
Review

Health information technology to support cancer survivorship care planning: A systematic review

Sean P. Mikles ¹, Ashley C. Griffin ², and Arlene E. Chung^{1,2,3,4,5}

¹Lineberger Comprehensive Cancer Outcomes Program, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA, ²Carolina Health Informatics Program, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA, ³Division of General Medicine and Clinical Epidemiology, Department of Medicine, UNC School of Medicine, Chapel Hill, North Carolina, USA, ⁴Division of General Pediatrics and Adolescent Medicine, Department of Pediatrics, UNC School of Medicine, Chapel Hill, North Carolina, USA, and ⁵Program on Health and Clinical Informatics, UNC School of Medicine, Chapel Hill, North Carolina, USA

Corresponding Author: Sean P. Mikles, PhD, MPH, Lineberger Comprehensive Cancer Center, UNC, 450 West Drive, Chapel Hill, NC 27599, USA; smikles@med.unc.edu

Received 11 March 2021; Revised 13 June 2021; Editorial Decision 14 June 2021; Accepted 23 June 2021

ABSTRACT

Objective: The study sought to conduct a systematic review to explore the functions utilized by electronic cancer survivorship care planning interventions and assess their effects on patient and provider outcomes.

Materials and Methods: Based on PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidelines, studies published from January 2000 to January 2020 were identified in PubMed, CINAHL, EMBASE, PsychINFO, Scopus, Web of Science, and the ACM Digital Library. The search combined terms for cancer, survivorship, care planning, and health information technology (HIT). Eligible studies evaluated the effects of a HIT intervention on usability, knowledge, process, or health-related outcomes. A total of 578 abstracts were reviewed, resulting in 60 manuscripts describing 40 studies. Thematic analyses were used to define meta-themes of system functions, and Fisher's exact tests were used to examine associations between functions and outcomes.

Results: Patients were the target end users for 18 interventions, while 12 targeted providers and 10 targeted both groups. Interventions used patient-reported outcomes collection (60%), automated content generation (58%), electronic sharing (40%), persistent engagement (28%), and communication features (20%). Overall, interventions decreased the time to create survivorship care plans (SCPs) and supported care planning knowledge and abilities, but results were mixed for effects on healthcare utilization, SCP sharing, and provoking anxiety. Persistent engagement features were associated with improvements in health or quality-of-life outcomes (17 studies, $P = .003$).

Conclusions: Features that engaged users persistently over time were associated with better health and quality-of-life outcomes. Most systems have not capitalized on the potential of HIT to share SCPs across a care team and support care coordination.

Key words: cancer, neoplasms, survivors, patient care planning, systematic review, informatics

INTRODUCTION

Background and Significance

Advances in the detection and treatment of cancer have led to improved mortality rates and health outcomes for cancer patients.¹ The number of post-treatment cancer survivors is estimated to reach 22.1 million people in 2030 in the United States, and cancer survivors are living longer lives after their diagnosis.² Post-treatment care is complex, multifaceted, and requires substantial care coordination and communication. Quality survivorship care includes surveillance for new and recurrent cancers, management of physical and psychosocial effects of both cancer and its treatments, and general health maintenance.³ Prior research suggests that care coordination interventions improve outcomes across the cancer care continuum.⁴ However, many of these interventions include the use of professional navigation or case management services,⁴ which can be resource-intensive in an already burdened system.⁵

The Institute of Medicine's foundational report on survivorship care, "Lost in Transition," suggested that compiling a patient's cancer-related information into a survivorship care plan (SCP) document would aid in supporting care coordination.⁶ An SCP contains a summary of the patient's cancer diagnosis and the course of their treatment (a "treatment summary"), and a future care plan for cancer surveillance and the management of late and long-term effects.⁶ SCPs have recently gained prominence, and the provision of SCPs is a requirement for accreditation by the Commission on Cancer.⁷ To date, systematic reviews of SCP interventions, which have been largely paper based, have found little evidence that SCPs improve care.⁸ Experts have criticized current SCP interventions as being poorly implemented,⁸⁻¹⁰ as there is generally poor adherence to the creation and dissemination of SCPs^{8,9} and failure to measure process outcomes such as the sharing of SCPs across the care team.¹⁰⁻¹²

