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Care coordination for complex cancer survivors in an integrated safety-net system: a study protocol

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Abstract

Background: The growing numbers of cancer survivors challenge delivery of high-quality survivorship care by healthcare systems. Innovative ways to improve care coordination for patients with cancer and multiple chronic conditions ("complex cancer survivors") are needed to achieve better care outcomes, improve patient experience of care, and lower cost. Our study, Project CONNECT, will adapt and implement three evidence-based care coordination strategies, shown to be effective for primary care conditions, among complex cancer survivors. Specifically, the purpose of this study is to: 1) Implement a system-level EHR-driven intervention for 500 complex cancer survivors at Parkland; 2) Test effectiveness of the strategies on system- and patient-level outcomes measured before and after implementation; and 3) Elucidate system and patient factors that facilitate or hinder implementation and result in differences in experiences of care coordination between complex patients with and without cancer.

Methods: Project CONNECT is a quasi-experimental implementation study among 500 breast and colorectal cancer survivors with at least one of the following chronic conditions: diabetes, hypertension, chronic lung disease, chronic kidney disease, or heart disease. We will implement three evidence-based care coordination strategies in a large, county integrated safety-net health system: 1) an EHR-driven registry to facilitate patient transitions between primary and oncology care; 2) co-locating a nurse practitioner trained in care coordination within a complex care team; 3) and enhancing teamwork through coaching. Segmented regression analysis will evaluate change in system-level (i.e. composite care quality score) and patient-level outcomes (i.e. self-reported care coordination). To evaluate implementation, we will merge quantitative findings with structured observations and physician and patient interviews.

Discussion: This study will result in an evaluation toolkit identifying key model elements, barriers, and facilitators that can be used to guide care coordination interventions in other safety-net settings. Because Parkland is a vanguard of safety-net healthcare nationally, findings will be widely applicable as other safety-nets move toward increased integration, enhanced EHR capability, and experience with growing patient diversity. Our proposal recognizes the complexity of interventions and scaffolds evidence-based strategies together to meet the needs of complex patients, systems of care, and service integration.

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Keywords: Care coordination, Cancer survivorship care, Primary care, Oncology

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Background

Nearly 70% of the 13 million people living with cancer are “complex cancer survivors,” i.e., those also dealing with other chronic conditions [1, 2]. Further, the prevalence of complex cancer survivors is expected to continue growing [3–7]. Poor, under- and uninsured individuals have the highest burdens of multiple chronic conditions and this is also similarly reflected among cancer survivors [8–18]. Complex cancer survivors need highly coordinated care to ensure optimal outcomes for their cancers, co-existing chronic conditions, and overall quality of life. However, following initial cancer treatment, needs of complex cancer survivors are not well met, resulting in poor health outcomes [4]. Management of a new cancer diagnosis often interrupts existing chronic disease care because patients undergo intensive cancer care for an extended period during which attention to their other conditions may wane. Further, patients with cancer often continue to be followed by oncologists and other specialists [19–22] with little or no care coordination with primary care clinicians. As a result, care is fragmented [23] and the providers siloed, [24–26] resulting in suboptimal care quality [27].

Effective care coordination organizes patient care activities and provider information-sharing to facilitate shared-care and appropriate service delivery [21, 24, 28–30]. Interventions to improve care coordination have been tested in primary care settings for conditions such as diabetes, hypertension, and depression [31–34] and shown to be efficacious in improving health care delivery and patient outcomes. However, few studies to date have targeted complex cancer survivors to improve care coordination between oncology and primary care [21]. With the increasing number of cancer survivors (18 million by year 2022) [7], we urgently need to identify innovative ways to improve care coordination for patients with cancer and multiple chronic conditions to achieve the triple aim of better care outcomes, better patient experience of care, and lower cost [35, 36].

To address this need, our proposed study, Project CONNECT, will adapt and implement care coordination strategies, shown to be effective for primary care conditions, among complex cancer survivors in a large, county integrated safety-net health system. The evidence–based care coordination strategies include: 1) an EHR-driven registry to facilitate patient transitions between primary care and oncology care; 2) co-locating a nurse practitioner trained in care coordination within a complex care team; 3) and enhancing teamwork through coaching. We will evaluate the effectiveness of the intervention on system- and patient-level outcomes and elucidate system and patient factors that facilitate or hinder implementation using mixed methods.

The aims of this study are

Aim 1

Implement a system-level EHR-driven intervention for 500 complex cancer survivors at Parkland, combining three evidence-based care coordination strategies.

