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Advancing Patient Centered Cancer Survivorship Care: Evaluation of a Dissemination Project

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Abstract

Care coordination among primary care providers and oncologists continues to be a challenge in cancer survivorship care. The Advancing Patient-Centered Cancer Survivorship Care Toolkit (“Toolkit”) was developed to provide a “workshop in a box” for comprehensive cancer control (CCC) stakeholders to advance patient-centered cancer survivorship care in their region. Methods: The Toolkit was disseminated through an e-learning module, established webpages, an online forum and social media. Toolkit dissemination was evaluated using the RE-AIM framework. For effectiveness, e-learning module and workshop participants were surveyed to assess changes in confidence in learning objectives. Results: The Toolkit web page received over 10,000 impressions. E-learning module participants (n=212) reported statistically significant improvement, ($p<0.001$), between the pre- ($M=3.42$, $SD=0.85$) and post-test ($M=4.18$, $SD=0.60$) mean scores on self-confidence to describe patient reported priorities for cancer survivorship care. Among virtual workshop trainees (n=121), 28 participants completed paired pre- and post-workshop surveys. Among those with matched responses, there were statistically significant improvements from pre- to post-workshop self-reported knowledge on what patients want in cancer survivorship care ($M=2.5$, $SD=1.0$ v. $M=3.3$, $SD=1.0$, $p=0.001$); confidence in describing critical components of patient-centered cancer survivorship care ($M=3.1$, $SD=1.2$ v. $M=4.2$, $SD=0.5$, $p<0.001$); and confidence in describing patient priorities for cancer survivorship care ($M=3.0$, $SD=1.1$ v. $M=4.1$, $SD=0.6$, $p<0.001$). Conclusion: Provision of technical assistance resources in a variety of formats can successfully build capacity of healthcare providers and

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comprehensive cancer coalition stakeholders to feel more prepared to deliver patient-centered, coordinated cancer survivorship care.

Keywords

Cancer survivorship; patient-centered care; technical assistance; comprehensive cancer control

Introduction

As of 2019, there were more than 16.9 million cancer survivors in the United States [1]. It is projected that the number of cancer survivors will grow to 20.3 million by 2026 [2]. In 2005, the National Academies of Science, Engineering and Medicine (NASEM) released a seminal report highlighting how high quality, patient-centered post-treatment cancer care is critical to optimize wellness in cancer survivors. The report also identified critical gaps that contribute to inadequate post-treatment care, including lack of coordinated care due to suboptimal communication as well as lack of training in cancer survivorship care [3].

More than a decade has passed since the release of the report and lack of coordination and communication between primary care providers and oncologists continues to be a challenge in cancer survivorship care [4]. This challenge could be due to the absence of clear delineations of care responsibilities and accountability. Medical oncologists prefer to manage cancer survivors' follow-up care for a variety of reasons, such as lack of confidence in primary care providers' capacity [5], personal relationships formed with patients [6], and/or ill-distinguished survivorship care responsibilities [7]. Primary care providers mostly prefer to co-manage survivorship care, but often cannot access adequate guidance and coordination from medical oncologists [8–10]. A key recommendation from the NASEM report called for training that "stresses the need for multidisciplinary approaches, integrated and coordinated care, and effective use of community-based resources" [3]. However, both primary care and oncology providers cite a lack of education and training on cancer survivorship care [8, 9, 6, 11, 12]. Additionally, oncologists and primary care providers have different viewpoints regarding their roles and models of care [7]. Training that supports positive outcomes at the patient and organizational level could be part of the solution to address this challenge.

Twenty years ago, the Center for Disease Control and Prevention (CDC) established the National Comprehensive Cancer Control Program (NCCCP) to support comprehensive cancer control (CCC) efforts using a coalition-based approach [13]. CCC programs and coalitions hold annual meetings and conferences that bring together a wide range of health care providers, community-based representatives, and other stakeholders with the aim of advancing survivorship care goals and objectives. CCC programs and coalitions are thus ideal dissemination partners to advance patient-centered cancer survivorship care.