Recently, there has been renewed interest in leveraging health information technology (HIT), such as home-based self-management systems and electronic health records (EHRs), to improve SCP interventions.^{5,13,14} HIT can facilitate care coordination, clinical decision making, communication across care teams, and could provide new ways to measure care quality.¹⁵ While many EHR vendors have functionalities that support oncology care, recent research suggests that only a minority of SCPs are developed within EHRs or leverage EHR documentation.¹⁶ EHR systems also often lack adequate data entry functions and structured data elements necessary to adequately document SCPs for oncology care.¹⁷ To date, no studies have specifically examined what types of HIT systems and functionalities have been implemented or may be effective in supporting cancer survivorship care planning activities. While prior systematic reviews of SCPs have focused on the creation and use of SCP documents,⁸ none have explored what types of HIT can support the generation and use of electronic SCPs and related coordination activities, and how those HIT functions impact care delivery.

Objective

The objective of this systematic review was to examine the efficacy of various HIT tools to support post-treatment cancer survivors through survivorship care planning and care coordination.

MATERIALS AND METHODS

Review framework

A pragmatic systematic review with a systematic search and a rapid review process was conducted.¹⁸ The design of the review and the

search strategy were guided by the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines.¹⁹

Search strategy

This review included interventions aimed at supporting cancer survivorship care planning after the end of primary treatment, and focused on the concept of the SCP due to its recent national focus. Search terms (see [Supplementary Appendix A](#) for search strings) consisted of a conjunction of terms related to cancer, survivorship, care planning, and HIT. Terms for care planning were supplemented with terms such as "follow-up care" or "needs assessment," which are used outside of the United States. A search was conducted in PubMed, CINAHL, EMBASE, PsychINFO, Scopus, Web of Science, and the ACM Digital Library, using structured terminologies like MeSH (Medical Subject Headings) when applicable. Reference lists of review articles found through the initial search, and authors' personal libraries were also reviewed for additional articles. The search included all full-text articles published between January 1, 2000, and January 1, 2020.

Eligibility criteria

All SCP interventions aimed at adult cancer survivors (18 years of age and older) that had a HIT component were included. Studies were not restricted based on cancer population or target end users of the technology (ie, patient or provider). Studies were included if research evaluated the intervention's effects on user satisfaction, usability, usefulness, measurements of cancer care knowledge or management ability, health outcomes and quality of life (QOL), healthcare processes, or workload. Interventions supporting end-of-life care were excluded because these are beyond the scope of survivorship care,⁴ as were interventions focused on the specific needs of adolescent and young adult survivors. Interventions only addressing physical activity, diet, or weight loss in cancer survivors were also excluded, as such interventions have been reviewed extensively.²⁰⁻²²

Study screening and selection

Two independent reviewers (S.P.M. and A.C.G.) performed the screening and full text reviews. For each stage, both researchers iteratively examined 10% of the articles for inclusion, calculated agreement with Cohen's kappa, and discussed discrepancies for adjudication. For both stages, a kappa of 0.8 was reached between reviewers after 3 iterations (30% of articles), after which the rest of the stage was completed by a single reviewer (S.P.M.). When studies were described in multiple manuscripts, the results from those manuscripts were grouped together by study. Article screening and review processes were tracked using Covidence (Melbourne, Australia).

Data extraction and synthesis

Two independent reviewers (S.P.M. and A.C.G.) initially extracted data for the included studies into an Excel spreadsheet. Each reviewer extracted data from half of the studies, assigned through the use of the random number function in Excel. Extracted data included the HIT system name, text describing system functions, country of origin, cancer population, target users, and study methodology. Descriptions of system functionality were extracted from appendices and referenced design studies when necessary.

Defining system functionality

A thematic synthesis process was used to identify HIT functionalities within each system described.²³ One reviewer (S.P.M.) reviewed all text descriptions to inductively form themes around system functions. A second reviewer (A.C.G.) also independently reviewed half of the descriptions, and themes were harmonized through discussion. Themes were then grouped into larger meta-themes, which were used to categorize interventions in each study.

