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REVIEW

Cancer research network: using integrated healthcare delivery systems as platforms for cancer survivorship research

**Larissa Nekhlyudov · Sarah M. Greene ·
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Abstract
Introduction Much progress has been made in cancer survivorship research, but there are still many unanswered questions that can and need to be addressed by collaborative research consortia.
Methods Since 1999, the National Cancer Institute-funded HMO Cancer Research Network (CRN) has engaged in a wide variety of research focusing on cancer survivorship. With a focus on thematic topics in cancer survivorship, we describe how the CRN has contributed to research in cancer survivorship and the resources it offers for future collaborations.
Results We identified the following areas of cancer survivorship research: surveillance for and predictors of recurrences, health care delivery and care coordination, health care utilization and costs, psychosocial outcomes, cancer communication and decision making, late effects of cancer and its treatment, use of and adherence to adjuvant therapies, and lifestyle and behavioral interventions following cancer treatment.
Conclusions With over a decade of experience using cancer data in community-based settings, the CRN investigators and their collaborators are poised to generate evidence in cancer survivorship research.
Implications for Cancer Survivors Collaborative research within these settings can improve the quality of care for cancer survivors within and beyond integrated health care delivery systems.

Keywords Cancer survivorship · Integrated health care systems · Heath services research

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Introduction

Since the release of the Institute of Medicine Report entitled "From Cancer Patient to Cancer Survivor: Lost in Transition," [1] the field of cancer survivorship research has grown. There is now greater awareness of the unique array of issues faced by cancer survivors, including the late effects of cancer and its treatment, recurrences, management of comorbid conditions,

and psychosocial outcomes. Further, there is growing appreciation of the importance of studying and improving the processes of care, including patient-centered communication, care coordination, and transitions from specialty to primary care settings. Many questions in the field of cancer survivorship have been addressed using existing national databases, such as Surveillance, Epidemiology, and End Results (SEER)-Medicare, academically based cohorts, as well as single institution trials and descriptive studies. However, despite the progress, cancer survivorship is still in the early phases of discovery. In its report, the Institute of Medicine described several ongoing settings for conducting cancer survivorship research. Among these was the HMO Cancer Research Network (CRN), a National Cancer Institute (NCI)-funded consortium of integrated community-based health care delivery sites with more than 11 million enrollees. Cancer survivorship research in the CRN benefits from the participating delivery systems' longstanding approaches to coordinated care, continuous patient enrollment, care prior to and following cancer diagnosis, inclusion of patients of all ages, comprehensive data resources including electronic medical records, and web-based tools for patients and multidisciplinary scientific expertise [2, 3]. These settings, along with their patients, health care providers and scientific partners have the ability to serve as "population-based laboratories" for development, testing, and implementation of strategies aimed at enhancing the care of cancer survivors. In this paper, we describe how the CRN has contributed to collaborative research in cancer survivorship and the resources it offers for future study of cancer survivorship. With a focus on thematic research areas of cancer survivorship, we build upon an earlier summary of cancer survivorship research in the CRN [4], which described the methodological approaches used in prior studies.

The HMO Cancer Research Network (CRN)

The CRN is currently comprised of 14 integrated health care delivery sites located across the United States (http://crn.cancer.gov/about/participants.html), collectively providing care to approximately 11 million individuals. The CRN population includes approximately 38,000 patients newly

Table 1 Number and percentage of enrollees diagnosed and living with cancer, by age group[a]

Age group	Number	Percentage
0–17	6,477	0.5
18–39	39,024	3.2
40–64	233,632	34.2
65+	156,571	62.1
Total	435,704	

[a] Based on current CRN membership, data obtained September 2012

Table 2 Number of enrollees diagnosed and living with cancer, by selected cancer type[a]

Cancer site	Number
Breast	99,796
Prostate	91,938
Colorectal	36,240
Lung	15,026
Ovary	5,797

[a] Based on current CRN membership, data obtained September 2012

diagnosed with cancer annually and over 400,000 patients diagnosed and living with cancer (of whom close to 40 % are under the age of 65; Tables 1 and 2). Continuously funded since 1999, the CRN has become a key resource for large, collaborative multi-center, multidisciplinary research that addresses the spectrum of cancer control, including studies of prevention, early detection, treatment, survivorship, surveillance, and end-of-life care [3, 5]. Cancer survivorship research is a major area of focus in the CRN; in addition to informal opportunities for investigator interactions, collaborations are built and ideas are exchanged in monthly cancer survivorship scientific interest group conference calls which include CRN, academic, government, and advocacy group leaders and investigators. In 2008, the NCI funded the CRN-based Cancer Communication Research Center (CCRC, 5P20CA137219, Dearing PI), one of five Centers of Excellence in Cancer Communication Research. The CCRC addresses optimal communication structures and processes in organizations, including care coordination, to facilitate patient-centered communication in cancer care across the continuum (www.crn-ccrc.org).