In 2013, the George Washington University launched a study called *Evaluating Cancer Survivorship Care Models* that resulted in the development and validation of a Patient-Centered Survivorship Care Framework [14] and Index (PC-SCI) to help health care providers develop, assess and track patient-centered survivorship care. Development of

the Framework was based on interviews with 170 breast, prostate and colorectal cancer survivors [14]. Creation of the PC-SCI was based on a survey from 1,278 cancer survivors. The PC-SCI includes a total of 36 constructs across seven factors that measure patient-centered survivorship care; its psychometric properties will be published elsewhere. To help translate research findings to practice, the constructs of the PCS-SCI were used to develop the Advancing Patient-Centered Cancer Survivorship Care Toolkit (“Toolkit”). For purposes of the Toolkit, PC-SCI constructs were adapted to create surveys that could be completed by patients and providers, respectively, to assess how well each construct is currently being met in survivorship care delivery. Leveraging existing infrastructures and relationships in CCC, this study documents a pilot project that aimed to disseminate patient preferences outlined in the PC-SCI through technical assistance workshops in close collaboration with CCC programs and coalitions.

Methods

Toolkit development and dissemination

The Advancing Patient-Centered Cancer Survivorship Care Toolkit (“Toolkit”) was developed to provide a “workshop in a box” for CCC stakeholders (e.g. National Comprehensive Cancer Control Program Directors, Comprehensive Cancer Coalition staff and leadership, coalition members from diverse community based organization, cancer care, business, and government sectors) in order to advance coordinated cancer survivorship care in their regions. The Toolkit, which can be found at <http://bit.ly/AdvancingCancerSurvivorshipCareToolkit>, contained a trainer manual and slide deck, needs assessment tools, clinical support tools, workshop tools, evaluation tools and survivorship resources based on a validated PC-SCI. A Community Advisory Board (CAB) that consisted of CCC leaders, survivorship care clinicians, and cancer survivors provided feedback and guidance on the Toolkit. The Toolkit was disseminated through an e-learning module, established webpages, an online forum and social media. Additionally, four virtual workshops, facilitated by the Toolkit’s authors and CCC leaders, provided step-by-step guidance to clinicians and CCC stakeholders on how to assess the current state of cancer survivorship services and prioritize quality improvements. An online forum was accessible to all workshop participants to exchange ideas, continue peer engagement outside of the live sessions, and access resources. In addition, a continuing education-accredited mini e-learning module was added to the GW Cancer Center Cancer Survivorship E-Learning Series. The module gave an overview of patient priorities of survivorship care, described the PC-SCI, introduced the Toolkit, and made it available to learners.

Data collection and evaluation

The study evaluation was guided by the RE-AIM framework [15]. RE-AIM stands for reach, effectiveness, adoption, implementation and maintenance. Specifically, constructs of Reach, Effectiveness, Adoption, and Implementation were measured in this study. Maintenance was not assessed. Reach was captured through the number of toolkit downloads, number of learners participating in workshops, number of learners completing an e-learning module and number of participants engaging on the online forum. To evaluate effectiveness of the workshops, changes in self-reported knowledge among workshop participants and

self-reported changes in motivation and skill were measured by pre- and post-workshop surveys. Adoption was measured as intent to implement lessons learned into clinical practice (post-test only) among learners who participated in the mini-module and workshops.

Implementation was measured in a follow-up survey to workshop participants to assess actual use of lessons learned in practice.

Workshops.—Surveys measuring workshop effectiveness were distributed via a direct link to REDCap sent to workshop participants (n=107) [16]. Participants were asked the following questions using a Likert scale of Poor/Strongly Disagree (1) to Excellent/Strongly Agree (5): 1) How would you rate your knowledge of what patients want in cancer survivorship care?; 2) I recognize the need for cancer survivorship care; 3) I can describe critical components of patient-centered cancer survivorship care; 4) I can describe patient priorities for cancer survivorship care; 5) I am motivated to help improve cancer survivorship care; and 6) I am motivated to make changes in my own practice to improve cancer survivorship care.

Web based polling was used to evaluate effectiveness for one set of the workshops (n=14). This decision was made due to the perception of the conveners regarding participant resistance to completing pre- and post-workshop surveys in order to avoid loss of data and to test multiple modes of evaluation. Participants were asked the following questions using a Likert scale of Poor/Strongly Disagree (1) to Excellent/Strongly Agree (5). 1) I can apply what I have learned to enhance my coalition's capacity to implement system level approaches to address survivor needs; 2) I was able to learn what other CCC programs are doing; 3) I was able to share what my CCC is doing; 4) The group discussions presented an opportunity to identify gaps and next steps; and 5) Overall, how would you rate the workshop? Additional questions to measure adoption were asked in a post-test, including assessment of learners' confidence to utilize the knowledge and strategy acquired during the workshop into practice. The percentages for each question were similarly based on a Likert scale from Strongly Disagree (1) to Strongly Agree (5). Questions included: 1) I am able to identify potential barriers to implementing survivorship goal(s) in my state; and 2) I feel equipped to develop potential strategies (solutions) to address identified barriers to achieving my state's survivorship goals.