Aim 2

Test effectiveness of the strategies on system-and patient-level outcomes using a rigorous, quasi-experimental design with outcomes measured before and after implementation.

Aim 3

Elucidate system and patient factors that facilitate or hinder implementation and result in differences in experiences of care coordination between complex patients with and without cancer.

Methods

Study design

Project CONNECT is a quasi-experimental implementation study and a mixed-method evaluation.

Setting

The study will be conducted at Parkland Health and Hospital System (Parkland), the public, integrated safety-net system for Dallas County. Parkland disproportionately serves under- and uninsured racial and ethnic minority populations that bear high burdens of multiple chronic conditions. The Parkland system includes 12, community-oriented primary care clinics staffed with board-certified family practitioners, internists, advanced practice providers, and nurses whose demographic background align with neighborhood characteristics (60% of physicians are African American, Hispanic, or Asian, 54% female, > 50% bilingual) [37]. The Parkland primary care clinics have been NCQA-accredited Level 3 patient-centered medical homes (PCMH) since 2015. Centralized on the hospital campus, the Parkland cancer program is accredited by the *American College of Surgeons Commission on Cancer* and participates in the Texas Cancer Registry and actively engaged in quality improvement initiatives, for example, partnering with the Centers for Medicare and Medicaid Innovation in the Oncology Care Model since 2016.

Patient population

The study includes 500 patients diagnosed with (a) Stage I-III breast or colorectal cancers and (b) diagnosed with one or more of the following chronic conditions: diabetes, hypertension, chronic lung disease, chronic kidney disease, or chronic heart disease.

Intervention design

We will implement a system-level EHR-driven intervention for 500 complex cancer survivors at Parkland, combining three evidence-based care coordination strategies:

EHR-based registry to facilitate patient transitions between primary care and oncology

To facilitate transitions between oncology and primary care, we will develop an EHR-based registry and workflow [38] using the Epic Reporting Workbench to identify eligible patients and deliver team-based coordinated care (Fig. 1). The Oncology and Primary Care Medical Directors will provide clinical expertise to develop the EHR registry and associated workflow and will also champion implementation of the care coordination strategies. During Year 1, Parkland will educate clinicians and staff about the proposed system change and inform primary care physicians on the ways that the health system seeks to address this need through new patient pathways and access. This training will be included in one of each primary care clinic's monthly training modules.

Co-locate a nurse coordinator trained in care coordination

Oncology will designate a full-time registered nurse ("nurse coordinator") with competencies in care coordination [39] as a key member of the patients' care team [40]. The nurse coordinator will be tasked primarily in clinical care coordination, continuity/transition management [41–43], and assisting patient self-management. [39, 44, 45] The nurse coordinator will review a list of patients from the registry who have initiated cancer treatment in ambulatory oncology using the EHR algorithm and confirm eligibility for this research (Fig. 1). We will confirm the algorithm's ability to identify Stage I-III complex patients via chart review audit of 50 patients. For cancer survivors established within community primary care, the nurse coordinator will first notify the primary care physician of the survivor's completion of initial cancer treatment and transition to the cancer survivorship phase. Patients diagnosed with cancers referred in or diagnosed through the emergency department (ED) will be assigned directly to the nurse coordinator who will establish a primary care provider and home within the Parkland system. In-person meetings at the start of cancer treatment will be established by the nurse coordinator when patients begin to attend oncology visits.

At the end of active cancer treatment, the nurse coordinator will initiate an EHR-driven treatment summary and follow-up guidelines, encourage continual interaction with primary care, and recommend transition to the care team post-treatment. S/he will systematically track patients to ascertain completion of initial cancer treatment and, each week, coordinate appointments and lab tests between primary and specialty clinics. Once appointments are made with the primary care physician and social worker, the nurse coordinator will track upcoming appointment results via the EHR-driven registry. Eligible patients will be seen again at treatment end by the nurse coordinator for a transition review. At the visit, the nurse coordinator will synthesize patients' medical and cancer history, and educate them on follow-up for cancer recurrence, self-management for chronic diseases, and long-term effects of their cancer treatment [44]. The nurse coordinator will also coordinate appropriate specialty care referrals, including smoking cessation, and health behaviors/psychosocial counseling

