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Learning the landscape: implementation challenges of primary care innovators around cancer survivorship care

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Abstract

Purpose This study describes the experiences of early implementers of primary care-focused cancer survivorship delivery models.

Methods Snowball sampling was used to identify innovators. Twelve participants (five cancer survivorship primary care innovators and seven content experts) attended a working conference focused on cancer survivorship population strategies and primary care transformation. Data included meeting discussion transcripts/field notes, transcribed in-depth innovator interviews, and innovators' summaries of care models. We used a multistep immersion/crystallization analytic approach, guided by a primary care organizational change model.

Results Innovative practice models included: (1) a consultative model in a primary care setting; (2) a primary care physician (PCP)-led, blended consultative/panel-based model in an oncology setting; (3) an oncology nurse navigator in a primary care practice; and (4) two subspecialty models where PCPs in a general medical practice dedicated part of their patient panel to cancer survivors. Implementation challenges included (1) lack of key stakeholder buy-in; (2) practice resources allocated to competing (non-survivorship) change efforts; and (3) competition with higher priority initiatives incentivized by payers.

Conclusions Cancer survivorship delivery models are potentially feasible in primary care; however, significant barriers to widespread implementation exist. Implementation efforts would benefit from increasing the awareness and potential value-add of primary care-focused strategies to address survivors' needs.

Implications for Cancer Survivors Current models of primary care-based cancer survivorship care may not be sustainable. Innovative strategies to provide quality care to this growing population of survivors need to be developed and integrated into primary care settings.

Keywords Cancer survivorship models · Primary care · Implementation research · Qualitative · Integration of care

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Introduction

People with a history of cancer are living longer. Of the approximately 14 million cancer survivors in the USA, most (64 %) were diagnosed 5 years ago and a growing number (15 %) were diagnosed more than 20 years ago [1, 2]. By 2022, it is anticipated that demographic shifts will increase the number of cancer survivors to 18.2 million [3]. In the next decade, long-term survivors (those five or more years post-diagnosis) will account for 11.9 million cancer survivors [3]. Nevertheless, the USA lacks adequate care coordination processes to facilitate the transition from oncology-based active treatment to primary care-based survivorship care and patients must navigate the aftercare phase with little or no guidance [4]. Clinicians and researchers continue to grapple with questions about how best to transition patients, how to organize long-term survivorship care, and how to communicate about and with subpopulations of survivors to meet their needs.

The long-term care needs of many cancer survivors can be integrated into primary care chronic care models, which have been demonstrated in several trials to be as effective as oncology care for both clinical and quality of life outcomes [5–8]. Follow-up care for cancer survivors includes assessing risk for recurrence and as well as monitoring for secondary cancers in the context of previous and/or current cancer therapies, genetic predispositions, lifestyle behaviors (e.g., physical activity, weight maintenance, sun protection, smoking cessation), and other co-morbid health conditions [4, 9, 10]. Efforts to translate these optimal care processes into practice have focused on advocating for clearer roles among the different providers, improved communications, and the implementation of survivorship care plans [9, 11, 12].

Primary care models of survivorship care that integrate survivors' needs into population health models have been proposed but have received surprisingly little attention [13]. Nationally, primary care is being transformed to respond to changing patient presentations, particularly multimorbidity, defined as the coexistence of multiple chronic conditions [14]. The clinical emphasis on multimorbidity is reflective of a paradigm shift from single-disease models (e.g., for asthma, diabetes, etc.) to models acknowledging that most patients, especially older patients, present with multiple conditions [15]. Multimorbidity also has implications for clinical oncology practice, impacting the treatment and symptom burden of patients during the acute care phase with effects that carry through into recovery and survivorship [16].

The challenges of integrating cancer survivorship care in oncology-based settings are the subject of ongoing research; however, there is a notable lack of research on implementing cancer survivorship models in primary care [17, 18]. There also remains a puzzling lack of exploration into how the long-term health needs of cancer survivors could be integrated into newly emerging models of primary care, even though the majority of cancer survivors (70 %) are managing at least one co-morbid condition that may warrant focused follow-up care [19]. Primary care physicians (PCPs) are willing to take responsibility for cancer survivors after the completion of treatment [20] and prefer a shared care model with oncologists [21]; however, oncologists and PCPs have yet to agree on the role of primary care in survivorship care [22]. In a recent study, over 50 % of PCPs reported providing survivorship care [22], but there is no empirical evidence demonstrating the capacity and commitment of primary care to deliver cancer survivorship care. It will be critical to assess organizational capacity when implementing strategic changes to primary care practices that can address overall population health [23, 24].

