A mixed-methods analysis of the capacity of the Patient-Centered Medical Home to implement care coordination services for cancer survivors

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Abstract

There are currently 15.5 million cancer survivors in USA who are increasingly relying on primary care providers for their care. Patient-Centered Medical Homes (PCMHs) have the potential to meet the unique needs of cancer survivors; but, few studies have examined PCMH attributes as potential resources for delivering survivorship care. This study assesses the current care coordination infrastructure in advanced PCMHs, known to be innovative, and explores their capacity to provide cancer survivorship care. We conducted comparative case studies of a purposive sample ($n = 9$) of PCMHs to examine current care coordination infrastructure and capacity through a mixed-methods analysis. Data included qualitative interviews, quantitative surveys, and fieldnotes collected during 10- to 12-day onsite observations at each practice. Case studies included practices in five states with diverse business models and settings. Eight of the nine practices had National Committee for Quality Assurance Level 3 PCMH recognition. No practices had implemented a systematic approach to cancer survivorship care. We found all practices had a range of electronic population health management tools, care coordinator roles in place for chronic conditions, and strategies or protocols for tracking and managing complex disease groups. We identified potential capacity, as well as barriers, to provide cancer survivorship care using existing care coordination infrastructure developed for other chronic conditions. This existing infrastructure suggests the potential to translate care coordination elements within primary care settings to accelerate the implementation of systematic survivorship care.

Keywords

Care coordination, Cancer survivors, Primary care, Patient-centered medical homes

INTRODUCTION

There are currently 15.5 million cancer survivors in USA [1, 2]. This number is expected to increase exponentially by 2026, reaching a projected 20.3 million. The majority of U.S. cancer survivors were diagnosed more than 5 years ago (67%) and nearly half are over 70 years old (47%), indicating the high prevalence of long-term survival among the aging population [1]. Long-term cancer survivors, those living beyond active treatment, are at risk for recurrent and secondary cancers, late and long-term

Implications

Practice: Care coordination infrastructure in place for other chronic conditions within primary care practices could potentially be adapted to address the needs of cancer survivors.

Policy: Policymakers and stakeholders interested in accelerating the implementation of cancer survivorship care in primary care settings should explore the need to engage and include primary care practitioners in cancer survivorship guideline development, the possibility of financial incentives for primary care practices to deliver systematic survivorship care, and the potential infrastructure gaps in primary care, including staff training and health IT, that currently limit wide scale implementation of cancer survivorship care.

Research: Future research should be aimed at understanding the disconnect between capacity and implementation of systematic cancer survivorship care as well as at identifying strategies to reduce barriers to implementation of cancer survivorship care in primary care settings.

effects from cancer therapies, and emotional and physical side effects from cancer treatment [3–5]. While the surveillance and management of these survivorship-related risk factors have traditionally been delivered by oncologists, primary care providers are increasingly involved in the care of survivors following active cancer treatment [3, 6, 7]. Prior studies, however, have noted several potential barriers to fully implementing a primary care-based cancer survivorship care model, including a lack of training among primary care providers, suboptimal transitions between oncology and primary care, competing financial and disease priorities, and unknown capacity to provide long-term cancer survivorship care [6, 8]. Cancer survivorship care is often not a

high priority in primary care practices, leaving inadequate services for cancer survivors [3, 6].

Professional cancer organizations have issued clinical practice guidelines for long-term follow-up of cancer patients [9, 10]. Several recent reports and guidelines have been updated to recommend the systematic delivery of cancer survivorship care in conjunction with primary care [11, 12]. In 2006, the Institute of Medicine's report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, listed coordination between specialists and primary care providers as one of four essential components of cancer survivorship care [13]. Survivorship care plans, which describe a patient's cancer treatment history, potential late and long-term effects, and recommended surveillance strategies among oncology and other care providers, have been suggested as one strategy to improve care transitions from oncology to primary care [14–16]. To date, the implementation of systematic cancer survivorship care, including the use of care plans, within primary care settings has been limited [6, 8, 13, 17].