E-learning series.—The E-learning series component was evaluated using surveys that were directly accessed on the Learning Management System (LMS) that housed the module. Participants were asked the following questions using a Likert scale of Poor/Strongly Disagree (1) to Excellent/Strongly Agree (5): 1) My knowledge base was enhanced as a result of the module content; 2) I gained new strategies/skills/information that I can apply to my area of practice; and 3) I would recommend this module to others. Additionally, learners were asked to rate their confidence in their ability to describe patient reported priorities for cancer survivorship care. Adoption was similarly captured at post-test by inquiring about learners' plans to implement new strategies/ skills/ information into practice and motivation to make changes to their work as a result of the module.

Results

Reach

Toolkit and Workshops.—The Toolkit was disseminated through various media, including GW Cancer Center e-newsletters and social media posts. As of June 25, 2021, there were 4,156 visits to the Toolkit landing page and 5,988 downloads of Toolkit components for a total of 10,144 impressions. Virtual workshops sessions were conducted over a span of two months and had a total reach of 121 participants (Table 1). Participants included representatives from six states and two tribal coalitions.

E-Learning Series.—Two-hundred thirty-six learners enrolled in the mini e-learning module and 212 of these learners completed the module.

Forum.—Thirty-seven individuals joined the online platform to access PCORI workshop materials; however, users of the platform did not engage in any active discussions and only one question was posted on the Q&A forum regarding a measure for increasing the completion and delivery of survivorship care plans. Some workshop participants expressed dissatisfaction with having to access an additional site for materials and some participants expressed feeling overwhelmed with the number of resources collated on the forum.

Effectiveness

Workshops.—Among states and tribal coalitions that were surveyed (n=107), each participant was asked to create a unique identifier that would maintain their anonymity while allowing the project team to match pre- and post-workshop surveys. However, despite giving instructions on how to create the identifier, many pre-test identifiers did not match post-test identifiers and, in one case, there were two post-tests completed by the same individual. In the case of repeated surveys, the entry with the most complete data was kept. If both entries had complete data, the response entered last was kept and the duplicate was eliminated. Not all workshop participants completed the pre and post workshop surveys. Of 53 pre-tests and 42 post-tests completed, one post-test was omitted from analysis as a duplicate, leaving 53 pre-tests and 41 post-tests. Of these, 28 were able to be matched. A paired sample t-test was conducted on the matched data (n=28). Due to the amount of lost data from matching, an independent sample t-test was also used to examine differences in the full sample (n=53 pre-test v. n=41 post-test) to determine if results varied from the paired t-test. Results did not vary in the independent samples t-test; therefore, only paired t-test results are reported.

Among states and tribal coalitions that were surveyed, there were statistically significant improvements from pre-workshop to post-workshop: self-reported knowledge on what the participants think patients want in cancer survivorship care ($M=2.5$, $SD=1.0$ v. $M=3.3$, $SD=1.0$, $p=0.001$); confidence in being able to describe critical components of patient-centered cancer survivorship care ($M=3.1$, $SD=1.2$ v. $M=4.2$, $SD=0.5$, $p<0.001$); and confidence in being able to describe patient priorities for cancer survivorship care ($M=3.0$, $SD=1.1$ v. $M=4.1$, $SD=0.6$, $p<0.001$) (Table 2). No other results were statistically significant. Approximately 89% of workshop participants rated the workshop as very good/excellent or good.

Among participants that were polled in lieu of being surveyed (n=14), 86% strongly agreed or agreed that the workshop provided knowledge to understand what other CCC programs are doing, indicated they were able to share their own coalition activities with others, and reported that they would apply what they learned to enhance their coalition's capacity to address survivorship needs. Ninety three percent (93%) of respondents strongly agreed or agreed that group discussions during the workshop presented an opportunity to identify knowledge gaps and next steps. All attendees intended to share or use the information and strategies discussed via different ways such as information dissemination and training with their coalition members, engaging new partners, and identifying evidence-based interventions to implement.