This article begins to address this knowledge gap by describing the experiences of several primary care innovators in the USA and Canada who implemented strategies to address the needs of long-term cancer survivors in their clinical settings.

Methods

A two-and-a-half day working conference focused on primary care transformation and "untraditional populations" was held in Denver Colorado on April 20–22, 2015 and hosted by the Rutgers, Robert Wood Johnson Medical School's Department of Family Medicine and Community Health. This conference was part of a series funded by the Agency for Healthcare Research and Quality (AHRQ) (R13HS021287) to explore critical issues in primary care redesign efforts that can provide higher quality, accessible care at lowered cost [25–31]. To achieve these goals, redesign efforts emphasize the following: (1) reorienting the primary care practice toward a population perspective [29]; (2) developing collaborative teams [32, 33]; (3) integrating the practice within the healthcare neighborhood [34–39]; (4) adapting health information technology to meet meaningful use criteria [40–42]; and (5) changing the roles and identities of clinicians and staff within the practice [43]. The two foci populations for this conference were cancer survivors and persons in need of substance abuse care. In this manuscript, we focus on cancer survivorship.

This exploratory, open-ended, qualitative methodology was chosen to elicit how the broader primary care context shapes the survivorship care implementation process and to explore how innovators adapted to their unique circumstances. The interactive nature of this inquiry allowed innovators to reflect on their experiences with implementation in the presence of content experts in primary care transformation, experts in cancer survivorship, and cancer survivors. This was a methodological design choice, a purposeful adaptation of the learning collaborative model often used as an inexpensive mechanism to support leaders who are implementing primary care transformation and to elicit an understanding of how organizations adapt to change [44]. Rather than focusing on adapting a new innovation, which is typical in learning collaborative forums, this conference focused on innovators' experiences to understand the process of implementation. Following a traditional aim of evaluative qualitative methodologies, the resulting data described how program goals were formed and how and why adaptations to these goals occurred [45].

The meeting agenda was organized with an eye toward eliciting stories of process change in primary care. The objective was to create a forum for interaction and reflection about the change process among implementers, content experts, and survivors. To achieve this objective, the meeting agenda included (1) introductions of each practice innovator's implementation story; (2) a large group inside/outside "fish bowl" discussion (i.e., a structured large group discussion with inner and outer circles where outside members could rotate in based on the topic) exploring the internal and external forces shaping the development of practice models; (3) small group breakout sessions to explore practice-level barriers and facilitators to model implementation; and (4) a large group discussion synthesizing key lessons across conference participants.

Practice and participant recruitment

Primary care practices focused on cancer survivorship care are rare in North America; therefore, we used a snowball sampling strategy to purposefully select innovators with this experience. We began by emailing 31 academic colleagues in September 2014, including clinicians and researchers who are engaged in collaborative work on survivorship in primary care spearheaded by the American Society of Clinical Oncology, the American Academy of Family Physicians and the American College of Physicians-Internal Medicine (see Table 1 for the process of innovator identification, including snowball sampling sources). We asked these individuals for recommendations of innovative primary care-centric cancer survivorship models in the USA and Canada. From these requests, we identified cancer survivor programs in the USA and Canada, specifically, seven primary care practices using a range of care models. Internet research and phone interviews with these practice leaders were conducted between September 2014 and January 2015 to create descriptive summaries of characteristics and key cancer survivorship care innovations. The innovators in primary care steering committee (see Table 1 for steering committee membership) reviewed the descriptive summaries and selected five cancer survivorship-focused practices that differed in size, location, and type/setting (e.g., family medicine, internal medicine, pediatrics, nurse-led, community health center). All five of the selected innovators in cancer survivorship accepted the invitation to participate (see Table 1 for selected primary care innovators).

Twenty-nine people in total attended the conference, including five primary care cancer survivorship innovators, five primary care substance abuse champions, three members of the innovators in primary care steering committee, two cancer survivorship experts, three community representatives (i.e., two cancer survivors and one substance abuse patient), two substance abuse experts, and four dissemination consultants, four staff members, and one representative from AHRQ. Twelve were considered participants in this research study (i.e., five innovators, three primary care transformation experts, two cancer survivorship experts, and two cancer survivors).

Informed consent was received from all practice innovators who were interviewed about their implementation experiences. The Rutgers University Biomedical and Health Sciences Institutional Review Board approved this study.

