A novel community-based delivery model to combat cancer disparities

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1. Introduction from the editors

In this special edition of Into Practice, Healthcare is featuring two case studies that highlight innovative approaches for addressing racial disparities in cancer care. The first case, titled “A Novel Community-Based Delivery Model to Combat Cancer Disparities,” describes a model for combining cancer prevention, diagnosis, education, and treatment services within a community health center. The second case study, titled “Using FastTrack to Implement an Academic Medical Center and Community Health Center Collaborative for Cancer Care Delivery” provides a more granular look at the logistics of integrating medical, administrative, financial, and social support services between the three key groups enabling this initiative: a community health center, a cancer center, and a tertiary academic medical center. Taken together, these two case studies provide an important roadmap for the delivery strategies necessary to tackle racial disparities in specialty care.

2. Background

Race and class have a devastating impact on cancer incidence, treatment, and mortality.1-3 Disparities in incidence and mortality may be due to a variety of factors including socioeconomic, biologic, and neighborhood factors.4,5 With regard to the question of poorer access to care, or lower-quality care, the 2002 Institute of Medicine report, Unequal Treatment, found evidence that racial and ethnic minorities tend to receive lower-quality health care than whites even when controlling for factors such as insurance status and income.6

Research has documented widespread disparities in cancer care across the spectrum of prevention, diagnosis and treatment. Due to a multitude of factors, patients most in need have the greatest difficulty in further benefitting from high-level tertiary center care.7,9 The systemic ripple effect not only affects excluded patients, but results in a disparate enrichment of the clinical trials and translational research that does not include them.5 Given the above realities and challenges, sustained positive results will remain difficult to achieve without a dedicated multi-level systemic approach.5,10-12

Research by Onega et al. has suggested that the effects of racial disparities for African Americans, particularly mortality risk for lung, breast, colorectal, and prostate cancers, were attenuated for patients at National Cancer Institute (NCI) cancer centers.11 Committed to research to improve outcomes across the spectrum from prevention to treatment, institutions with an NCI-cancer center designation share in common a robust transdisciplinary research program, often including inter-institutional collaborations; they provide clinical and scientific training in oncology-related fields;

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and they offer education and outreach programs focusing on cancer prevention and screening. The vast majority of these institutions are also treatment centers, providing cutting edge care to patients and the opportunity to participate in clinical trials.13

In January 2012, Dana-Farber Cancer Institute (DFCI), an NCI-designated Comprehensive Cancer Center, initiated a clinical outreach program as part of a comprehensive cancer Cancer Care Equity Program. The goal of this initiative is to improve local outcomes for the underserved across the spectrum of cancer-related disease by facilitating clinical access to preventive medicine, treatment, and clinical trials at the cancer center (Fig. 1). Through these efforts, the initiative aims to broaden access for vulnerable patient populations and join community partners in the quest for equitable care across the spectrum of cancer related disease.

3. Problem

Existing strategies to address cancer-related health disparities have primarily focused on screenings, education about screenings, prevention,14,15 tobacco cessation and, to a lesser extent, follow up for abnormal screening results and referrals to specialty providers.14–22 Successful delivery models have included the establishment of screening clinics, screening visits, screenings administered by trained primary care providers, and referral tracking systems.17,23–25 Several interventions have utilized patient navigation delivery models.26–29 While these models have improved the rates of, and time to, diagnostic resolution for underserved populations, evidence of their impact on treatment rates and outcomes is lacking, and they are likely to be most effective when combined with other strategies.23,29

The impetus for this intervention came from clinical observations made during routine clinical practice. Of greatest concern was the paucity of patients of racially underserved populations being seen at DFCI, as evidenced in lower clinical trial enrollments and the lack of integrated cancer care spanning the continuum from prevention to survivorship. These concerns were bolstered by a needs assessment commissioned by the DFCI Community Benefits office in 2009, which found that racially underserved populations in the area had access to cancer screening, yet continued to suffer from higher mortality rates. Subsequent Internet searches of other NCI cancer center websites to learn about their health disparities initiatives revealed that there were few clinical cancer outreach programs in U.S. urban communities. The programs that did exist were generally restricted to a limited number of cancer types, and primarily focused on screenings, education, tobacco cessation, patient navigation, clinical trial accrual efforts, or survivorship programs. Only three clinical outreach programs offered diagnostic services;30–32 one of these also provided treatment, but only for three select cancer diagnoses.30

Given this need, delivery models incorporating collaborative care between oncology specialists and primary care providers offer the potential to improve patient care in several areas, including continuity of care, managing co-morbidities, and supportive care.33 A wide range of primary-specialist collaborative care models exist: affiliations between community health centers (CHCs) and specialty practices or hospitals; telephone and videoconference provider–provider consultations; visiting specialist services/outreach clinics in primary health care settings; co-locations of independent primary and specialty care practices; specialists from other institutions stationed at CHCs; specialists employed within a CHC; CHCs that provide primary and specialized care for specific patient populations (e.g., behavioral health, substance abuse); and specialty practices that employ primary care providers.34–39 Although the literature on patient-centered medical homes, co-location, integrated care and coordinated care describes successful collaborations in other disease areas,29–43 and calls have been made for establishing such collaborations for oncology,53,44 no program providing a comprehensive approach to cancer care integrated within a primary health care center was identified.