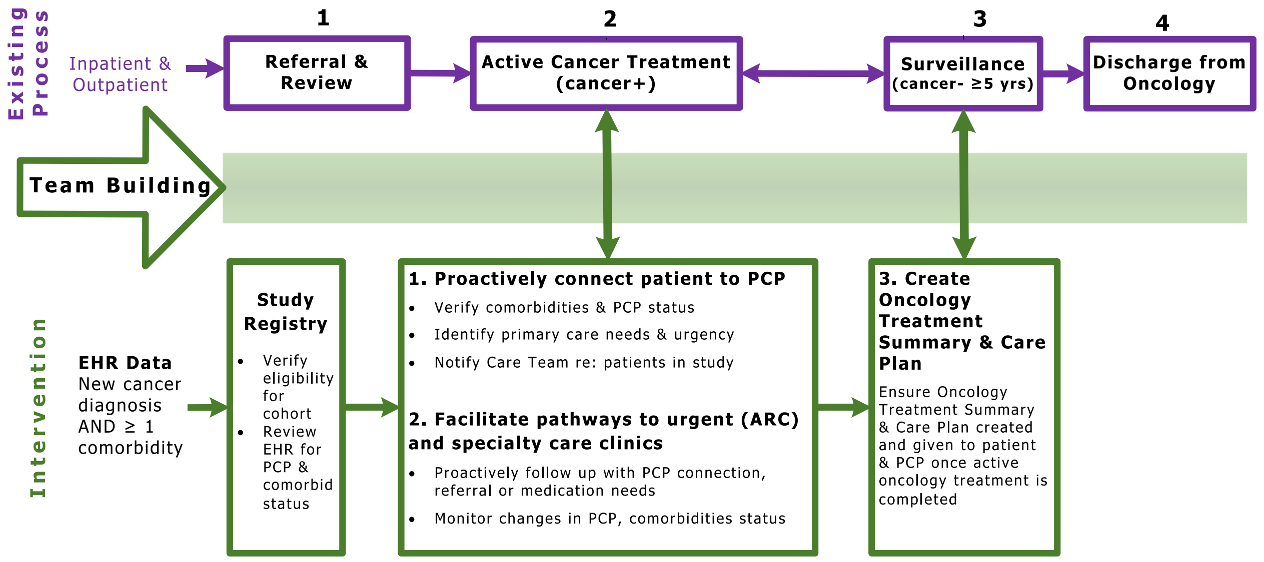

Fig. 1 EHR-driven pathway between oncology and primary care

resources already available at Parkland. Information and education will be culturally and literacy-level appropriate, per Parkland standards, as a healthcare provider for diverse and vulnerable communities.

Enhance teamwork through coaching and technical assistance

An external practice facilitator will provide coaching and technical assistance to enhance team-based care [46–48]. Ongoing support from expert quality improvement trainers is critical to successfully implement and sustain system changes [41]. Prior to implementation launch, the coach will meet with the nurse coordinator in-person to start the rapport-building process and establish goals and expectations for the coordinator/coach relationship. Then, during the implementation phase, the nurse coordinator and coach will hold regular (30 min, weekly) meetings aimed at providing motivational work and direct recommendations to challenges as they arise, as well as providing specific guidance to identify and assess patients, clarify team member roles, facilitate communication, manage care transitions, and monitor or adjust work flow [49]. The external coach will draw on the principles of process improvement cycles (e.g. Plan-Do-Study-Act), appreciative inquiry, and other coaching strategies over the course of the study to help the nurse coordinator and larger team learn continuously from on-the-ground implementation [50–52].

Evaluation design

Framework

We used the empirically informed *Primary Care Practice Change Model*, developed by Cohen and colleagues, to guide our mixed-methods evaluation design [53]. Built on principles of complex adaptive systems theory [53–56] and drawing from results of prior primary care system-level interventions, the model emphasizes the role of multi-level factors influencing implementation. Specifically, it identifies four key elements: internal motivators, external motivators, resources and opportunities for change [56]. These elements can act independently but, because system resources and opportunities are highly interconnected, a change in one can reverberate across the system [53]. For example, resources available to Parkland to support change (e.g. leadership and relationships among practice members) may influence the extent to which clinicians and staff adapt work flow to implement the new EHR-driven strategy to link survivors with primary care. Coupled with availability of a new care coordinator within a dedicated complex care team, this may improve care within the system. Similarly, motivated staff may identify new ways to foster implementation of the strategies. Using provider interviews and structured observations, we will examine how and why motivation of clinic members influences implementation. Using mixed-methods, we will track how these different elements inside and outside the system interact to influence change [57], and support or hamper sustainability of the intervention strategies [58–61]. We will identify system- and patient-level factors influencing implementation of the care coordination strategies to systematically pinpoint barriers amenable to ongoing quality improvement and to enable subsequent dissemination to other safety-net settings [62].