The concept of a Patient-Centered Medical Home (PCMH) has gained support over the past two decades as a model for primary care practice redesign [18–20]. The PCMH model includes best practices in access, prevention, and management of chronic diseases [21–23], care coordination [24], and patient responsiveness [25], and thus has the potential to meet the unique needs of cancer survivors and long-term survivorship care within primary care settings. Care coordination in the primary care practice, as defined by the Agency for Healthcare Research and Quality and other literature, involves “organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care [26].” PCMH efforts to redesign primary care, including leveraging information technology to improve outcomes and communication [27], developing collaborative teams [28], and integrating the practice within the healthcare neighborhood [29], are elements necessary for coordinating the care of complex chronic conditions, including cancer survivors.

Effective long-term care management for survivors will depend in part on effective care coordination within primary care settings. Currently, there is little evidence of primary care practices implementing systematic cancer survivorship care [3, 30]. There is also a limited understanding of whether existing care coordination strategies within PCMH settings can be adapted for long-term survivorship care. Therefore, this study examines whether advanced primary care practices have the infrastructure and capacity to provide care coordination for cancer survivors to inform and accelerate strategies for implementing cancer survivorship care in primary care settings.

METHODS

Data for this analysis were obtained from a large mixed methods comparative case study funded by the National Cancer Institute that focused on describing the attributes of primary care practices, nationally recognized as workforce innovators, and strategies currently being used to deliver care for cancer survivors in these settings. The aims of the larger parent study were to: (a) compare cancer survivor care in high performing primary care practices that specifically targeted National Committee for Quality Assurance (NCQA) recognition (e.g. NCQA level 3 PCMHs) with those that evolved to meet needs of individuals, families and communities; (b) examine care innovations these practices used to meet the needs of cancer survivors; and (c) identify and describe environmental attributes that enable innovation in primary care practices to meet the needs of patients with complex conditions. The study utilized a mixed methods design that combined qualitative and quantitative data collected from practices to create mixed-methods summaries for systematic comparison [31, 32].

Practice recruitment and sample

The parent study focused on recruiting primary care practices to understand how primary care has implemented strategies, if any, for cancer survivors. Details of the study design are described in Rubinstein et al. [30]. In brief, a sample of nine primary care practices was recruited from a national list of 151 workforce innovators compiled for the Robert Wood Johnson Foundation in 2011–2012. The list was developed by snowball sampling, starting with contacting the authors of 331 articles identified in a literature review of workforce innovations in U.S. primary care since 2000 [33]. These authors then nominated innovative practices across USA for inclusion in the list. Practices were ranked by a Steering Committee, assembled by our research team for the larger descriptive study, and highly ranked practices were iteratively selected for recruitment to ensure variation in geographic region and organizational structure. Of the 14 practices responding to our invitation by October 2016, 9 participated, 2 declined, and 3 were unresponsive after initially expressing interest. While not a requirement of the study, all but one of the practices were accredited as NCQA Level 3 PCMHs [34]. Based on the literature and the extensive research experience of our team, comparative case studies generally reach initial saturation after five to six cases (practices) [35]. At the time of this analysis, five initial cases were followed by four purposefully selected confirming and disconfirming cases using replication logic in the larger parent study [35]. Saturation was reached after nine practices. This study was approved by the Rutgers University's Biomedical and Health Sciences Institutional Review Board.