Data collection for CRN studies

Studies conducted within the CRN benefit from several sources of data, including: electronic medical records; tumor registries that are affiliated with the local SEER or state-based registries; and claims-based utilization data and pharmacy data (Table 3). Data are accessible via individual sites' virtual data warehouse (VDW). Specifically, automated data at each site are translated into a common language and format; a program for a particular study may be written at one site and then distributed to and run at the other participating sites with minimal modification, as needed. Once the participating sites run the program on their health plan data, a combined limited dataset is provided to the lead site for analysis. While individual sites' data are stored locally, common data structure across sites allows for efficiency of data collection, distribution, and analysis. Further, preliminary counts of subjects available for studies may be searched by a number of criteria, including age, tumor type, diagnosis, stage, years of diagnosis, and site, using the CRN Cancer Counter website (a password-protected utility available to CRN investigators). Several methodological studies with direct implications to cancer

Table 3 CRN data for observational and interventional studies in cancer survivorship

Automated health plan data[a]

    Claims (diagnoses, inpatient and outpatient encounters, procedures including surgery, laboratory, radiology, chemotherapy)

    Enrollment (dates of coverage, type of insurance, and benefits)

    Demographics (gender, age, and race/ethnicity)

    Census and geocoding (education, income, and race information)

    Provider characteristics (for encounters, procedures, and test ordering)

    Pharmacy (dispensing information, National Drug Codes (NDCs), including chemotherapy)

Electronic medical records[b]

    Full text encounters

    Lab results

    Pathology results

    Vital signs, height, and weight

Tumor registry data[a]

    Cancer diagnosis, histology, stage and grade, date of diagnosis, dates of treatment, among other data elements

National death index[c]

    Date and cause of death

[a] Data available in the Virtual Data Warehouse (VDW) among all sites

[b] Data available through abstraction of medical records and in the VDW for some sites

[c] Data available through linkage

survivorship research in the CRN have shown that patients diagnosed with cancer remain enrolled in the CRN health plans [2], chemotherapy utilization data available in the CRN is valid [6–8], and that algorithms to identify cancer recurrences that are not available in cancer registries may be developed [9].

In addition to accessing automated data via the VDW, most sites have mature electronic medical records that may be efficiently accessed for chart review using natural language processing [10, 11] and manual abstraction [12–14]. These data are not typically present in purely administrative data sources. Direct access to patients and providers can be available for qualitative and/or quantitative survey studies, as well as interventional research (Table 4). Lastly, several sites have collected biospecimens and are building biorepositories that may be available for research [15].

Institutional review board approvals and data use agreements are required for all CRN studies; many of the regulatory and administrative procedures have been streamlined to allow for more efficient processes [16–18].

Thematic approach to cancer survivorship research in CRN

In this paper, we outline eight cancer survivorship themes in which selected studies have demonstrated notable strengths and/or the potential of the CRN research environment and propose opportunities for future collaborative research. The themes include (1) surveillance for and predictors of recurrences, (2) health care delivery and care coordination, (3) health care utilization and costs, (4) psychosocial outcomes, (5) cancer communication and decision making, (6) late effects of cancer and its treatment, (7) use of and adherence to adjuvant therapies, and (8) lifestyle and behavioral interventions. These themes are congruent with the essential aspects of survivorship research as outlined by the Institute of Medicine report. A comprehensive listing of cancer survivorship research in the CRN is available at http://crn.cancer.gov/projects/survivorship.

Surveillance for and predictors of recurrences

Several CRN studies have addressed surveillance for recurrences following invasive and in situ breast cancer and colorectal cancer [19–24]. These studies have relied on multiple data sources, including medical records and administrative claims. Across each of the studies, findings have suggested that even in integrated health care delivery systems, receipt of surveillance care is inadequate. Further, a recent study found that many survivors receive surveillance care that is not recommended [25]. The CRN has conducted a study evaluating predictors of recurrence of ductal carcinoma in situ (DCIS), a designated area of focus in cancer comparative effectiveness research [26] and a series of studies examining patterns of care on recurrences among older women with breast cancer [20, 27–29].