Gathering qualitative and quantitative data before, during, and after implementation will enable us to assess the factors that influence implementation at the system- and patient-levels [56, 63]. Using an intervention mixed methods approach to evaluation will enable us to observe how contextual factors shift during the course of the study [57, 64], to systematically pinpoint facilitators as well as barriers amenable to ongoing quality improvement and to generate transportable lessons for dissemination [62]. To inform real-world implementation intervention, it is important to: (a) describe how the system-level strategies are implemented; (b) elucidate contextual factors affecting implementation at system- and patient-levels; and (c) identify alternate explanations for observed effects on outcomes to generate counterfactual inference.

Measures

Table 1 provides an overview of hypotheses, design (sample), data collection time points and outcome measures used.

Data collection

System-level data collection

Electronic health records (EHR) extraction We will extract Epic EHR data to evaluate whether patients are meeting quality of care guidelines for multiple chronic conditions and follow-up National Comprehensive Cancer Network (NCCN) guidelines for cancer surveillance. A composite care quality score will be calculated for each patient as the percentage of eligible recommended services received and clinical targets met. We will also measure rates of ED utilization and hospitalizations (secondary outcomes) for ambulatory care-sensitive chronic conditions at the same time points as the primary outcomes [65, 66]. Data will be extracted 12 and 24 months before implementation and 12, 24, and 36 months during implementation.

Further, we will extract EHR data to characterize (1) visit patterns with the nurse coordinator; (2) the extent to which care coordination, disease management and referrals to specialty providers and receipt of referrals occur; (3) patients who do not receive appropriate follow-up services; (4) missed appointments or loss-to follow-up; and (5) processes related to care coordination.

Table 1 Hypotheses, design (sample), data collection time points, & outcome measures

Hypothesis	Design (sample)	Time points	Outcome measure (*data source*)
System-level primary hypothesis: A higher proportion of complex cancer survivors will meet quality of care guidelines for their chronic conditions and for cancer follow-up care 12 months post-implementation	Repeated cross-sections of distinct samples of patients at each time point (n~ 500)	• 12 and 24 months pre-implementation (historical controls) • 12, 24 and 36 months during implementation	Primary outcome: Composite care quality score (*EHR*) Chronic disease score - % patients receiving guideline-appropriate services (process measures) and meeting guideline-recommended targets (intermediate outcomes) Cancer follow-up care score - % patients receiving NCCN guideline-appropriate cancer surveillance
Patient-level hypothesis: Patient-reported care coordination scores will significantly improve over time among complex cancer survivors 12 months post-implementation	Repeated measures on same patients (*n* = 402)	• Baseline • 6 and 12 months post-baseline	Care coordination using patient perception of care scale [65] (*patient surveys)* - Coordination of care – overall and at visit - Specialty care access - Education/information - Preferences, social support, health literacy - Health-related quality of life

We will measure clinical care coordination performed by the nurse coordinator, including: number of referrals to other specialists; number of specialist appointments attended; and number of visit notes sent back to care team members' Epic EHR inbox.

Structured observations Quiet observation of daily clinical work with opportunistic discussion with staff at the primary care clinics, oncology clinics, and the complex care team will describe usual care prior to and document how workflow changes after strategies are implemented [67, 68]. Adapted from anthropological participant observation, this method lends itself to multiple levels of observation and analysis [69–72]. Research staff will conduct 40 h of structured observation prior to implementation and at 3 and 6 months post-implementation.

Provider interviews Providers (*n* = 30), sampled based on their involvement in cancer survivor follow-up care and chronic disease management, will be invited to interviews assessing their perspectives on patient uptake and other challenges and opportunities. The principal investigators will develop interview guides, train and supervise the team in conducting interviews. Patients and providers completing the interview will be offered an incentive for their time and effort.

Patient-level data collection

Patient surveys Surveys will be administered three times by phone at completion of active cancer treatment (baseline) and twice thereafter at 6 and 12 months. Patient surveys assess care coordination using the Picker Patient Perception of Care Scale [73–75], key patient-reported confounding variables (age, race/ethnicity, insurance, income, education, employment and marital status), and potential mediators and moderators (attitudes towards follow-up care, patient activation, self-efficacy, emotional and social support, health literacy, and health-related quality of life) using validated instruments [17, 76–82] (Table 2). Prior to fielding surveys, we will conduct 15 cognitive interviews (with patients who will be excluded from the larger project) to ensure measures not already validated in Spanish are adapted for language, literacy and cultural appropriateness.