E-Learning Series.—Due to a change in the learning management system (LMS) in June 2020, e-learning series module results were reported separately for data in the old v. new LMS. Out of 137 learners on the old LMS, 94.9% agreed/strongly agreed that their knowledge was enhanced as a result of the module; 88.3% agreed/strongly agreed that they have gained new strategies/skills/information they could apply to their area of practice. Out of 75 learners who completed the post-evaluation survey in the new LMS, 92.0% agreed/strongly agreed that their knowledge increased after completing the module and 88.0% agreed/strongly agreed they would recommend the module to others. Mean scores of participant confidence in ability to describe patient reported priorities for cancer survivorship care showed statistically significant improvements from pre- ($M=3.42$, $SD=0.85$) to post-test ($M=4.18$, $SD=0.60$), $p<0.001$.

Adoption

Workshops.—Forty-one workshop participants completed post-tests to inform adoption. Of these individuals, 85.4% agreed/strongly that they would implement new strategies and use new resources into their work as a result of the workshop; 75.6% agreed/strongly agreed that they will be able to apply what they learned in the workshop to their work; 82.9% agreed/strongly agreed that examples given at the workshop were practical; 82.9% agreed/strongly agreed that the workshop increased their knowledge of what patient-centered cancer survivorship care looks like (please see table 3 for more details). Of the state coalitions that were polled (n=9), 67% of the respondents indicated that they would apply what they have learned to enhance their coalition's capacity to address survivorship needs. Eighty nine percent (89%) of the participants strongly agreed or agreed that they were able to identify potential barriers to implementing survivorship goals in their state. Seventy eight percent (78%) agreed that they felt equipped to develop an action plan to address their state's priority survivorship goals. Eighty nine percent (89%) of the respondents agreed that they were able to develop potential strategies to address identified barriers to reaching survivorship goals.

E-Learning Series.—Out of 137 learners on the old LMS, 86.1% agreed/strongly agreed that they planned to implement new strategies/skills/information into their practice. Out of 75 learners who completed the post-evaluation survey in the new LMS, 89.3% agreed/strongly agreed that they were motivated to make changes to their work as a result of the

module and the same percentage of learners intended to apply what they have learned in this module to their work.

Implementation of Workshop Lessons Learned

Participants of the virtual workshops were surveyed two to three months following the workshop to assess actual implementation of lessons learned. Feedback from participants who responded to the follow-up survey (n=9) reported the following successes in implementing lessons learned: referral process improvement, obtaining appropriate resources for patients, and improved care coordination. One participant said that as a result of the workshop, there was “more talk about communication and making the referral process smoother” (participant 2). Another team mentioned that they made progress assisting patients with resources (participant 4) and “finalized a survivorship guide” (participant 9). Improved care coordination was another benefit of participation. One team experienced “Better communication with medical staff and other providers to keep up with the patient once out of our care” following the workshop (participant 6).

Initial challenges faced included lack of resources, including “administrative support and time” (participant 3), “The biggest challenge for the cancer centers is having the time, staff and funding” (participant 7). Additionally, one experienced challenges coordinating quality improvement planning and implementation in a virtual environment: “The greatest challenges we had in working with this process were having to do it virtually and having representation from all roles involved with patient care at the cancer centers” (participant 7).

Changes to the Toolkit

As a result of conducting four sets of virtual workshops, the project team identified a variety of improvements that could be made to the Toolkit and revised it accordingly. Examples of changes include: updating the slide deck graphs to correspond to current data and adding links to local data for easy access during presentations. The online platform (i.e., the forum component) was deactivated due to lack of use. Activity sheets on the facilitation guide were linked out from the main web page for ease of access and use. Additional resources were added to the survivorship resource list. In addition to workshop feedback, some changes were informed by continuous monitoring of the toolkit usage.

Discussion

Cancer survivorship is one of four NCCCP priorities. A study published in 2020 found that 86% of cancer control national plans identified survivorship as a priority in their cancer control programs [17]. To advance these CCC goals, availability of resources and training to build capacity in delivering high-quality, patient-centered survivorship care are critical. This project aimed to support CCC survivorship goals by disseminating evidence through a variety of practical learning approaches: a downloadable Toolkit, a series of virtual workshops, and an E-learning module to promote patient-centered cancer survivorship care. These diverse educational mechanisms were designed to reach those with different preferences in learning and to mutually reinforce each other for layer learning.