Because tumor registries and automated data systems lack reliable information about cancer recurrences, access

Table 4 Data collection methods for observational and intervention studies in cancer survivorship in the CRN

Automated data/VDW-based analyses	Similar to SEER-Medicare analyses, but including patients under age 65, utilization prior to cancer diagnosis, pharmacy data not available prior to Part D, laboratory results, vital signs, and height/weight
Patient and caregiver surveys/interviews	Self-reports may be compared to information in other data sources, such as tumor registry and utilization/claims data
Provider surveys/interviews	May be combined with automated information about patient panels, medical testing, and procedures
Chart reviews	Full text medical records that can be used solely or in combination with other data collection methods
Clinical trials/interventions	Identification of patients based on treatment exposure, randomization of interventions, with availability of pre-diagnosis information and follow-up care

to complete, longitudinal paper, and electronic medical records within the CRN sites provides an opportunity to obtain detailed tracking of this important outcome that may be less feasible or not possible in other research environments. Further, studies examining surveillance patterns and cancer recurrences in the CRN also benefited from the availability of long-term follow-up of patients within the health care systems, and the DCIS study used pathology and tumor blocks to evaluate clinical and pathological factors. The feasibility of tumor specimen collection across the CRN has been examined and reveals a potentially useful resource [15].

To date, CRN studies of surveillance for recurrent cancer have mostly focused on breast cancer and primarily been descriptive. The CRN may serve as a venue to test the comparative effectiveness of surveillance recommendations; which may be applied to existing and newly developing guidelines. Retrospective and/or prospective research may be directed at determining the methods and intervals with which surveillance should occur. As clinical guidelines are developed, the CRN may also serve as a venue to test the effects of clinical decision support systems and reminders (to patients and providers) on enhancing surveillance for cancer recurrences. For example, patients who are not receiving optimal testing (both underuse of recommended and overuse of non-recommended) may be identified and targeted for interventions. Lastly, the CRN medical records and automated data may be used to develop and test algorithms to identify cancer recurrences; the lack of such data in tumor registry datasets such as SEER is clearly a limitation in survivorship research.

Health care delivery and care coordination

Much of the research about health care delivery and care coordination in cancer patients has been conducted using SEER-Medicare data [30–35]; however, these data do not include those under age 65 and enrollees in managed care. As an estimated 40 % of cancer survivors are under age 65 [36], and managed care has a penetration of 22 % among the population overall [37], the CRN offers an opportunity to broaden the knowledge in this area of research. Several CRN studies are evaluating the processes of care among cancer survivors, with a focus on care coordination and survivorship care plans, a priority area in cancer survivorship research [38]. A recent study conducted at ten CRN sites sought to identify practices, barriers, and research opportunities in meeting the care needs of cancer survivors in integrated healthcare delivery systems [39]. Interestingly, the findings revealed that the use of electronic medical records and the longstanding approach of shared care for all chronic diseases were thought by the key informants to facilitate cancer survivorship care in these settings. Survivorship care

plans are being tested in one CRN site. Further, an ongoing randomized clinical trial based on a prior CRN study [40] is evaluating the effect of an oncology nurse care management program on patient symptoms, psychosocial needs, perceptions of care coordination, and quality of care (5P20CA137219, Dearing PI, Wagner, Project Leader).

While several models for cancer survivorship care have been proposed [41, 42], the comparative- and cost-effectiveness evidence for these approaches is still lacking. Further, much of the research on cancer survivorship care and coordination has focused on care provided at academic and community-based cancer centers [43, 44]. The CRN settings offer a unique opportunity to develop, test prospectively, and implement innovative models of care, effective transitions of care, including the role of survivorship care plans, which may then be used to inform and enhance cancer survivorship care in diverse healthcare settings.