Patient interviews Open-ended patient interviews (*n* = 70) will be conducted at baseline and throughout the 6 to 12 months post implementation of the complex care team. Both survey respondents, as well as a subset of

Table 2 Patient survey constructs

Constructs	Baseline	Follow-up
Demographics	X	
Health literacy	X	
Coordination of care	X	X
Patient involvement in care	X	X
Health-related quality of life	X	X
Comorbidities	X	
Pharmacy	X	X
Self-efficacy	X	
Social support	X	
Attitudes towards follow-up		X
Depression (PHQ-9)	X	X
Patient satisfaction with navigation (PSN-L)	X	X

non-respondents, will be invited to participate in a telephone interview with research staff trained in qualitative methods. Interviews will elucidate the experience of coordination for patients with multiple chronic conditions and enable us to see how cancer may create additional needs or perceptions by asking patients to talk about their experiences and communication with their provider teams. A subset of non-cancer patients with multiple chronic conditions will also be interviewed for additional comparison. Patients completing the interview will be offered a gift card for their time and effort.

Analyses

System-level

We will use segmented logistic regression and linear mixed regression models to assess effect of care coordination strategies on system and patient outcomes. To evaluate system-level hypotheses, we will first use chi-square tests to compare proportion of eligible patients meeting guidelines at 12 and 24 months before implementation to proportion of patients meeting guidelines 12, 24 and 36 months after system-level strategies are in place. We will then use segmented logistic regression models [83] to identify the time point at which observed trend in proportion of patients meeting guidelines (trajectory rate) markedly changes. We will then test trend for proportion of patients meeting guidelines before implementation of system-level strategies.

Power Preliminary Parkland data indicate 40% of colorectal cancer survivors (2008–10) met guidelines for cancer surveillance and chronic disease outcomes. To demonstrate a minimum increase of 10% in the primary outcome after implementation of system-level strategies as compared to before implementation, a sample of 170 patients at each time point will provide 80% power at the 0.05 significance level based on the chi-square test for comparing proportions. We have many more patients than needed; as system-level outcomes will be evaluated using EHR data, we will include all eligible patients and conduct subgroup and sensitivity analyses to better characterize effects.

Patient-level

For patient-level hypotheses, we will use linear mixed models to estimate effects on change in scores. Through specification of fixed effects, the mixed model allows for control of confounding variables, and can account for sources of natural heterogeneity by adding random effects that are unique to a particular individual. We will test different covariance matrices for random effects and will choose the matrix yielding the smallest Akaike information criterion or largest restricted maximum likelihood estimate. Residual analyses and plots will examine adequacy of the final model. Retrospective data might be missing. If data are missing at random (MAR), a linear mixed regression model is appropriate to address the issues of repeated measures and missing data in longitudinal studies. If the missing data are not missing at random (NMAR), we will explore the missing data pattern and a technique such as pattern mixture model will be used to adjust for NMAR bias.

Power Preliminary data show mean care coordination score without intervention is 81.1 (standard deviation = 17.6) [84–86]. Assuming intra-subject correlation of 0.7 and minimum detectable standardized effect size of 0.25 (standardized effect size = effect size/standard deviation), we will need 402 patients to attain 80% power at α = 0.05 using proposed mixed-effects linear regression analyses. To accommodate 20% attrition, we will recruit 476 patients- below the 500 available in a 4-year span.

Mixed-method

We will combine qualitative and quantitative methods in a *convergent interactive analytic* design to examine interdependencies between conceptual model elements**.** Further, we will conduct observations at multiple time points to assess the gradual nature of implementing system change [87], staggering data collection over time, enabling each method to cross-inform our overall strategy [88]. For instance, interim analyses indicating successful implementation will inform provider interviews to elicit contextual data regarding factors contributing to increases in receipt of guideline-appropriate care [64]. Triangulating such data strengthens validity and decreases deficiencies or biases that might arise from any single method [89–91]. Our multi-disciplinary research team minimizes researcher bias by bringing together experts with differing perspectives to review and critique synthesis and interpretation of qualitative findings. By examining "factors that affect interpretation of what happened during the study (internal validity) [92] and consider what others need to know to transport the study elsewhere (external validity)," [57] our study will generate the evidence base for care coordination among complex cancer survivors and facilitate dissemination.