Data collection

Over an 18-month period in 2015 and 2016, field researchers on the study team visited each practice for a total of 10–12 business days, spending up to 8 hr/day conducting participant-observation research [36]. Data collection methods included direct observation of practice functions and systems using an observation template [36], informal key informant interviews of practice staff [37], 5–10 “patient pathways” of cancer survivors in which the patient is followed throughout their visit and interviewed about their experiences [38], semi-structured depth interviews with multiple practice staff members [39], and a structured survey on practice characteristics. Depth interviews were formal, digitally recorded, one-on-one sessions of 30–60 min. Interview guides, tailored for each interviewee’s role in the practice, consisted of three to six “grand tour” questions [40], including questions focused on the practice’s existing infrastructure and/or protocols for cancer survivorship care, perceptions about primary care’s role in cancer survivorship, and ideas about resources needed to eliminate interviewee-identified barriers to comprehensive survivorship care in the primary care setting. Depth interviews were transcribed verbatim. Patient pathway interviews (15–30 min) covered patients’ experiences with each practice as cancer survivors but did not ask specifically about their care coordination needs.

Data analysis

This sub-analysis used a comparative case study, which was guided by the following research questions: (a) What are the current care coordination strategies in place at innovative PCMHs? and (b) Is there existing capacity to provide cancer survivorship care within these PCMH settings? Our data analysis process was guided deductively by the essential components of cancer survivorship care, as described in the *IOM From Cancer Patient to Cancer Survivor: Lost in Transition* report [13], and inductively by emerging themes. We employed Yin’s method of treating each individual case as a separate study in its own context [41], and subsequently used Miles and Huberman’s well-established strategy of creating matrices to display the data across case studies for comparative analyses [42]. Three research team members reviewed the qualitative data and extracted all sections relevant to care coordination.

The extracted qualitative data were analyzed through iterative cycles of reading that enabled researchers to write case summaries that identified existing care coordination strategies at each practice. Quantitative information from structured surveys, which were completed by the practice manager or lead physician at each practice, was examined and compiled into two tables to describe practice characteristics and population health management/care coordination infrastructure. Practice

characteristics included location, ownership, years in existence, number of clinicians (medical doctors or nurse practitioners), number of patient visits per year, distribution of patient population by socio-demographic characteristics (insurance type, race/ethnicity), PCMH reimbursement/incentives and participation in an accountable care organization (ACO). Population health management and care coordination infrastructure included whether the practice had implemented any of the following: registries to track specific conditions, use of electronic medical records, e-prescribing systems, electronic follow-up with patients, reminder systems for screening tests, protocols for counseling or intervention, or presence of nurse or health educators. The larger analysis team, which included the researchers who had collected the data, met regularly throughout the process to review data, identify emerging themes, and examine and integrate the qualitative and quantitative data for the in-depth comparative case studies.

RESULTS

Case studies included three physician-owned, two federally qualified health centers (FQHC), one nurse led university-based, one nonprofit capitation model, one hospital, and one insurance-owned practice. These nine practices were located across five states (Colorado, Maine, New York, Pennsylvania, and Washington). Over half of the practices reported being part of an ACO or integrated network. Five practices were located in suburban areas, while two were located in rural and two in urban settings. Practice size ranged from 1 to 19 full-time physicians, with 9,000–84,000 patient visits per year. As expected, practices in urban settings had a larger proportion of Medicaid-insured/uninsured and minority patients. Eight of the nine practices were designated as NCQA Level 3 PCMHs, but only five practices reported receiving reimbursement for the designation. Practice characteristics are shown in Table 1.

While none of the practices had implemented systematic cancer survivorship care, we were able to focus on the potential to implement such care by examining existing care coordination infrastructure for other chronic conditions within and across these innovative PCMHs. Three major themes emerged that depict existing care coordination infrastructure within PCMHs relevant to the essential components of cancer survivorship care detailed in the *IOM Lost in Transition* report [13]: (a) Practices utilize clinical information systems to assist in the management of patients with chronic conditions; (b) Practices have created staffing positions to provide more extensive care to patients with chronic conditions; (c) Practices have implemented strategies for the management of diverse health conditions.