Health care utilization and costs

Much of the research on cancer survivorship health care processes and costs has been conducted in the SEER-Medicare data resource [45–47]; and shares the limitations associated with that resource described above. Costs of care and the effects of high cost on both patients and health care systems are important areas of research in cancer survivorship [48]. An ongoing project involving four CRN sites (R01CA114204, Hornbrook PI) aims to estimate the cost of cancer across all phases of care among patients with various cancer types. Evaluating costs of cancer survivorship in the CRN has the advantage of addressing questions about the cost effectiveness of different models of care (e.g., specialty versus primary care), surveillance strategies (e.g., imaging versus clinical follow-up), adjuvant therapies (e.g., tamoxifen versus aromatase inhibitors), prevention modalities (e.g., smoking cessation, exercise programs), among others. Further, health care and prescription medication cost data may be used in conjunction with patient-reported out of pocket costs and financial burden.

Psychosocial outcomes

Cancer survival has increased substantially due to treatment advances, but psychosocial morbidity remains an important and understudied area [49]. CRN studies have examined long-term psychosocial outcomes following bilateral and contralateral prophylactic mastectomy [50–52] and the impact of intestinal ostomies on colorectal cancer survivors and their caregivers [53–57]. The CRN offers several opportunities for expanding survivorship research on psychosocial outcomes. Patient-reported outcomes are becoming increasingly important in the dialogue about effective

care for cancer and other health conditions. The CRN sites offer unique advantages for the collection of these outcomes, since patients are comparatively easy to locate from membership files, and participation rates are relatively high. Patient-reported outcomes could be collected through patient-facing web portals offered by each of the health systems, and could potentially be integrated into the electronic medical records to facilitate long-term follow-up, care coordination, and more effective surveillance. The same health system features that support follow-up, care coordination, and surveillance would constitute an optimal environment for testing interventions and developing evidence-based guidelines for screening and management of psychosocial distress among cancer survivors.

Cancer communication and decision making

Communication and decision making are important and emerging areas of cancer survivorship research in the CRN. Through the aforementioned CRN Cancer Communication Research Center, the CRN is at the forefront of testing effective patient–provider communication and decision making, and its effect on health outcomes, health care quality, and safety. One ongoing study described patients' and providers' experiences with communication around adverse events and errors in cancer care and aims to develop and disseminate practical recommendations, provider training materials, and patient informational materials to improve communication around these issues [58, 59]. Additional efforts are being conducted including feasibility and usability evaluation and small-scale implementation of a new NCI-developed web-based cancer survival prognostic tool (Cancer Survival Query System); a study of a real-world diffusion of Comprehensive Health Enhancement Support System, a web-based support tool for breast cancer patients [60, 61]; and the development of websites for parents of pediatric cancer patients to prevent home medication errors and as a resource for primary care providers (www.cancersurvivorshipprimarycare.org).

Future research in the areas of communication and decision making in the CRN may focus on strategies and decision aids to enhance patient-centered communication and test their impact on psychosocial and health outcomes in the context of survivorship care [62]. The CRN may lead in the collection of patient-oriented outcomes and integration of these data into the electronic medical record; key features of the CRN study environment. The CRN may also serve as an environment to test the use and implications of emerging technologies (e.g., electronic communication, social media, and e-health) on patient–provider communication. Building on the CRN infrastructure and resources these topics are highly researchable in this setting.

Late effects of cancer and its treatment

Little is known about late effects of treatment and effective methods for monitoring and treatment. The CRN may serve as an optimal environment to further research in this area. Current studies are examining the association between stroke and chemotherapy (1R01CA121303, Geiger PI); the cardiotoxic effects of breast cancer chemotherapy [63]; the cardiac morbidity associated with radiation therapy for breast cancer [29]; and the feasibility of studying late effects following treatment of adolescent and young adult cancers. These studies utilized the strengths of the CRN by including comprehensive pre-cancer data, tumor registry, pharmacy, and utilization data. While identification of late effects using automated data is challenging [64], the CRN again offers an opportunity to take advantage of available pre-cancer data, including the presence of comorbid medical conditions, and comprehensive full-text medical records that may be used to supplement tumor and automated claims data.

Use of and adherence to adjuvant therapies

Understanding patterns of and reasons for lack of adherence to adjuvant treatment is important for improving the health of cancer survivors. The availability of automated pharmacy data in the CRN, not previously available in SEER-Medicare, allows investigation of oral medication adherence and has been leveraged by several studies examining the use of adjuvant aromatase inhibitors and tamoxifen among women with breast cancer between 1996 and 2003 [65], and evaluation of predictors of adherence to adjuvant therapies [66, 67]. These studies found rising use of aromatase inhibitors over time, but suboptimal adherence overall to oral adjuvant therapies. Further, a recent study found that adherence was associated with improved survival [68]. As the number of oral chemotherapy agents for other cancers increases, such studies will become relevant to many cancer types. The CRN is an optimal setting for evaluation of adherence to adjuvant therapies, examining the comparative effectiveness of different agents and testing interventions to enhance adherence.