We will use *NVivo 9.0* (QSR International, AUS) to collate and analyze qualitative data. Use of this software makes the analytic process transparent so that investigators can track evolving analyses [93]. Research staff will transcribe field notes from structured observations and gather existing protocols and documents relating to care of complex patients to enter into the database. We will triangulate across diverse data sources, to understand how providers adapt the strategies to suit the Parkland context [56, 67]. To focus our analysis of model elements and their interdependencies, we will develop a matrix of key concepts, populating cells with observational data and inserting brief excerpts of raw text to substantiate claims or interpretations. This analytic step facilitates cross-case comparisons (e.g. pre- and post-implementation, or between patient types) and in-depth explorations of specific concepts [94]. Through monthly meetings, we will test emergent themes and interpretation against the knowledge base of our study team [95]. We will review coding agreement and resolve discrepancies through consensus [96, 97].

Discussion

Significance

Prior research has not addressed multiple-disease management models; the field has largely focused instead on single cancer sites or individual diseases [21, 98–101]. Our proposal recognizes the complexity of interventions and scaffolds three evidence-based strategies together to meet the needs of complex patients, systems of care, and service integration. The 2013 IOM report on high-quality cancer care calls explicitly for translation of evidence into practice and research on complex cancer survivors [102]. Our study evaluates proven intervention strategies among cancer survivors of different types contending with other multiple chronic conditions.

Although ~ 11% of cancer survivors are uninsured [4], little research has been conducted in this population who bear a disproportionate burden of multiple chronic conditions, including cancer [26, 103–106]. Similarly, care coordination strategies have mainly been implemented in healthcare systems with insured populations [107–109]. Safety-nets have important policy significance [12]: the Affordable Care Act used Medicaid expansion as a primary mechanism for extending coverage to the uninsured [10, 110]. Because community providers may not accept Medicaid, most of the new beneficiaries will likely obtain care from safety-net providers [111–113]. Finally, because Texas declined Medicaid expansion, this Dallas/Fort Worth-based study is relevant to ~ 20 non-expansion states.

Strengths and limitations

A potential limitation of our study is the inability to evaluate using a randomized controlled trial and differential participation of survivors. However, quasi-experimental designs are uniquely suited to evaluate health services system-level interventions implemented in real-world settings [114, 115]. By incorporating additional design features such as data collection at multiple time points and a mixed-methods evaluation, we strengthen the rigor and validity of our findings by addressing history, maturation, and permit counterfactual inference [57, 92, 116]. By including two cancer types, we can evaluate potential differential effects of each care coordination strategies for different groups of survivors with multiple comorbidities. Furthermore, the use of patient-reported outcome measures makes our research patient-centered [117] and provides data on patient-level variables influencing outcomes of system-level interventions [118].

Impact

Our intervention and mixed-methods design will result in an evaluation toolkit identifying key model elements, barriers and facilitators that can be used to guide care coordination interventions in other safety-net settings. Because Parkland is a vanguard of safety-net healthcare nationally, findings will be widely applicable as other safety-nets move toward increased integration, enhanced EHR capability, and experience with growing patient diversity [119]. Through leadership in America's Essential Hospitals, the national association of public hospitals and health systems, Parkland will be well-positioned to provide educational programs for leaders of more than 260 member institutions and disseminate best practices in care coordination, management of multiple chronic conditions and cancer survivorship to the nation's safety-net systems.

Abbreviations

ED: Emergency department; EHR: Electronic health record; MAR: Missing at random; NCCN: National Comprehensive Cancer Network; NCQA: National Committee for Quality Assurance; NMAR: Not missing at random; PCMH: Patient-centered medical home; PHQ-9: Patient health questionnaire; PSN-L: Patient satisfaction with logistical aspects of navigation

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Availability of data and materials

Not applicable

Authors' contributions

SJCL and BAB conceptualized the study and provided critical feedback and edits throughout the development of the article. KKJ drafted the first draft of the manuscript and provided feedback throughout. ES, KO DC, NOS, and JVC assisted in editing. EM constructed the tables/figure and assisted in editing. All authors read and approved the final manuscript.

Ethics approval and consent to participate

Protocol was approved by the University of Texas Southwestern Medical Center IRB (STU# 102015–090) and the Office of Research Administration, Parkland Health & Hospital System. UT Southwestern is the IRB of record for Parkland Health and Hospital System.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

Publisher's Note

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