Analyzing associations between functions and outcomes

After function meta-themes were formed, study results were extracted. Both reviewers (S.P.M., A.C.G.) iteratively dual-extracted results from a randomized sample of 10% of the studies and categorized results into 4 areas: (1) usability, (2) knowledge, (3) processes, and (4) health-related outcomes. Each result was categorized as being positive if it reported a high score for a positive outcome (ie, upper half of a given measurement scale) or negative if it reported a low score. Results were subsequently categorized as being statistically significant if there was improvement or degradation in an outcome for HIT intervention users derived from pre/post or intervention/control comparisons that met the significance level defined in the study (usually $P < .05$). After each review iteration, result categorizations were harmonized through discussion. After 3 iterations of this process, S.P.M. completed result extraction.

Statistical analyses were performed to assess associations between function meta-themes and study results related to knowledge, processes, and health. For each type of result, sets of contingency tables were constructed comparing the numbers of studies with and without a given feature that had positive, significant positive, negative, or significant negative results, and associations were assessed with a 2-sided Fisher's exact test using a significance level of $P < .05$. A similar analysis was performed to determine whether "complex interventions," which included [supplementary non-HIT](#) features such as consultation phone calls or paper-based informational materials, performed better than interventions with only HIT components.

Quality appraisal

During results extraction, the reviewers assessed the quality of the studies with the Mixed Method Appraisal Tool (MMAT).²⁴ Agreement in quality assessment was achieved by calculating the cumulative sum of "yes" answers to MMAT questions for each study and for each reviewer and calculating a 2-way mixed, single score intraclass correlation coefficient (ICC) through the "irr" package in R software version 3.6.2 (R Foundation for Statistical Computing, Vienna, Austria). Once the ICC for the quality metrics reached a threshold of 0.75 for an iteration, a single reviewer (S.P.M.) completed the rest of the quality appraisals.

RESULTS

Description of studies

After removing duplicates, 578 abstracts were identified and 209 underwent full text review (see [Figure 1](#)). Sixty articles encompassing 40 different research studies met inclusion criteria. [Supplementary Appendix B](#) lists the reviewed studies and their characteristics. Interventions most often targeted patients or patient-caregiver dyads ($n = 18$, 45%), followed by providers ($n = 12$, 30%) and both patients and providers ($n = 10$, 25%). The majority of interventions focused on breast cancer ($n = 16$, 40%), followed by general inter-

ventions addressing multiple cancer types ($n = 12$, 30%), and then head and neck cancers ($n = 7$, 18%). Twenty-eight (70%) studies used an electronic system developed outside of an EHR, 7 (18%) studies used an EHR or existing data registry, and 6 (15%) studies used a combination of an EHR and an external system. A substantial portion of these studies ($n = 17$, 43%) used electronic tools as part of a complex intervention that included written educational materials, clinical visits, in-person review of SCP documents, or provider consultations.

Thematic analysis identified 5 meta-themes for system functions (see [Table 1](#)). Systems collecting patient-reported outcomes (PROs) used both standardized and nonstandardized instruments to collect data. Automated content generation involved either the auto-population of a treatment summary template with existing EHR data, or assembling care plans from libraries of premade content using rules-based algorithms considering diagnosis, treatment, or symptom data. One system reported the use of electronic interfacing to send existing EHR data to an external system that then generated an SCP from premade content.²⁵ Electronic sharing consisted of exporting the SCP in a digital format such as a PDF or using e-mail, and there were none that used interfacing tools to digitally send the SCP between EHRs. Pervasive engagement features consisted of periodic notifications through text or e-mail that requested data entry, encouraged logging into the system, provided educational content, or alerted the user when concerning PRO data were entered. In 1 case, a Fitbit was integrated to create visualizations of step count data.²⁶ Communication tools included the use of messaging or Web-based message boards for patients; messaging features between patients, providers, and caregivers; or the ability to send referrals to other providers, which were always sent internally through an EHR.

The collection of PROs, persistent engagement tools, and communication tools were most often targeted at patients, and electronic sharing tools were most often targeted toward providers. [Table 2](#) summarizes the number of studies utilizing each type of function by target user group.