Table 1 | Practice characteristics

Practice ID	Location	Ownership	Years in existence	# of MDs	# of NPs or PAs	# of Patient visits per year	% Medicaid or uninsured patients	% Minority patients	PCMH re-imbursement	Part of ACO or integrated network
P3	Suburban	Physician Owned	12	12	7	84,000	9	5	yes	yes
P4	Suburban	Physician Owned	35	11	2	19,933	10	10	yes	yes
P5	Suburban	Hospital Health System	20	16	4	37,828	8	6	no	yes
P6	Rural	FQHC	31	15	2	25,000	unk	unk	unk	yes
P7	Suburban	Health System	27	3	1	9,447	6	unk	yes	no
P8	Rural	FQHC	1	19	8	33,233	19	4	yes	yes
P9	Urban	University Nurse-Led	5	1	4	11,035	87	71	no	no
P10	Suburban	Physician Owned	25	3	3	19,380	1	21	no	yes
P11	Urban	Capitated Nonprofit	102	15	3	44,000	5	79	yes	no

FQHC Federally Qualified Health Center; unk Unknown/Missing.

Practices utilize clinical information systems to assist in the management of patients with chronic conditions

While none of the practices in our study used clinical information systems to systematically prompt or track care for cancer survivors, we found a range of existing strategies in all practices that can be adapted to track survivors in some capacity. This was evidenced by the high utilization of clinical information systems to assist in the management of patients with other chronic conditions (e.g. diabetes, cardiovascular disease). Our quantitative data showed that an established data infrastructure existed across all 9 settings for population health management (Table 2). Specifically, all practices reported the use of electronic health records (EHR), e-prescribing, and registries to track multiple conditions. Additionally, nearly all practices had electronic modes of follow-up with patients (e.g. patient portals) and reminder systems in place for recommended screenings and tests.

The qualitative data, however, tells a more nuanced story about the degree to which this data infrastructure is actually used for routine care coordination. Some practices (P8, P11) indicated a strong reliance on sophisticated and well-integrated clinical information systems for population health management, including the monitoring of quality measures, identifying emerging patient needs, tracking care management processes (e.g. screening, pre-visit planning) and administering health coaching sessions and other care coordination protocols. For example, P8 had developed a data management department that included staff dedicated to using health data to conduct pre-visit planning and population health reports:

[There are] three Performance Improvement Specialists who are responsible for data mining and pre-visit planning... [and a]... Performance Improvement Coordinator, who runs myriad monthly reports that are uploaded to P8's intranet.... These behind-the-scenes data miners, the VP of Transformation said, "empower health center staff to be paying attention to the patient." She continued, "Even though they're not located at a health center, they're part of the care team." (P8, Fieldnotes, March 25, 2016)

Similarly, P11 relied on their fully integrated EHR system to keep track of patient registries, identify needed follow-up, and upload reports from specialists:

[The medical assistant] explains it's mostly for diabetes. They [MAs] check to see if the provider has seen the patient on the list within six months, if they are due for labs, foot exams, etc. They also call them to check whether they've seen an ophthalmologist. (P11, Fieldnotes, October 25, 2016)

We observed variation in the breadth of conditions for which practices maintained registries. While all nine practices reported having registries in place, the number of conditions tracked via registries ranged from one to seven conditions (Table 2). Diabetes and hypertension were the most commonly tracked, followed by mental health conditions (e.g. depression/anxiety), congestive heart failure, and chronic kidney disease. Two of the nine practices (P4, P7) reported having cancer registries created by local hospitals. According to a physician at P4, the cancer registries from hospital cases were driven by insurance companies who wanted primary care to follow up after hospital discharge. P4 also used the EHR to