Data collection

All conference sessions were digitally recorded and extensive notes were taken by qualitative researchers at each session. These totaled approximately 15 hours of recordings and 30 pages of typed notes. Prior to the conference, each practice innovator wrote a 2–4-page summary of their practice's innovations, which served as a starting point for one-on-one, digitally recorded interviews.

Innovator interviews ranged from 30 to 90 minutes in length and were conducted by a sociologist and a masters-prepared social work doctoral student with extensive qualitative interviewing experience (JH and DO). A semi-structured interview guide was developed to elicit information about innovators' experiences in implementing practice changes related to survivorship care. The interview guide included general questions about the innovator's role in the practice and direct questions about their approach to survivorship care (e.g., how care is provided, collaborative relationships with cancer care medical networks, and sustaining practice changes).

Analysis

Our analytic approach was initially guided by two research questions: (1) What primary care models exist for delivering care to long-term cancer survivors?; and (2) What key issues do innovators face as they implement survivorship care models? Our qualitative analysis used a multistep immersion/crystallization approach [46, 47], an iterative process that included cycles of reading, summarizing, and rereading the notes and interview data. Sections of text were reviewed by an oncology social worker and three qualitatively trained PhDs with expertise in cancer survivorship and primary care transformation (DO, JH, SVH, HL).

The first cycle of data analysis was unstructured and inductive. From that analysis emerged a series of

Table 1 Process of identification of primary care-centric cancer survivorship innovators

Sources asked to identify primary care cancer survivorship innovators ($n = 32$)	
Name	Affiliation
Amy Abernethy, MD, PhD	Professor, Duke School of Nursing
David Ahern, PhD	Special Advisor, NCI Health Communication and Informatics Research Branch; NCI Behavioral Research Program
Rob Annis, MD	Primary Care Lead, South West Regional Cancer Program
Neeraj Arora, PhD	Research Scientist and Program Director, NCI Outcomes Research Branch of Applied Research Program
Sandy Buchman, MD	Clinical Lead, Quality Improvement and Primary Care Engagement in Palliative Care, Cancer Care Ontario
Jay Burton, DO[a]	Founder, Primary Care Cancer Survivorship Program of Western New England
Craig Earle, MD	Program Director, Health Services Research, Ontario Institute for Cancer Research
Cathy Faulds, MD	Palliative Care Physician, St. Joseph's Health Centre, London Ontario
Thom Flottemesch, PhD	Senior Research Leader, Truven Health Analytics
Patricia Ganz, MD	Professor, David Geffen School of Medicine at UCLA; Director, Center of Cancer Prevention and Control Research, Jonsson Comprehensive Cancer Center
Eve Glazier, MD	Internist, UCLA Internal Medicine
Eva Grunfeld, MD[a]	Giblon Professor and Vice Chair, Research, University of Toronto, Department of Family and Community Medicine
Tara Henderson, MD, MPH	Director, Childhood Cancer Survivors Center, The University of Chicago
Shawna Hudson, PhD[a]	Associate Professor and Division Chief, Department of Family Medicine and Community Health, Rutgers Robert Wood Johnson Medical School
Larry Kushi, ScD	Director, Scientific Policy at Kaiser Permanente Northern California Division of Research
Hugh Langley, MD	Regional Primary Care Lead, South East Regional Cancer Program, Kingston Ontario
Jun Mao, MD, MSCE	Chief, Integrative Medicine, Memorial Sloan Kettering Cancer Center
Mary McCabe, RN, MA	Director, Cancer Survivorship Initiative, Memorial Sloan Kettering Cancer Center
Larissa Nekhlyodov, MD, MPH[a]	Associate Professor, Population Medicine, Harvard Medical School
Kevin Oeffinger, MD	Director, Adult Long-Term Follow-up Program, Memorial Sloan Kettering Cancer Center
Linda Overholser, MD, MPH[a]	Internist, Thriving After Cancer Treatment is Complete Clinic, University of Colorado
Jan Owen, MD	Primary Care Lead, Southwest Regional Cancer Program, Zurick, Ontario
Lynne Padgett, PhD	Rehabilitative Psychologist/Program Director, NCI, Behavioral Research Program
Carly Parry, PhD, MSW, MA[a]	Senior Program Officer, Improving Healthcare Systems, Patient Centered Outcomes Research Institute
Pam Pawloski, PharmD	Research Investigator, HealthPartners Institute for Education and Research
Janet Pregler, MD	Clinical Professor, UCLA General Internal Medicine, David Geffen School of Medicine
Gordon Schacter, MD, CCFP, FCFP	Primary Care Lead South West, Local Health Integration Network, London
Scott Secord, MSW, RSW	Community Mental Health and Health System Integration Lead, Brant Community Healthcare System
Jeff Sisler, MD, CCFP, FCFP	Vice-Dean, Continuing Competency and Assessment, Faculty of Health Sciences, University of Manitoba
Jon Sussman, MD, MSc, FRCPC	Director, Supportive Care Research Unit, Juravinski Cancer Centre, Ontario
Steve Taplin, MD, MPH	Deputy Associate Director, NCI, Healthcare Delivery Research Program
Phil White, MD	Family Practice Oncology Network Chair and Medical Director, University of British Columbia
Innovators In Primary Care Steering Committee (N = 6) selected final key informants	
Benjamin Crabtree, PhD[a]	Principal Investigator Professor, Department of Family Medicine and Community Health, Rutgers Robert Wood Johnson Medical School
Carlos Jaen, MD, PhD, FAAFP[a]	Professor and Chair, Department of Family and Community Medicine, University of Texas Health Science Center at San Antonio
Kelly Kelleher, MD	Director, Center for Innovation in Pedatric Practice; Nationwide Children's
William Miller, MD, MA[a]	Leonard Parker Pool Chair of Family Medicine, Lehigh Valley Network Professor fo Family Medicine
Paul Nutting, MD, MSPH[a]	Director of Research, Center for Research Strategies;
Kurt Strange, MD, PhD	Professor of Family Medicine; Epidemiology and Biostatistics; Oncology Research