This study demonstrated the feasibility of broadly reaching interested stakeholders through dissemination of a series of technical assistance resources focused on patient-centered cancer survivorship care. Workshops utilizing the Toolkit successfully improved learners self-reported knowledge about cancer survivor healthcare needs and confidence in describing critical components of patient priorities for cancer survivorship care. The lack of significant learner improvement in understanding the necessity of cancer survivorship care, motivation to help improve cancer survivorship care and motivation to make changes in the participants' practice to improve cancer survivorship care is likely due to high understanding and motivation at baseline. Overall, findings support the use of this Toolkit among CCC groups to facilitate needs assessments and quality improvement projects in collaboration with cancer survivorship care providers and community-based organizations.

Data from the E-learning mini module showed a high completion rate with more than 80% of the learners reporting enhanced self-reported knowledge and attainment of new skills in providing cancer survivorship care. The module provided an accessible platform for healthcare professional learners.

A lesson learned in this project was that creation of an additional forum for information exchange and networking was not valued by learners. Particularly for clinicians, adding an additional place to seek information was perceived as burdensome. Future educational interventions for clinicians should optimize efficiency and ease of access to critical information in order to improve the user experience.

Strengths and Limitations.

A strength of this study was the inclusion of various metrics for evaluation, using RE-AIM. An additional strength was the support of a diverse CAB to provide feedback and guidance on the learning products developed. The diversity of the community advisory board ensured that application of the Toolkit would support varied medical oncology and primary care settings, including rural, urban, and tribal-affiliated clinics. CAB members' expertise spanned academic hospital systems, cancer research centers, Hispanic community organizations, rural public and Tribal health systems, and cancer survivors. The feedback from the CAB informed approaches to bolster care coordination and communication between primary care providers and oncologists. Limitations of the study included: use of non-validated evaluation measures, substantial loss of data due to difficulty in matching workshop learners' pre- and post-workshop surveys and individual choice not to complete evaluation surveys, the small sample size, the self-report nature of surveys, and limited time to follow up post-workshop to determine actual use of lessons learned.

Conclusion

Cancer survivorship care providers and coalition stakeholders are highly motivated to learn how to improve patient-centered care. Provision of technical assistance resources in a variety of formats can successfully build knowledge and confidence in the delivery and coordination of cancer survivorship care among diverse learners. CCC groups are well-positioned to convene coalition members to assess and strategically plan for ongoing cancer survivorship care improvements. The Advancing Cancer Survivorship Care Toolkit is one resource to

help coalitions assess and prioritize improvements in coordinated cancer survivorship care for their region.

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Availability of data and material:

Data reported here is available upon reasonable request to the corresponding author.

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Table 1.

Reach of Dissemination of Advancing Patient-Centered Cancer Survivorship Care Toolkit

Dissemination Approach	Reach
Toolkit available online	10,144 impressions
E-learning module	212 learners
Virtual workshops	121 learners

Table 2.

Change in Learning Objectives from Pre-test to Post-test (n=28)

	Pre-test M (SD)	Post-test M (SD)	p-value
Self-reported knowledge on what participants think patients want in survivorship care	2.5 (1.0)	3.3 (1.0)	0.001
Confidence in being able to describe critical components of patient-centered cancer survivorship care	3.1 (1.2)	4.2 (0.5)	<0.001
Confidence in being able to describe patient priorities for cancer survivorship care	3.0 (1.1)	4.1 (0.6)	<0.001
Understanding necessity of cancer survivorship care	4.6 (0.6)	4.6 (0.8)	1.00
Self-reported motivation to help improve cancer survivorship care	4.4 (1.0)	4.4 (0.8)	0.90
Self-reported motivation to make changes in the participants' practice to improve cancer survivorship care	4.5 (0.7)	4.4 (0.6)	0.40

Table 3.

Workshop Effectiveness and Adoption of Lessons Learned, n=41, n (%)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I will implement new strategies and resources into my work as a result of the workshop	0 (0)	0 (0)	(6) 14.6	22 (53.7)	13 (31.7)
I can apply what I learned today to my work	0 (0)	2 (4.9)	8 (19.5)	14 (34.1)	17 (41.5)
The examples given in the workshop were practical	1 (2.4)	0 (0)	6 (14.6)	21 (51.2)	13 (31.7)
The workshop increased my knowledge of what patient-lefted cancer survivorship looks like	1 (2.4)	1 (2.4)	5 (12.2)	19 (46.3)	15 (36.6)