Table 2 | Population health management and care coordination infrastructure

Practice ID	Registry to track specific conditions	Registry conditions ^a	Electronic medical records	E-prescribing	Electronic follow-up with patients	Reminder system for screening tests	Protocols for counseling or interventions ^b	Nurse or health educators
P3	Yes	D, H, CAD, MH, HC, CHF, CKD	Yes	Yes	Yes	Yes	T, AL, E, PA, MH, F	Yes
P4	Yes	D, H, C, A, CAD, O, HC, CKD, COPD	Yes	Yes	Yes	Yes	T, AL, OD, E, PA, WL, CS, DM, STI, MH	Yes
P5	Yes	D	Yes	Yes	Yes	Yes	T, AL, OD, E, PA, WL, CS, DM, CCS, STI, MH	Yes
P6	Yes	D, H	Yes	Yes	Yes	No	T, AL, OD, DM, MH	Yes
P7	Yes	D, H, C, A, CAD, MH, HC	Yes	Yes	Yes	Yes	T, AL, OD, WL, CS, DM, MH	Yes
P8	Yes	D, H, A, CAD, O, MH	Yes	Yes	Yes	Yes	T, AL, E, PA, DM, MH	Yes
P9	Yes	D, H, A, HC	Yes	Yes	No	Yes	T, AL, OD, E, PA, WL, CS, DM, CCS, STI, MH	Yes
P10	Yes	D, H, A, CAD, MH	Yes	Yes	Yes	Yes	E, PA, WL, DM, MH	Yes
P11	Yes	D, MH, CKD	Yes	Yes	Yes	Yes	T, AL, OD, E, PA, WL, CS, DM, CCS, STI, MH	Yes

^aRegistry conditions: D = Diabetes, H = Hypertension, C = Cancer, A = Asthma, CAD = Coronary Artery Disease, O = Obesity, MH = Mental health, HC = High Cholesterol, CHF = Congestive Heart Failure, CKD = Chronic Kidney Disease.

^bProtocols for interventions: T = Tobacco Use, AL = Alcohol Use, OD = Other Drug Use, E = Eating Habits/Patterns, PA = Physical Activity, WL = Weight Loss, CS = Cancer screening/prevention, DM = Diabetes Management, CCS = Contraceptive counseling and services, STI = STI screening/management, MH = Depression/Anxiety/Other Mental Health, F = Fall Risk Assessments.

create lists of referrals for different patient populations, by diagnosis, to check that their referrals had been completed and the PCP had the results:

[Medical Assistants] can look on our portal to see cancer survivors, diabetics ...they can just pull in there by diagnosis. But also things like when we send somebody to a referral, to an oncologist or a gastroenterologist, that's tracked in the system. And so when they're not seen, or there isn't a letter from the GI person in the system, then they can keep track of that, and then do outreach and find out why that didn't happen. (P4, Physician Interview, March 25, 2015).

Few practices discussed whether the existing registries used for other conditions and various population-health protocols (e.g. for transitions between care settings or for follow-up appointments with specialists) could be adapted for cancer survivorship care or what current barriers in existing infrastructure would need to be addressed for cancer survivors.

Practices have created staffing positions to provide more extensive care to patients with chronic conditions

As previously reported from our larger parent study, no practice sites had implemented systematic cancer survivorship care, and thus, no staff were devoted to survivorship care specifically [30]. Therefore, we focused our analysis on whether existing staff

capacity could be adapted to coordinate cancer survivorship care. Our analysis indicated all practices had some staff responsible for care coordination for patients with chronic conditions beyond routine clinical encounters. While training, professional background, responsibilities, and time allotted for staff serving in care coordination roles varied across settings, all shared the basic elements of connecting patients to specialty care, providing counseling or self-management strategies to patients, and maintaining a list of the practice's "high-need" patients.

In some practices, the care coordination role was performed by an individual or combination of individuals with primary responsibility to provide care management to certain patient populations. In other practices, the role was performed by existing staff members, with other clinical responsibilities, who had care coordination duties added to their job descriptions.

There were also differences in the number and type of staff members responsible for care coordination activities, ranging from fully implemented care management teams of physicians, RN care managers, medical assistants with additional training to provide care coordination, trained health coaches, and nonclinical patient support staff to assist with a range of care coordination efforts (P11) to one RN responsible for a limited slot of care coordination appointments for "high acuity" cases each month

(P10). For example, in addition to running a clinic for patients needing routine coagulation tests (i.e. prothrombine time) and working with patients on pain medication, P10's established care coordination RN had a set number of appointment times open for "high acuity" patients.