Effects on the SCP generation process

Some studies discussed the time required to create an SCP and the accuracy of information in SCPs. Creation of an SCP through manual data entry required approximately an hour.^{27,28} Systems leveraging rules-based algorithms required 6 to 22 minutes of data entry.^{25,29-34} Systems that auto-populated SCPs with existing EHR data were estimated to require between 2 and 30 minutes of additional manual data entry.³⁵⁻³⁷ One system that utilized both existing EHR data and a library of educational materials found that the SCPs took less than a minute to generate.²⁵ Barriers noted for efficiently creating and using SCPs included the time required to review medical records from multiple organizations,²⁷ inability to update SCPs after the initial SCP was created,³³ and the lack of data sharing between the SCP and EHR.³⁸

Studies exploring the completeness and accuracy of SCP information found that manually entered data tended to have more errors than auto-populated EHR data, but that auto-populated EHR data may omit important tumor staging information.^{33,35,39} The evaluation of an intervention that mixed manual data entry and auto-populated EHR data found the EHR data to be more complete than manually entered data, which included information on follow-up care and late-term effects.⁴⁰ While electronic HIT interventions could decrease the amount of time required to create an SCP, some

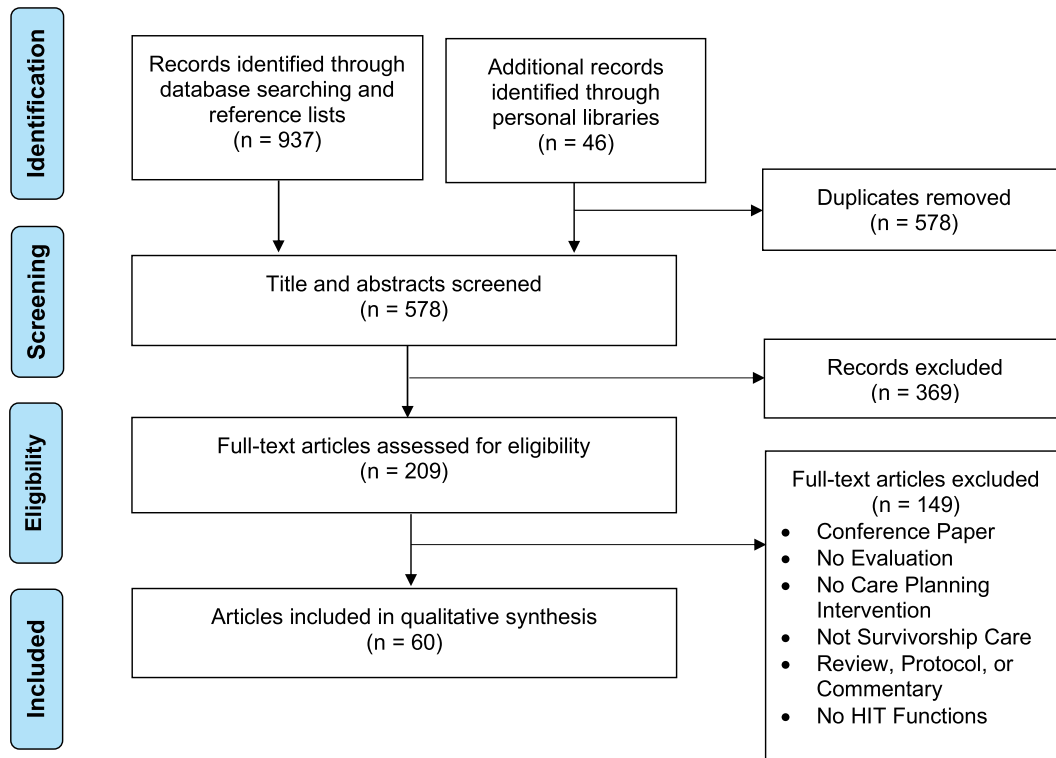


Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram. HIT: health information technology.