A key challenge in integrating cancer care into the CHC setting is the role of referral pathways. Typically, cancer-related care may be obtained through multiple pathways, depending on the presence and severity of symptoms, whether a patient has an established primary care provider, and subsequent evaluation findings (Fig. 2). In each pathway, delays in diagnosis and treatment may occur due to missed appointments, time lags in appointments with specialists, lack of follow up by primary or specialist care providers, or lack of patient follow up. A limited body of research has documented racial and socioeconomic disparities in referrals to oncologists or oncology subspecialists.45–47 Delays and under-referral to these specialists are problematic given evidence that the care they provide yields improved outcomes.45,48–50

4. Solution

4.1. Intervention development and implementation

To address these issues, the decision was made to establish a clinical outreach facility within a community primary health care center. As described in the broader literature, there are several advantages to specialist clinical outreach programs in primary health care settings. The combination of the direct access to the underserved communities, the continuity of care provided in these centers, and the position of the CHC as a community center allows for an interaction that is superior to that of outpatient hospitals or physician offices.51 Furthermore, co-location fosters effective communication and collaborations between primary care providers and specialists, especially in the case of interventions that include multiple opportunities for interactions such as educational sessions, seminars and joint consultations.54,36 Indeed, there are well-documented problems relating to incomplete transfer of medical information from primary care to specialists and back again, especially with respect to referral for oncology and hematology.52

By directly involving and encouraging contact between oncologists and the clinicians that serve the community it was anticipated that the intervention would establish trust and comfort that would encourage referrals and collaborations. Patients, in turn,
could experience the convenience of having oncology appointments in the same building where they receive their primary care and avoid travel to another neighborhood and the unfamiliar terrain of the cancer center. Finally, having visible DFCI oncology providers in vulnerable communities necessarily conveys a commitment to treatment equity.

For the pilot project, DFCI decided to utilize its relationships with its tertiary care academic medical center partner Brigham and Women’s Hospital (BWH), and Whittier Street Health Center (WSHC), a CHC located in an underserved community, to establish a cancer outreach facility that combined prevention, diagnosis, education and treatment services. A longstanding relationship between DFCI and the WSHC, as well as the integrated cancer care services already offered through an existing collaboration between DFCI and BWH, helped to lay a foundation for this partnership. During the implementation phase, the development and integration of services among the three participating institutions was achieved by incorporating clinical and administrative stakeholders from each institution into working group sessions through a structured facilitation process.53

4.2. Program design

The intervention established a community cancer care facility located within WSHC and staffed by DFCI oncologists, a program nurse and other personnel. This arrangement enables the oncologists and primary care providers to work closely together to coordinate patient care through expedited referrals, ongoing provider–provider communications, and a shared medical records database. At the same time, patients experience the convenience and comfort of receiving cancer evaluation services on-site at their primary care health care center. The conceptual model details the patient referral pathways and services across institutions (Fig. 3), and the roles of the outreach program personnel are described in a companion diagram (Fig. 4).

4.2.1. Clinical evaluation

Primary care providers refer patients to the on-site cancer care facility for diagnostic evaluation of suspected cancers, abnormal screening, and selected long term follow-up. They may also refer patients with previous cancer histories to re-establish connections with oncology. Integrated evaluation services are provided on-site at the community cancer care facility in a designated clinical space. The facility includes a dedicated staff of DFCI clinical oncologists and a DFCI program nurse/nurse navigator. The areas of expertise among the oncologists include breast, gynecologic, thoracic, genitourinary, and hematologic cancers, but each functions as a generalist clinical oncologist at the outreach facility and sees patients of all cancer types on their rotation days. This arrangement requires that each medical oncologist discuss cases that are outside their area of subspecialty and that cases are “handed off” in a group practice manner.