Table 1 (continued)

Cancer Survivorship Primary Care Innovators/Key Informants (N = 5)	
Jay Burton, DO[a]	Founder, Primary Care Cancer Survivorship Program of Western New England
Sarah Givens, RN, CON[a]	Oncology Nurse Coordinator, North Perth Family Health Team
Larissa Nekhlyudov, MD, MPH[a]	Associate Professor, Population Medicine, Harvard Medical School
Linda Overholser, MD, MPH[a]	Internist, Thriving After Cancer Treatment is Complete Clinic, University of Colorado
Amy Shaw, MD[a]	Medical Director of Primary Care Oncology and Survivorship Program, Annadel Medical Group

[a] Attended the 2.5-day conference

distinct themes around the need for organizational change to address cancer survivorship. We therefore reviewed several conceptual models and found that the 2004 primary care practice change model resonated with innovators' experiences [48]. The practice change model focuses on interdependences among four main elements: (1) motivation of key stakeholders to achieve a change target; (2) resources for change, including instrumental, personal, and interactive; (3) external practice motivators for change, including the larger health care environment (e.g., growing adoption and use of survivorship care plans); and (4) opportunities and options for change [48]. After identifying the practice change model as a guiding analytic frame, we conducted a second, more focused round of reading and summarizing the data. The analysis team met weekly to discuss data analysis and to resolve differences in interpretation through consensus. The following results are presented according to the central elements of the practice change model.

Results

Setting characteristics and practice models

Five practices, four in primary care and one in oncology, were highlighted for their innovations in primary care-focused survivorship care (see Table 2).

Consultative model Practice 1 (Colorado) was in an academic general internal medicine department. The innovator was an internist and the medical director of a survivorship program designed for adult survivors of childhood cancer. The program originated when a pediatric oncology colleague reached out to the adult internal medicine team about developing a bridge program for young adult survivors who were ready to graduate from pediatric long-term follow-up care but had nowhere else to go. PCPs collaborated with pediatric oncologists at an affiliated academic cancer center across the street and provided adult comprehensive primary care using an interdisciplinary team.

Subspecialty model Practice 2 (Massachusetts) was set in a community-based multispecialty medical practice with its own oncology practice and proximity to a National Cancer Institute-designated comprehensive cancer center. The innovator was a general internist who maintained a half-time panel with a large number of cancer survivors. Initially, the care model included a nurse practitioner (NP) with no prior training in survivorship. She had reviewed patients' cancer records, focusing on general primary care needs, and prepared patients for the physician to take an in-depth cancer-related history and review follow-up needs. The physician was also a member of the cancer center's collaborative team, which used a consultative model to evaluate, develop care plans, and transition adult survivors of childhood cancers to primary care.

Subspecialty model Practice 3 (Massachusetts) was a physician-owned primary care practice in a two-practice system. The innovator of this practice, a general internist, became an advocate for cancer survivorship issues following his own personal diagnosis of cancer. He cultivated a patient panel with a subset of patients in various stages of the cancer experience (e.g., newly diagnosed, active treatment, follow-up). This program emphasized patients' psychosocial needs following diagnosis and throughout treatment. The model included a recently approved non-profit wing to provide psychosocial services to cancer survivors referred from the two practices and from the larger community. At the time of data collection, the non-profit had begun to provide cancer survivor support groups.