Lifestyle and behavioral interventions

Another area of potential strength in the CRN is the ability to evaluate the effect of lifestyle and behavioral changes following cancer diagnosis and treatment, and to test interventions. An ongoing study is following women diagnosed with breast cancer and evaluating factors such as diet and physical activity through clinical data and patient surveys [69, 70]. While the potential of this line of research has not been fully realized in the CRN, it serves as an optimal

environment to evaluate the comparative and cost effectiveness of lifestyle interventions. Further, CRN may partner with other consortia, such as the NCI-funded Transdisciplinary Research on Energetics and Cancer Centers that are examining a range of biologic and physiologic mechanisms of energy balance, and evaluating the multidimensional factors that may impact nutrition, activity, and weight among cancer survivors.

Discussion

The NCI-funded Cancer Research Network is a resource for cancer survivorship research and has the ability to identify gaps in the quality of cancer survivors' care, address comparative effectiveness of strategies aimed at improving care and/or affecting important outcomes, examine care from patient-, provider-, and system-based perspectives, and inform the ongoing evolution of cancer survivorship care toward a more patient-centered approach. Due to the CRN sites' primary function as health care delivery systems, the potential to advance both clinical care and research is exemplified in these environments. Partnerships with survivorship researchers and health care systems outside of the CRN would not only further strengthen the existing lines of inquiry but also develop and expand focus in areas where the CRN has capacity that has not been fully realized (for example, interventions, late effects, and lifestyle research).

Prior and ongoing studies in the CRN have leveraged the numerous strengths of these settings including access to patients and providers for direct contact; comprehensive data including longitudinal electronic medical records and health utilization data; the large sizes of available populations of all ages; ability to follow patients for long periods of time; geographic diversity and variation in the site-specific populations that reflects the underlying population in the >geographic area; community-based health care systems; efficient systems developed for accessing information; and multidisciplinary scientific expertise of the CRN investigators. As a result, these settings provide a "real world" laboratory for conducting observational studies and developing, testing, and implementing interventions, and provide distinct advantages of the CRN environment over existing national datasets, cohorts, and single institution initiatives. Efforts are under way to expand the potential for genomic research within the CRN settings, including assembling and managing bio-specimens that may later be linked to the automated data, electronic medical records, and/or patient surveys. Such research will help us understand the genetic risks for cancer treatment-related late effects and outcomes [71].

Research conducted within the CRN has limitations, including generalizability to non-integrated health care delivery systems, potential cost of conducting multi-site research and need to efficiently navigate the network for collaborative research. Some of these limitations have been addressed by linkages between individual sites and the local cancer centers, an online centralized query system, continuous development of the VDW, refinement of IRB structures and policies for CRN studies, and ongoing evolution of our health care systems, which are adapting to a changing landscape in both care delivery and insurance coverage. These changes afford the opportunity to conduct natural experiments that address the impact of variations in health insurance design, benefits, and cost sharing. There are a number of factors to consider when collaborating with the CRN including the type of project and specific aims, data and sample size needs, number and types of CRN sites that best provide the desired patient samples and/or investigator expertise, cost, timeline, among others. Detailed information about collaborating with the CRN, including an inquiry form that may be used to initiate contact with the organization is available on http://crn.cancer.gov/. Interested individuals may also contact the local CRN site PI.

While cancer survivorship research has benefited from growing attention, numerous questions remain. Future cancer survivorship research in the CRN may focus on finding optimal methods for surveillance for cancer recurrences including emerging technologies; developing new models of care; documenting the excess risk and costs of late effects and testing methods for their detection and mitigation; assessing innovative methods of cancer communication, coordination of care, and examination of health care costs; as well as testing the implications of energy balance on cancer survivorship outcomes. The current health care system is not well-equipped to deal with a burgeoning population of cancer survivors, at the same time, evidence-based guidance about how to identify and address the critical needs of survivors is needed. With 14 years of experience using cancer data in community-based settings, the investigators in the CRN and their collaborators are poised to use this real-world laboratory to conduct a range of survivorship research projects to generate evidence in cancer survivorship research and pave the way to improve the care received by the growing population of survivors within and beyond integrated health care delivery systems.

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