Table 1. Meta-themes of system functions, theme descriptions, and examples

Theme	Description
Collection of patient-reported outcomes	Collecting information from the patient about current symptoms or health status.
Automated SCP content generation	Assembling portions of an SCP from existing EHR data and/or libraries of educational content.
Electronic sharing	Tools to facilitate the sharing of a completed SCP document through electronic means.
Pervasive engagement features	The use of alerts, reminders, or persistent data entry to encourage system engagement over time.
Communication tools	Tools to facilitate electronic messaging between the patient and their care team or other survivors.

EHR: electronic health record; SCP: survivorship care plan.

Table 2. Distribution of system functions across target user groups

Users Engaged	Studies	PRO	Automated Content	Electronic Sharing	Persistent Engagement	Communication Tools
Patient (and caregiver)	18	14	9	4	10	6
Provider	12	2	9	7	0	0
Provider and patient	10	8	5	5	1	2
Total	40	24	23	16	11	8

PRO: patient-reported outcome.

found that additional time was spent providing technical support to patients.^{26,41}

Effects on patient and provider outcomes

Knowledge and care management abilities

Eighteen (45%) studies reported results related to changes in cancer care knowledge and the ability to manage care.^{26,29,31,38,41–56} Positive results (n = 17, 94%) across studies included high scores for knowledge of cancer surveillance and care coordination,^{26,29,31,43} cancer and its treatments,^{31,41,43,46,48,51,52,55–57} and symptom man-

agement^{29,53}; increased patient activation,^{26,50} personal control,⁴⁷ empowerment,^{45,46,49} and confidence in communication abilities³⁸; and improved reflectiveness about their condition.³⁸ Negative results (n = 2, 11%) included lack of patient empowerment⁵² or confidence in their knowledge for when to speak to a physician.⁵⁷

Healthcare processes

Seventeen (43%) studies reported outcomes related to healthcare processes such as the creation and sharing of an SCP, engagement with clinical services, or changing care management practices.^{28–}

^{32,34,42,44-46,50,52-56,58-64} Fifteen (88%) studies reported positive results, including effective symptom management,^{44,63,64} adherence to follow-up care,²⁹ service efficiency,²⁹ patient-provider communication,^{44,46} and improved goal setting.²⁸ Providers also noted willingness to incorporate the intervention into practice³¹ and increased identification of patient concerns through the use of an SCP.³²

Effects on engagement with healthcare services were mixed. Some analyses found increased healthcare usage^{44,53} and contact with primary care providers and specialists,⁶² but others found that there were fewer specialist visits⁵⁴ or concerns that patients may not engage with their clinicians if they have online information.⁴⁹ Two studies reported increased referrals to outside resources,^{45,55} though one also noted that few referrals were acted upon.²⁹ While some results indicated patient willingness to change behaviors or engage in supportive care,^{31,50,52} others indicated little willingness to engage with suggestions in the SCP.^{31,50,58}

There were mixed results related to sharing an SCP among the patient's care team. Intentions to share care plans ranged from 56%²⁹ to 90%.³⁴ One study found that participants regularly reporting an intent to share the SCP with their primary care provider,⁴⁶ but 2 studies found that very few patients reported actually sharing an SCP.^{46,52} Patients in one study reported that they did not plan to share their SCP due to perceptions that their provider would not care about the SCP, or that it did not accurately reflect their current care practices.^{52,60,61}

Health and QOL

Eighteen (45%) studies reported outcomes related to health or QOL, such as physical and psychosocial symptoms or measures of unmet needs.^{26,29,32,38,41,42,44-46,49,53,54,56,63,65-73} Positive results included psychosocial effects such as high levels of social functioning,⁴¹ low rates of depression,^{29,70} fatigue,^{26,70} high general QOL,^{32,44,46,72} and decreases in unmet needs.^{29,72} Some systems also saw improvement in physical symptom distress,²⁹ symptom burden,^{42,63} and improved physical self-efficacy.⁶⁶ There were also positive effects on health behaviors, such as improvements in physical activity,^{26,41,69} vegetable intake,⁶⁹ and digestion and sleep.²⁶ One system that engaged caregivers saw decreases in caregiver depression and unmet needs.²⁹ Another study found a statistically significant negative impact on a measure of employment-related concern.⁴²