Nurse navigator model Practice 4 (Ontario, Canada) was a primary care practice whose innovator was an embedded oncology nurse navigator. The practice used a case management/care coordination approach for all patients who were diagnosed with cancer or discharged from acute oncology. The nurse navigator was funded

Table 2 Description of innovator practices with primary care-centric cancer survivorship models ($n = 5$)

Setting	Model description	Providers (current, previous, or planned to be involved)	Survivor population	Year program began
Academic medical setting	Consultative, multidisciplinary, primary care based	-MD (GIM) -Pediatric oncologist -Health psychologist -Oncology RN coordinator - Plan add SW navigator	Adult survivors of pediatric cancer	2008
Community-based multidisciplinary practice	Initially, NP would meet with patients, review cancer records focusing on general primary care needs and set them up to see MD for in-depth review of cancer related history and f/u needs. Since NP left this is done entirely by the MD	-MD (GIM) - Nurse Practitioner (left practice)	Adult survivors of pediatric cancer and adult survivors of adult cancers	Not reported
Multispecialty practice	MD maintains a panel of cancer survivors focused on surveillance, symptom management and psychosocial support; has received separate non-profit status to further develop psychosocial supports for survivors	-MD (GIM) -Medical assistant Separate non-profit - Social worker-lead psychosocial program -Volunteers	Adult survivors	2014
Primary care practice	Oncology nurse navigator embedded in Family Health Team (FHT) case management model from diagnosis through end-of-life care	Family Health Team includes: - Allied health professionals - 10 Family physicians, primary care and triage nurses, 2 nurse practitioners and support staff	Adult survivors; 256 with confirmed diagnosis, majority of patients in active treatment or post treatment; ~ 25 % of patients in palliative phase of cancer care	Formative program development began in 2007; Established program in 2009
Oncology practice that recently merged with a large Multidisciplinary group	MD has panel of patients who are symptomatic from their cancer treatments, are newly diagnosed and need help with decision making, or have ongoing needs not being met by their oncologist or PCP	MD (FM) that is Medical Director of Survivorship Program - Lobbying to add a nurse practitioner and another MD to the program	80 % breast and 20 % other cancer types	Not reported

through a Primary Care Agreement with the Ministry of Health and Long-Term Care in the Province of Ontario, which allowed the practice to choose to focus on cancer care. The model provided case management services from diagnosis through end-of-life care.

Blended model Practice 5 (California) was an oncology-based survivorship program in a private oncology group that was part of a larger medical group. The innovator was a family physician who had previously maintained a panel of cancer survivors in her private practice. Upon joining the oncology group, she had inherited the patient panel of a medical oncologist who had left. Initially, the practice focused on managing the symptoms of breast cancer patients and transitioning those who could be adequately managed to primary care. Oncologists outside of the group began referring patients who were experiencing late or long-term effects from cancer or treatment, and, if appropriate, these patients were transitioned back to primary care.

Motivation of key stakeholders

Many innovators had long-standing, personal reasons for pursuing improvements in survivorship care. One physician's personal diagnosis of cancer and firsthand experience with the inadequacy of services for cancer patients ignited his passion. Two other physician innovators described developing a commitment to cancer care early in their careers. One physician's long-time interest in oncology led to a research fellowship in cancer health services. Another physician, who pursued medicine as a second career after her father's death from cancer, took extra rotations in oncology during medical school. In the nurse-led model, the practice champion described how after working for 6 years in cancer centers she was actively recruited by the primary care practice site because of her expertise in oncology care.

In interviews and large group sessions, innovators discussed educating their colleagues as a strategy for increasing motivation for survivorship-based practice changes. The need to increase the motivation of practice stakeholders was an ongoing, pivotal issue. In an academic practice, where the affiliated comprehensive cancer center advocated moving the adult survivors of childhood cancers clinic into the general internal medicine department, other clinicians questioned the appropriateness of moving these patients into primary care. The other clinicians asked, "Shouldn't [cancer patients] be in the cancer center? How is this different from primary care?" It was not apparent to the innovators' colleagues that cancer survivors required any adjustments from the standard delivery of primary care. Education and advocacy eventually led to program support, but efforts to develop shared understandings were still needed. In the nurse navigator model, the innovator described initial resistance, since abated, to using standing orders to provide cancer screenings in a well women's program that included survivors. In one of the subspecialty models, the innovator recalled a conversation with an organizational leader who asked, "What does it mean for the organization to bring more complex patients into the organization? What does that mean for the organization in terms of the resources that they have to utilize on these patients?" Innovators guidance and sense-making about why these programs were necessary helped garner support from other stakeholders and curbed resistance as they led implementation efforts.