The extent and integration of care coordination activities throughout practices varied. For example, at P3 these activities consisted of having five LPNs conducting care coordination part-time, but efforts were primarily done through phone outreach. The LPNs did a variety of care coordination activities related to chronic conditions such as diabetes, heart failure, and new onset depression, while the determination of which complex patients received care coordination services was based on a categorization determined by their Medicare ACO:

Both [LPN 1] and [LPN 2] agreed that they develop a relationship with care coordination patients and really get to know these patients. Even if they don't talk to the patients all that often, they're still frequently going through their charts and ensuring that these patients are up to date on their labs and screenings, etc. The result is that the nurses come to have an intimate familiarity with these patients' health problems... For patients who have been hospitalized because of COPD, CHF, a fall, or a heart attack, care coordinators will contact them following discharge once a week for four weeks and then once a month for six months. High Hierarchical Condition Categories patients are contacted 1–2 times per year unless there is an urgent issue, and then contact will be more frequent. Chart reviews happen every sixty days. (P3, Fieldnotes, March 30, 2015)

In contrast, P9, a suburban nurse-led FQHC linked to a university, which provided holistic care, had several care coordination roles and protocols that reflected the practice's overall mission. For example, care coordination services included a nurse case manager who worked with identified complex cases, while a referrals coordinator assisted with scheduling specialty appointments or ancillary services. In addition, the practices held bimonthly meetings to discuss cases, used pharmacy student interns to follow-up with medication issues, and maintained a strong behavioral health team on site for warm handoffs:

The one piece that I think is unique to [P9] is our integrated care model. I think we have a very good understanding of the different levels of having integrated care teams. They meet every week or every other week, really discuss patient care. They work on different collaboratives for diabetes, asthma, pain – chronic pain management... And a lot of the care that we provide really is through the behavioral health specialists with substance use disorders [patients]. ...So I think that unique role of having behavioral health leads, they've set up the meetings, they set up the strategies for patient care, they talk about patients that are a little bit more high risk, and come up with treatment plans that everyone has input in. (P9, CEO Interview, June 13, 2016)

While the structure and staffing of care coordination activities varied among practices, all had staff members who were responsible for providing enhanced care coordination. This is a critical and transferable component for providing systematic cancer survivorship care within primary care settings. A clear barrier to adapting these staffing capabilities, however, is that no systematic survivorship care, or a focus on cancer survivorship care at all, is currently in place within these innovative primary care settings.

Practices have implemented strategies for the management of diverse health conditions

All practices reported the implementation of protocols to address multiple health behaviors, risk factors, or chronic conditions (Table 2). Qualitative and quantitative data indicated formal strategies for 5–10 different targets in each practice, including tobacco use, alcohol use, other drug use, weight loss, depression/anxiety, eating habits/patterns, physical activity, diabetes management, contraceptive counseling services, and cancer screening/prevention. Half of all practices in our sample reported having protocols in place to improve cancer screening/prevention, indicating awareness of some cancer care-related guidelines. Although screening guidelines apply to cancer survivors differently, having cancer-care related protocols in place for the other patients may limit barriers in bringing survivorship care on the radar for primary care settings.