There were mixed effects on fear and anxiety on having an SCP. Five studies found statistically significant improvements in anxiety, fear, health-related distress, and emotional state.^{26,63,66,67,72} Qualitative data in 2 studies indicated that SCPs did not lead to anxiety⁴¹ or worry⁵⁶ for most participants. However, one trial found statistically significant negative effects related to symptom-related concerns and changes in emotional states,^{53,71} and a decreased belief that treatment would help.^{54,71} Other studies found that warning messages in SCPs could cause anxiety⁶⁵ or remind people of their condition.^{38,56} Healthcare providers felt that interventions could make patients dwell on their disease,⁴⁹ and suggested that providing information beyond the conditions directly affecting the patient could cause concern.⁷³

Associations between features and outcomes

When assessing the associations between HIT features and outcomes (knowledge, processes, and health) among studies, only 1 significant relationship was found (see [Table 3](#)). Studies assessing interventions

with persistent engagement features had a higher proportion of statistically significant positive results related to health or QOL (89% with persistent engagement features, 13% without; $P = .003$). There were no significant associations between HIT features and knowledge or process outcomes.

Satisfaction, usability, and usefulness

Across studies, quantitative measures of usability, usefulness, and satisfaction were overall positive.^{25,26,28-31,33-35,38,40-42,44-46,48-50,52-56,58-61,65,73-82} Participants appreciated having all of their cancer care information in one place.^{26,28,46} Patients provided negative feedback when they felt that SCPs provided general information that was felt to be impersonal or vague.^{41,57,78} Providers also preferred integrating SCPs into their existing EHRs.⁸⁰

Patients also found some features to be difficult to use. One system that provided patients access to limited EHR data found that the data confused 40% of participants.⁴¹ Interventions that collected PROs found that some participants had difficulties understanding^{41,58} or answering^{50,58} questions in the instruments used, and that graphs of sensor data such as step counts could be difficult to interpret.²⁶ Providers were conflicted as to whether the collection of PROs would positively impact care by bringing new issues to light,⁴⁵ or whether it would cause patients to report old or clinically irrelevant information.³³

Patient feedback for 2 interventions called for the ability to communicate with their care team in real time.^{57,74} However, other studies reported low usefulness ratings and little use of care team-patient communication functions.^{44,75} Other qualitative feedback indicated that patients would rather talk to their providers in person than through online methods.⁷⁵ Feedback from one study suggested that persistent provider engagement encourages greater system usage by patients.⁴¹ Similarly, system usage statistics from some studies indicated that systems with active engagement features prompted subjects to use the systems regularly,^{26,44} whereas systems lacking such features were visited only a few times.^{35,78,83}

Quality appraisal

Across the 60 manuscripts reviewed, 4 (6%) used only qualitative methods, 16 (27%) used mixed quantitative and qualitative methods, and 40 (67%) used quantitative methods only. The range of MMAT metrics that were adequately addressed within the manuscripts ranged from none to all with an average score of 47%. The MMAT metrics that were least likely to be adequately addressed included accounting for confounders in nonrandomized studies (11%), groups in randomized studies being comparable at baseline (11%), and participants representing target population in nonrandomized studies (17%).

DISCUSSION

This systematic review demonstrates there are a variety of HIT tools currently used to support the creation and use of SCPs, and many studies reported positive outcomes for cancer survivors, caregivers, and care teams. Thematic analyses found 5 main types of HIT tools: electronic PROs, automated SCP content generation, electronic sharing of SCPs, pervasive engagement features, and communication tools. Collectively, these tools demonstrated improvements in user knowledge and abilities, healthcare processes, and health and QOL. However, HIT features to persistently

Table 3. Proportions of positive, statistically significant positive, negative, and statistically significant negative results between interventions with and without given functional features.