Resources for change

All innovators described generating buy-in as a continual process for gaining access to resources. Inquiries from administrative and clinical stakeholders often raised concerns about the perceived cost of providing care to complex patients. One physician had left a previous practice after being pressured to reduce her 30-min appointments to only 15 min. "They [practice leadership] told me I had a choice," she said. "I could leave or stay, but if I stayed, I had to get rid of my cancer patients and send them back to the oncologist. And that just wasn't something I was willing to do."

One innovator recalled "my partners [looking at me] like I had three heads" when he first brought up the idea of developing a cancer survivorship program. To allay his partners' concerns, he'd had to work with limited resources. "Everything that I've done for the…cancer survivorship part of my practice has been on the cheap," he said.

Innovators said that while their practices possessed resources that could improve survivorship care (e.g., electronic health records, care coordinators, interested support staff), gaining access to resources, let alone maintaining and sustaining access, was a constant challenge. There was also resistance described when roles were changed in ways that were different from previously held practice norms. Reflecting on the start-up of the nurse navigator model, the innovator said, "For the first while, it was a little tough go… People there felt I needed to do the traditional nursing role… So it took a struggle, it took a meeting, and it took me putting my foot down and saying, 'If you want me to do this, you've got to let me do it.'"

Motivators outside the practice

In the five practices outside motivated and incentivized innovations competed with cancer survivorship to receive priority status. Such innovations included efforts to implement or enhance the utility of electronic health records (EHR), quality improvement initiatives to achieve PCMH designation, and use of population managers to focus on traditional primary care populations (e.g., diabetics, hypertensives, etc.). In a large group discussion, one innovator said, "We could add newly diagnosed high-risk survivors to the care coordinators…, but the care coordinators are already overloaded. They are working on patients that are incentivized by insurance companies." Another innovator described pushback to a proposed change for documenting survivorship in the EHR:

> And so what I'm trying to implement is basically four parts… cancer diagnosis, cancer treatment, complications of cancer treatment, and surveillance… I've met with resistance just to do that…because that requires somebody to do data entry, and that requires somebody to keep actual details of treatment, and…someone to think about what the surveillance is or actually read up on it, and there's a lot of pushback on just that simple change in the record.

The productivity-based reimbursement system was also cited as a major barrier. At best, integrating innovations for cancer survivors into ongoing change efforts was not prioritized; at worst, it was penalized. “Those of us who continue to care for these patients are financially penalized for doing so, and it disincentivizes PCPs to care for these patients in their own practices,” one innovator said. “The productivity pay structure…rewards doctors for high-volume care, not necessarily high-quality care,” said another innovator. “Cancer survivors so often have complex and changing healthcare issues [that] comprehensive survivorship care will always be low-volume care.”

Innovators actively sought funding and talked about the need for future funding to sustain or grow their programs. In one academic practice, a grant that supported general survivorship initiatives, including program development and planning, was nearing its end, forcing the cancer center’s clinical team members to seek alternative funding. One innovator described partnering with a local hospital to subsidize the cost of a physician to work in the survivorship program. He had also developed a separate non-profit organization to use community fundraising monies to support survivorship programming, such as psychosocial support and navigation, which were not billable in the primary care system. Others struggled to find such resources. As a family physician in a community oncology setting said, “I would like to have some of the supporting structure: a nurse practitioner, a nurse navigator. I would like to have access to philanthropic dollars.” However, such resources were not forthcoming.

Opportunities for change

There was a shared view among innovators that primary care and oncologist colleagues did not understand the rationale for focusing on cancer survivors as a distinct population. One innovator, an internist, recalled describing her growing interest in cancer survivorship to a medical oncologist colleague over 10 years ago. The colleague replied, “Isn’t that what I do?” Other innovators spoke of challenges that arose when a population-based strategy was perceived as an intrusion into existing patient-provider relationships. One innovator faced resistance from oncologists who did not want to refer patients to a survivorship program. “As far as they’re concerned, they own the patients, the patients stay with them, and they don’t want anyone else intervening,” she said.

