵

Ezendam et al¹⁷ similarly reported that most PCPs (84%) prefer receiving care plans via the EHR. Mayer et al⁶ found both paper and electronic versions were acceptable, while Salz et al²⁰ suggested that printed documents are preferred (however, receipt via the EHR did not appear as an answer option). EHRs may facilitate other aspects of survivorship care; qualitative interviews have found oncologists and PCPs rely on EHRs to communicate and track survivor care.²⁶ Our results suggest that efforts should focus on integrating care plan information within and across EHRs rather than designing external Web sites or mobile apps. Dissatisfaction with searching for patient data was notable and will likely impede PCP use of plans external to the EHR. Care plan information outdates rapidly,¹⁴ and all of our PCPs wanted some schedule of updates, a concern previously raised by Kantsiper et al.¹⁸ Our survivors not infrequently either changed PCPs (13%) or acquired a PCP (13%) between 2011 and 2014. Currently, no mechanism

exists for ensuring that a care plan reaches a PCP not caring for the survivor at plan creation.

Barriers to PCP use of care plans suggested by this study include (1) individual-level factors (eg, clinician being unaware that care plans exist), (2) organizational-level factors (eg, lack of policies to ensure complete and consistent provision of care plans), (3) technology factors (eg, difficulty locating plan, with EHR not being able to update static care plans or care plans existing external to the EHR), and (4) work task factors (eg, care plans not being designed to support PCP survivor-related work activities). Some of these issues may be resolved by dynamically integrating care plans within EHRs. Dynamic and EHR-integrated plans could automatically generate updates (eg, if guidelines for genetic testing changed) and ensure care plans are available to new clinicians when survivors change PCPs.

Data are limited on PCPs evaluating personalized care plans prepared for survivors that they follow clinically.^{19,22,23} Moreover, data on PCP views regarding EHR-generated care plans are lacking. Here, we report on PCP views of EHR-generated sample and personalized care plans with regard to clinical workflow and behavior, as well as usefulness in coordinating care and making clinical decisions. Most of the UW cohort (88%) reported being unaware of or not accessing the personalized care plan, similar to one previous study.¹⁷ This may be due to inconsistent policy on how and when to notify the PCPs about the care plan, an issue being addressed at the UW as a result of this survey. Conversely, Shalom et al²² reported a high rate of PCP awareness of plan existence. Their results may be explained

Table 3. PCP Preference for Timing and Updates of Care Plans and Perceived Facilitators and Barriers to Use of Care Plans

Parameter	WREN Cohort: Sample Plan (n = 46)* (%)	UW Cohort: Personalized Plans (n = 26)* (%)
Need and timing for possible care plans updates		
Never	0	0
After every oncology visit	28	4
Yearly	24	27
Every few years	2	0
Based on information changes, not time	54	62
Other	9	8
Best time to deliver care plan to PCP†		
Immediately after cancer diagnosis	9	0
Immediately after primary treatment	43	62
1-2 years after diagnosis	0	4
When patient discharged from oncology follow-up	33	35
Other	15	4
Endorsed facilitators of care plan use by PCP†		
Increased awareness of existence	87	81
Routinely provided care plans for all	85	73
Standardized location	89	88
Care plan specific to primary care	61	50
Shorter care plan, with ideal length fill-in	33	31
Other (with fill-in)	20	8
Endorsed barriers to care plan use by PCP†		
Content too generic	26	23
Plan difficult to understand	28	12
Plan too long	67	54
Not sure how to find it	83	62
Not located in patient chart	74	65
Don't know to look for it	76	65
Don't know that it exists	85	81
Plan disrupts clinical workflow	26	23
Follow-up care continues with oncologist	24	19

Abbreviations: PCP, primary care provider; WREN, Wisconsin Research and Education Network; UW, University of Wisconsin.

* Denominators for individual questions vary based on whether participants answered.

† Participant instructed to select all that applied.

by (1) re-provision of care plans before PCPs were contacted to participate in the study, (2) selection bias if PCPs who used the care plan were more likely to participate in the interviews, and/or (3) greater penetration of care plans in an area served by a specialized survivorship clinic. PCPs may benefit from education on the existence and use of care plans to achieve their desired impact.^{7,24} Further efforts should also be devoted to ensuring that EHRs meaningfully integrate care plans into practice so that they can be routinely found and used. This will

be challenging if care plans continue to be housed external to EHRs or be scanned into EHRs as “outside documents.” Such scanned documents are often hard to find or view, and are most certainly difficult to update.

Our study has several key strengths. First, we have nearly twice the PCP participants of the two prior US studies on personalized care plans.^{20,22} Second, ours is the only study (to our knowledge) to evaluate the desirability of EHR-generated care plans. Third, we assessed both rural and urban PCPs working within a variety of small and large health care systems. Fourth, our study highlights the need to use EHRs more effectively by understanding the information needs of PCPs participating in survivorship care and how EHRs affect this care. Our findings suggest that a standard location for care plans, visible to the entire clinical team, is important to ensure that PCPs receive, recognize, and can readily reference care plans at later time points. However, our study also has some limitations. Our response rate was less than 50%, likely due to the fact that we asked busy clinicians to review a several-page document and answer a survey without compensation. Another limitation is that our PCPs came from a single geographic area, the American Midwest. However, other studies have had findings consistent with ours, suggesting that these results are generalizable.^{17,23} Finally, our study was limited to care plans designed for breast cancer survivors, and might not be generalizable to non-breast cancer survivors.

In conclusion, this study demonstrates that PCPs find EHR-generated care plans useful in coordinating and providing care to cancer survivors. These results support current recommendations that care plans be provided to each survivor's PCP as part of an effort to improve specialist–primary care communication. However, our results also suggest the need for continued modifications to improve care plan adoption and use by PCPs. Further research is warranted to create and assess the impact of clinician-oriented care plans. Additionally, the oncology community needs to address the challenge of consistently providing, delivering, and updating care plans, as well as developing processes for better informing PCPs regarding the existence and value of care plans, and the appropriate follow-up care for cancer survivors.

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