Interview data describe variation in how these interventions and care management strategies are developed. Some clinics tended to develop protocols based on financial drivers. That is, externally-funded initiatives or goals set by their larger health systems or ACOs determined their efforts (P3, P4, P6). At P3, the ACO in which they participate in drove many initiatives, including the introduction of care coordination roles a few years prior to their participation in this study. The P3 president explained that the practice considers trends in reimbursement in their care delivery:

And what we know is going on in the reimbursement system and the goals at the level of the federal government is that primary care is going to be reimbursed if you can take care of—The better you take care of them [patients], the more you'll be paid. And the more people you can take care of at a high-level quality, the more money you'll be able to make. (P3, Physician President interview, March 19, 2015)

In contrast, other clinics (P4, P6, P11) tended to develop protocols to manage chronic conditions from data-driven reviews of their patient population or from priorities set by the practice staff based on interactions with patients. At P6, a physician champion created a care management team that included a registered nurse (RN) with diabetes education training, a health coach, a referrals coordinator, and

external case management social workers. While figuring out how to assist higher-risk patients, the team had learned that uncontrolled diabetics were partly the result of social barriers that could not be addressed solely by patient education. Identifying these needs prompted the case management team approach:

Once you start, you're aware of the social determinants, you realize that there's so much out there that patients need that you can't provide for them. You start thinking, well, could anyone else help with that? Well, yeah, if we had someone like [the RN diabetes educator] who could help people learn more about their diet or help them quit smoking or whatever, just working with them one-on-one... that might be a help. ...[And] we had to make sure we had a behavioral therapist [and] someone who could help people with their insurance... (P6, Physician interview, June 28, 2016)

Two consistent issues raised by many providers when discussing the management of chronic conditions were suboptimal communication with specialists and limited clinical information from external specialty practices and hospitals (P3, P4, P6, P9). While communication between primary care providers within the same practice or health system existed via electronic data systems, it was rare between primary care providers and specialists, even when they shared the same EHR. A lack of communication with specialists and the need to “track down” patient information from specialists continued to be challenges for care coordination efforts at these practices.

Some practices had developed initiatives to address these limitations, including hiring additional support staff to follow up with specialty offices for patients (P11) or implementing additional health information technology infrastructure to access records at other organizations (P10). These efforts, however, were not without additional costs, nor were they fail-proof in obtaining comprehensive records for specialty visits. For example, P11's clinical manager said that while there were nonclinical staff at the practice who were responsible for obtaining records from specialty offices, the practice's financial ability to pay for these staff member roles were fully dependent on their existing capitation contract:

[T]his money really allows [us] to provide for the ancillary, value-added, non-reimbursable services. All the health coaching, patient support services, and other services wouldn't be possible without it but ... it's hard though. It's hard to pay all of our staff. We'd like to pay them more. (P11, Fieldnotes, October 20, 2016)

The communication challenges with specialists evidenced in the care for other chronic conditions highlights potential difficulties in maintaining a

two-way dialogue between primary care and oncology. Many practices in our sample noted there was a lack of formal relationships with cancer centers or oncologists within their medical neighborhood. Aside from ACO or system-based affiliations, any existing relationships with oncologists reported by practices were either through personal relationships or because a practice had employed an oncologist part-time (P11). Many clinicians referred to the one-way “black box” of patients being transitioned from primary to oncology care, leaving very little actionable information sent to primary care providers once cancer patients initiate active treatment. Although all nine of the innovative practices in our sample had implemented protocols to manage various chronic conditions, suggesting a basic infrastructure for implementing systematic cancer survivorship care, many pointed to the limited relationship with oncology as an area for much needed improvement.

DISCUSSION

These findings add to the growing empirical evidence for the potential to translate care coordination elements in primary care practices for cancer survivorship care. Although we observed no implementation of services for cancer survivorship care in our larger parent study [30], this analysis identified potential capacity, as well as barriers, to provide such care using existing care coordination infrastructure developed for other chronic conditions. Specifically, we observed the existing use of registries to track specific categories of patients, clinical, and nonclinical office staff to build a team approach for coordinating care, and protocols for addressing and managing a wide range of conditions, as potential elements to accelerate the implementation of systematic survivorship care within primary care settings. Nevertheless, given the lack of awareness of cancer survivorship issues in primary care and multiple competing demands within primary care, investments in resources and training are needed in order to fully implement cancer survivorship care in the primary care setting.