While there was consensus that survivorship care plans were necessary, there was also skepticism among innovators that these alone would suffice in encouraging survivorship to become a primary care priority. Two of the innovators had developed survivorship care plans in their roles at cancer centers; they used these documents to educate PCPs about risk stratification of cancer survivors. “We write a consultation letter to the primary care provider, and I try to be very PCP-friendly in my communication…to educate them in the process,” one innovator said. “For example, [I write,] ‘Because the patient had X, she is at risk for Y, therefore we need to do Z.’”

Another innovator said that in addition to the standard elements in a care plan, she “tells a story about the patient… Here’s the story of their cancer… This is what’s going on with their life, this is what’s impacted them the last couple of years… This is some of their backstory.” She shared her notes with both patients and their PCPs as a way to reassure patients who feared their PCPs did not know them as well as she did. “[I tell patients,] ‘Your doctor knows as much about you as I know about you. You can now go back to them. They know you.’”

Innovators were concerned about the lack of a common definition of survivorship and what this meant for implementation efforts. “The hospital was very comfortable just stopping at yoga classes, and so that was their ‘survivorship’…as a feather in their bonnet…to say, ‘Look how great we are,’” one innovator said. Other survivorship programs focused only on cancer recurrence, which frustrated another innovator. His “breast cancer survivorship rant” included telling patients, “All these people are doing is giving you a mammogram, doing a breast exam, [and saying,] ‘See you next year or see you in six months.’… I’m looking at you comprehensively. You are more than your breast or breasts or your mastectomy.”

There was a similar lack of definitional clarity even in those organizations that took a risk-stratified approach to survivorship care. In these cases, it was unclear which types of patient providers should monitor. One innovator described how this played out in an oncology-based program when her colleagues referred patients to her who needed only surveillance, despite her expertise in managing the late and long-term effects of cancer treatment. She explained “Because I’m seeing patients for symptoms, they come in as often as necessary. So I’ll do a consult, figure out what the issues are, and then see them as often as I need to.”

Finally, there were mounting frustrations among innovators that despite their passion and dedication, the programs they spearheaded were wholly dependent on their individual efforts. They discussed strategies for addressing this issue and proposed solutions that included more explicit articulation of the value-added potential of caring for survivors in primary care settings, developing a common language around cancer survivors and risk stratification, and improving primary care-focused advocacy efforts.

At the practice level, innovators described issues of legitimacy and prioritization as a first-level barrier, but there were other issues, too, such as a lack of metrics for survivorship and the influence of state and federal policies tied to ongoing healthcare reform. One practice innovator asked the larger group “who advocates on behalf of primary care providers” with respect to cancer. She continued:

> We have AAFP [American Academy of Family Physicians], we have SGIM [Society of General

> Internal Medicine], we have ACP [American College of Physicians], we have probably a few organizations of nurse practitioners – but my sense is that I've never seen them working together or forming a larger body, a lobbying body to fight on behalf of primary care. For example, the American Society of Clinical Oncology is a really strong advocate for cancer, for oncologists, and if there's ever some sort of a bill or some sort of proposal to do something to undercut oncology, they're there. They're fighting it. And I just don't think that anyone is out there truly, truly fighting on our behalf, and I think that that is absolutely necessary, and I think that we need that…to bridge our silos.

In large group discussions about opportunities for change, participants articulated the lack of appreciation of primary care as an environment in flux in survivorship care conversations. As innovators processed their challenges, a wider consensus emerged about how survivorship could fit into this changing environment, but only if there were better understanding of the primary care context. Even more frustrating, however, was that primary care was not under serious consideration in efforts to improve cancer survivorship care.

Discussion

All five practices in this study had implemented primary care-centered cancer survivorship models, which demonstrate that it is potentially feasible for primary care to take on more responsibility for cancer survivors. Nevertheless, it also became apparent from discussions and interviews that none of these models was likely to endure in the absence of tremendous effort by a champion (see Table 3, summary of barriers to change for primary care cancer survivorship models). Given the amount of advocacy required by innovators to access basic resources for their survivorship programs, it would seem that the potential for developing and sustaining survivorship care models in the primary care context is in dire need of further attention. The most important recommendation that emerged from this study was the need to develop a research agenda focusing on the primary care context more broadly as it relates to cancer survivorship. Moreover, survivorship care models, particularly for long-term cancer survivors, should emphasize strategies that encourage the integration of survivorship care planning into existing models of care within primary care.