Feature Present?	Studies	Total Positive %	<i>P</i>	Significant Positive%	<i>P</i>	Total Negative %	<i>P</i>	Significant Negative %	<i>P</i>	
Studies with knowledge/ability results (n = 18)										
Collects PROs	Yes	13	1.000	.278	0.308	.326	0.154	1.000	0.000	1.000
	No	5	0.800		0.600		0.000		0.000	
Automated content generation	Yes	10	1.000	.444	0.600	.066	0.200	.477	0.000	1.000
	No	8	0.875		0.125		0.000		0.000	
Electronic sharing	Yes	6	1.000	1.000	0.500	.627	0.167	1.000	0.000	1.000
	No	12	0.917		0.333		0.083		0.000	
Persistent engagement features	Yes	5	0.800	.278	0.400	1.000	0.000	1.000	0.000	1.000
	No	13	1.000		0.385		0.154		0.000	
Communication	Yes	3	0.667	.167	0.333	1.000	0.000	1.000	0.000	1.000
	No	15	1.000		0.400		0.133		0.000	
Complex intervention	Yes	10	0.900	1.000	0.500	.367	0.000	.183	0.000	1.000
	No	8	1.000		0.250		0.250		0.000	
Studies with process results (n = 17)										
Collects PROs	Yes	13	0.846	1.000	0.154	1.000	0.538	.577	0.000	.235
	No	4	0.750		0.250		0.250		0.250	
Automated content generation	Yes	8	0.875	1.000	0.250	.577	0.875	.577	0.125	.471
	No	9	0.778		0.111		0.111		0.000	
Electronic sharing	Yes	6	0.667	.515	0.000	.515	0.667	.335	0.000	1.000
	No	11	0.909		0.182		0.364		0.091	
Persistent engagement features	Yes	4	0.750	1.000	0.500	.121	0.250	.577	0.000	1.000
	No	13	0.846		0.077		0.538		0.077	
Communication	Yes	3	0.667	.465	0.333	.465	0.333	1.000	0.000	1.000
	No	14	0.857		0.143		0.500		0.071	
Complex intervention	Yes	10	0.900	.537	0.200	1.000	0.400	.637	0.100	1.000
	No	7	0.714		0.143		0.571		0.000	
Studies with health/quality-of-life results (n = 17)										
Collects PROs	Yes	12	0.750	.600	0.583	.620	0.250	.280	0.000	.074
	No	5	0.600		0.400		0.600		0.400	
Automated content generation	Yes	6	0.667	1.000	0.667	.620	0.333	1.000	0.167	1.000
	No	11	0.727		0.455		0.364		0.091	
Electronic sharing	Yes	4	0.750	1.000	0.250	.294	0.250	1.000	0.000	1.000
	No	13	0.692		0.615		0.385		0.154	
Persistent engagement features	Yes	9	0.889	.131	0.889	.003 ^a	0.222	.335	0.111	1.000
	No	8	0.500		0.125		0.500		0.125	
Communication	Yes	4	1.000	.261	1.000	.082	0.250	1.000	0.250	.427
	No	13	0.615		0.385		0.385		0.077	
Complex intervention	Yes	10	0.600	.338	0.400	.335	0.400	1.000	0.200	.485
	No	7	0.857		0.714		0.286		0.000	

The results are split by type of outcome considered: knowledge/ability, healthcare processes, and health/quality of life. All *P* values were calculated with a 2-sided Fisher's exact test.

PRO: patient-reported outcome.

^aSignificant at a level of *P* < .05.

engage users, such as reminders, were the only type of tool found to be significantly associated with improved health and QOL outcomes. This may be due to the increased engagement fostered by those systems, which suggests that SCP interventions should be dynamic and change longitudinally along with patients' needs.¹⁴ The use of algorithms to generate SCPs based on existing data reduced time to create an SCP, and importing existing data from an EHR into an SCP treatment summary could also improve the accuracy and completeness of data in the SCP. Although the most commonly used, PROs were not associated with improvements in any outcome area. However, in many interventions, PRO measures were only collected during the creation of the SCP and not longitudinally, limiting the ability of the interventions to evaluate changes in status over time.

Implications for cancer survivorship and research

Few studies addressed the sharing of SCPs across a care team or communication between providers in a care team, demonstrating that HIT interoperability has not been adequately explored for SCPs. This may be due to the small number of studies that contained HIT tools integrated within the EHR in this review. Recent research indicates that most SCPs in the U.S. are not developed within EHRs, and that providers often rely on fax and mail to distribute SCPs across the care team.¹⁶ The reliance on manual work to share an SCP and patient perceptions that their care team would not use an SCP may have led to the mixed results related to intentions to share SCPs.