While it was encouraging that all nine practices in our study had existing care coordination infrastructure in place to manage chronic conditions, some of the motivation behind the infrastructure or strategies was due to organizational or financial drivers. Practices explained some initiatives for addressing specific chronic conditions were based on larger top down directives from their broader health system affiliation. The lack of organizational or financial drivers for implementing cancer survivorship care may be a strong barrier for primary care practices. With the continuously growing and competing list of priorities in primary care, practices are increasingly faced with decisions on which priorities to

focus on for the best interest of their patient population and how to address these conditions through team-based approaches [43, 44]. Without financial drivers to provide cancer survivorship care or metrics for providing guideline directed care, primary care practices have little incentive to focus on cancer survivors as a group compared to other competing demands.

The observed gaps in communication between primary care providers and specialists for other chronic conditions suggests the implementation of cancer survivorship care in primary care settings would require enhanced efforts to transfer key clinical information and to create potential incentives to maintain two-way dialogue between primary care and oncology. Stronger relationships between oncology and primary care are critical for effective communication as patients transition into and out of active cancer treatment. These types of relationships were not evident throughout all practices. Despite efforts to introduce and implement survivorship care plans from the field of oncology [3, 45], no practices in our study reported having seen cancer survivorship care plans for patients. Commitment from oncology to establish a relationship with primary care is also necessary for long-term care of survivors. Stronger engagement with primary care practitioners, including in the development or dissemination of actionable guidelines for cancer survivorship care within primary care settings, are needed.

While we also observed strong potential to adapt existing care coordination capabilities for cancer survivorship care within primary care settings, the actual process of implementing such care will require additional training of providers and staff to address survivorship care needs. Our findings suggest innovative practices have the infrastructure and potential capacity to implement team-based care to cover the physical and social needs of complex chronic conditions. However, improved interoperability of clinical information systems between primary care and specialists as well as the ability to identify and track cancer survivors using in-house data are needed. As others have noted, although there are diagnostic codes for personal history of malignant neoplasm as well as procedure codes for services related to survivorship care, it is unclear whether these are employed consistently across primary care or other providers, thereby limiting the ability for practices to track and bill for long-term care and surveillance efforts for cancer survivors systematically [46]. Investments are needed, such as those for training primary care staff and infrastructure for clinical information systems, to address the needs of cancer survivors over other competing demands [3].

This is one of the few studies to examine the potential to implement cancer survivorship care by examining current care coordination systems in place for other chronic conditions within primary

care practices; however, some limitations should be mentioned. Our purposive sample of high functioning, innovative PCMHs likely had better care coordination infrastructure in place compared to less advanced primary care practices, but also may have been more likely to face multiple competing priorities, thereby limiting generalizability of our findings. Characteristics of patients in these practices, particularly those in urban practices, may also limit the generalizability of cancer survivors in our study. Despite these limitations, we sampled practices in an iterative process for confirming and disconfirming cases systematically. As more practices across the U.S. focus on medical home models, practices may have similar capacities to these PCMH structures in the future [47]. Lastly, we did not ask about care coordination as a primary focus for the parent study. While we learned much about care coordination processes within practices, our interview focus did not specifically aim to answer how existing care coordination capacity could be applied to cancer survivorship.

Our study provides insight into existing care coordination elements within primary care practices that can be adapted for cancer survivorship care as well as barriers that need to be addressed for cancer survivorship care in primary care settings. The IOM's *Last in Transition* report on the specific needs of cancer survivors, as well as the adoption of the PCMH model, has been around for over a decade. Yet, systematic cancer survivorship care is minimal to nonexistent in primary care settings. Future research warrants further exploration of the disconnect between "the capacity to provide" and "the implementation of" systematic cancer survivorship care.

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Compliance with Ethical Standards

Conflict of Interest: All authors declare that they have no conflicts of interest.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the Rutgers Biomedical and Health Sciences Institutional Review Board. 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. *Statement on the welfare of animals:* This article does not contain any studies with animals performed by any of the authors.

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

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