According to these innovators, the emphasis on survivorship care plans as the cornerstone of primary care capacity building requires critical reexamination. Research has shown that care plan receipt affects PCPs' engagement in survivorship care planning [49], but evidence about care plans' utility in improving clinical and patient-reported outcomes has been less compelling [8, 50]. The first study to comparatively evaluate the use of survivorship care plans to usual care [8], as well as a subsequent trial [50], found no clinical benefit to their implementation. Ensuing commentaries raised questions about the importance of context, standard transition practices (e.g., discharge visits with oncologists) [51], and the possible limited generalizability of study findings given the strength of the Canadian primary care system [52]. Yet, implications of

Table 3 Summary of barriers to change for primary care cancer survivorship models

Practice change model element	Key themes
Motivation of key stakeholders	Change champions as educators and advocates • Charismatic, clinical leaders champion capacity building and skills development to improve care for cancer survivor population • Motivated by professional interest in the population and personal connection to cancer experience • Motivated to increase knowledge and awareness about cancer survivorship needs among their colleagues
Resources for change	Challenges to gaining and sustaining resources for change • Buy in from decision makers about legitimacy of cancer survivors as a primary care appropriate population focus • Resources in the practices (electronic health records, care coordinators and personnel) are not being utilized for survivorship care improvements • Completing demands in primary care practice (personal physician and organizational)
Outside motivators	Cancer survivorship innovation in primary care is an unfunded mandate • Innovations being incentivized and carried out in primary care are driven by insurers, grant programs, etc. These are not cancer survivorship focused. • Connect to cancer hospital/center, system, interested in developing a net for the patients with a history of cancer who are no longer in need of acute care.
Opportunities for change	Legitimize cancer survivors as a population in need of primary care-focused strategies • Develop tracking systems, metrics for tracking cancer survivors that are primary care friendly. • Implement risk stratification operationalization that is more granular to refine the 'who should be doing what for which group of survivors' issue.

these findings could support an alternative argument that the strength of the primary care system matters for cancer survivors. Among innovators, the prioritization of care plans over larger systemic issues that impede survivorship care in primary care settings represents a missed opportunity.

Furthermore, there is a clear need for dissemination and implementation studies that evaluate ecologies of practice to guide implementation of survivorship models across both oncology and primary care. The challenges faced by primary care innovators are not, after all, unique to primary care. Two national opportunities for change in the oncology context, the LIVESTRONG Centers for Excellence Program [53] and City of Hope's multidisciplinary educational program, delineated similar implementation barriers [54]. These barriers included reimbursement issues, space constraints, turnover, competing projects diverting resources from survivorship, inadequate leadership support for clinical process changes, and newly implemented or poorly integrated clinical information systems [53, 54]. Primary care systems may face additional challenges as clinicians strive to meet patients' competing healthcare needs.

Innovators reported that cancer survivors are not considered a high-priority population by primary care systems; therefore, strategies to manage this population are absent from national primary care practice redesign efforts. Innovators described how their cancer survivorship change efforts competed with and were viewed as a distraction from other priorities. Regardless of primary care's general lack of attention to cancer survivors, the survivor population continues to grow, and over time, these patients will likely receive most or all of their care outside of the cancer care system. It is therefore imperative to develop models that resonate with primary care paradigms. Cancer survivors figure prominently into other populations that are already conceptualized as being relevant to primary care, such as the aging, high utilizers, and patients with multimorbidities. Still, there has not yet been a concerted effort to develop a language that bridges primary care and cancer survivorship paradigms. This represents the most obvious need and the most fruitful opportunity for change if we hope to prime the primary care landscape for developing strategies responsive to cancer survivorship in the coming decades.

The present study has several limitations. Data collection was based on snowball sampling. This was necessary because there are few primary care-focused cancer survivorship delivery models and no evident method to systematically identify them. All study data were based on innovators' reflections and were collected during a 2-day, expert-focused primary care workshop. Observations and interviews at the practices themselves would yield greater depth of understanding in how implementation occurs on the ground. Although beyond the scope of this study, future studies should include more detailed descriptions of practices' patient populations, as well as incorporating feedback from patients and other providers about the efficacy and feasibility of these models. While innovators' experiences provide important implementation lessons, they are not necessarily reflective of what occurs in practices lacking a motivated survivorship champion. Future descriptive studies of primary care practices should also assess the receptivity of various stakeholders to cancer survivorship models. Finally, five practices comprise only a small universe, and we risk overlooking other models currently in development or in the nascent stages of implementation. It will be the task of future research to describe additional primary care-focused survivorship models as they become available, as it is likely that new and different models will emerge over time.

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Compliance with ethical standards

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Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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