None of the interventions supported referrals or coordination activities that crossed organizational boundaries. Using technology to

share information between care settings and providers is a substantial opportunity because many oncology offices are small, community-based practices⁸⁴ that may not offer diverse ancillary services. A majority of cancer survivors also prefer that oncologists and primary care providers share responsibilities for their care.⁸⁵ Additionally, a lack of care coordination and communication between these settings can lead to adverse patient outcomes.⁸⁶ Medical records for cancer survivors can be spread across multiple specialties and settings,⁸⁷ making it difficult to aggregate data for SCPs. While HIT tools could ease information sharing across settings, few interventions leveraged SCPs as a care coordination tool.¹⁰ Future research should explore the use of data exchange standards and standardized terminologies to exchange granular SCP information between digital systems. Future EHR functions and stand-alone systems could leverage the existing eCOTPS (electronic Clinical Oncology Treatment Plan and Summary) standard⁸⁸ to communicate information about post-treatment plans between care settings. Also, newer standards such as the mCODE (Minimal Common Oncology Data Elements) standard,¹⁷ which leverages FHIR (Fast Healthcare Interoperability Resources), should be further developed to consider survivorship use cases.

There were mixed results regarding whether the information in an SCP could provoke anxiety over the cancer diagnosis or be comforting due to improved ability to address the condition. Mixed results related to the perceived usefulness and usability of functions such as PRO collection and communication tools also suggests that HIT to support SCP processes may require a collection of features that can be tailored to the needs of specific patients and their care teams, and that these may have the most value if used longitudinally. A tailored approach is in line with current survivorship care trends toward the provision of personalized care.¹³

Limitations

A potential limitation of this review is the quality of the studies assessed, which was moderate overall. Many studies did not adequately address representativeness of study populations, address differences between comparison groups, or consider potential confounding variables. Future studies should assess diverse groups of survivors to better understand how user characteristics can impact system usage. Some studies did assess differences in suitability for different groups, finding that system effectiveness could vary based on treatment types and educational attainment,⁷⁰ perceived personal control,⁸⁹ information coping styles,⁷⁹ age,^{67,70} cancer types,⁷⁷ and Internet usage.⁹⁰ Future studies should also explore the specific needs of subpopulations and the use of system configurability to address the needs of multiple populations.

Owing to the heterogeneity of the results considered and study designs, a meta-analysis of the results could not be conducted. Instead, the results were categorized into binary positive and negative categorizations, and therefore cannot account for measured effect sizes across results. Many of the interventions were complex and included multiple features, and statistical analyses could not explore potential interactions between different features due to a lack of statistical power from the small sample sizes. Some systems, such as OncoKompas and OncoLink, were evaluated in multiple studies which could potentially bias the results due to the undue influence of these systems. Also, the paucity of negative outcome results overall may indicate publication bias in this literature. Overall, however, the breadth of results provides a wide range of guidance for future SCP system designers.

CONCLUSION

The current body of literature on SCP interventions with HIT components indicates that there is a positive though limited impact on cancer survivorship care. Interventions that had the greatest impact on the patient's health and QOL had features that engaged the user longitudinally, emphasizing that cancer survivors need a dynamic care plan that changes along with their health status. Most systems have not capitalized on HIT to facilitate communication of information across a care team to better coordinate care. Future system designers should focus not only on engaging system users, but also on connecting users to their care teams and resources to improve survivorship care.

FUNDING

SPM is supported by a National Institutes of Health/National Cancer Institute National Research Service Award sponsored by the Lineberger Comprehensive Cancer Center at the University of North Carolina (T32 CA116339). ACG is supported by National Institutes of Health/National Library of Medicine training grant 5T15LM012500-04.

AUTHOR CONTRIBUTIONS

SPM, ACG, and AEC conceived and designed the study and methods. SPM and ACG extracted data and coding of themes, and undertook the analyses. All authors contributed to interpretation of results and approved the final version of the submitted manuscript.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

DATA AVAILABILITY STATEMENT

The data underlying this article will be shared on reasonable request to the corresponding author.

CONFLICT OF INTEREST STATEMENT

Authors have no conflicts of interest to disclose.

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