The process of patient evaluation and referral focuses on expediting diagnostic evaluations and treatment initiation. Prior to the initial visit with a clinical oncologist, the program nurse performs the initial patient assessment and triage. After conducting an initial examination and consultation with the patient, the clinical oncologist decides on the appropriate follow-up examinations and referral pathway in consultation with the other clinical oncology physicians. The program nurse then oversees scheduling for appointments, screenings and referrals, and coordinates communications among the primary care provider, clinical oncologist, specialists, and patient.

Once appointments are scheduled, the program nurse acts as a patient navigator to follow up with patients both at the outreach facility and referral locations, providing appointment reminders, assisting with transportation, and arranging for additional patient services with access management, case managers, social workers, and interpreters across participating institutions. To facilitate this process, she maintains a patient navigation tracking database specifically developed for the intervention which includes the initial appointment information, details on each phone call made to or by the patient, additional patient services requested, tests

Fig. 2. Cancer diagnosis pathway.
Source: Developed by authors based on clinical observations.
ordered, follow up appointments, referrals, and the patient’s attendance for each appointment across the three participating institutions. In addition, the program nurse connects patients to prevention and survivorship programs, aids in the formation of oncology clinical support and survivor programs, and collaborates with primary health center staff to augment existing survivor programs with additional resources. Finally, she coordinates educational programs for providers and conducts educational events in the community.

4.2.2. Expedited referrals and access

Patients with an active cancer-related issue are referred to DFCI and/or BWH. To avoid losses in follow-up and delays in receiving...
care, an expedited referral system has been implemented across the three participating institutions, including access management processes for patients whose insurance is not accepted at the tertiary care centers. During the implementation phase of the intervention, senior level representatives from each institution’s financial services departments worked together to develop procedures to ensure coverage for patients whose insurance was not accepted by all three institutions. As a result, insurance approvals for all institutions are secured prior to the patient’s initial appointment at the outreach facility. The program nurse also works with patients to identify and resolve additional issues that could result in missed appointments.

4.2.3. Multidisciplinary communication

The intervention incorporates several features to facilitate communications on multiple levels. Ongoing formal and informal provider–provider consultations occur by phone, email and in-person. Being located in the same building has permitted ad-hoc joint consultations among the primary care provider, oncologist and patient. Each morning that the clinical outreach program is seeing patients, the program nurse briefly visits each of the primary care provider office areas, and throughout the day primary care providers frequently call or stop by the clinical outreach facility for informal curbside consultations. In addition, centralized medical records are maintained within the primary health care center’s database. This enables the primary care providers to track their patients, and the oncologists to immediately access the patient’s full medical history. Communication is further facilitated through bi-weekly question and answer (Q&A) sessions as described below. Perhaps most important, patients begin their oncologic evaluation in the comfort and familiarity of the same building where they receive primary care, which may reduce the extreme anxiety that often accompanies a first oncology visit and the ensuing detriment to physician–patient communication.

4.2.4. Community education

Community-level education is provided by the intervention through seminars held at WSHC and other community venues. Provider education is incorporated through didactic sessions led by the oncologists, program nurse, or invited guests, and bi-weekly informal question and answer (Q&A) sessions open to all primary health center staff members. The bi-weekly Q&A sessions typically focus on a specific cancer-related topic, but also provide an opportunity for primary care and specialist providers to present case studies, oncologists to clarify screening and referral guidelines, and primary care providers to educate the oncologists about the patient population. Periodically, a portion of this time is allocated to discuss broader issues related to the functioning of the clinical outreach program. These sessions have also facilitated ad-hoc provider-provider consultations among attendees immediately preceding and following the meeting.

4.3. Challenges encountered

Several issues had to be addressed in order for the conceptual model to progress to the implementation stage.

4.3.1. Funding

Initial conversations around the development and implementation of the clinical outreach program stalled due to concerns about the feasibility of securing funding. Federal grant funding for this type of clinical innovation was not available, leaving only institutional or philanthropic funding as options. After the business plan was prepared, a philanthropic donor expressed interest to the DFCI Development Office in funding a community oncology program, and the intervention was determined to be a good fit. Once this philanthropic funding was secured the dialog was able to move forward.

4.3.2. Institutional support

Support for the program had to be obtained from leadership across all of the major departments in DFCI including executive management, the clinical directors from each disease center, nursing leadership, and finance leadership. It was also necessary to work closely with External Affairs in order to avoid duplicating already established efforts underway through existing community benefits programs. Since the Community Benefits office had previously established survivorship, education and screening programs at WSHC, it was agreed that the clinical outreach program and Community Benefits team would collaborate to expand and enhance these initiatives rather than develop new ones. Finally, support had to be obtained to provide administrative support and allocate a significant percentage of the faculty director’s time to overseeing the program.

4.3.3. Establishing a partnership with the CHC

A longstanding relationship between DFCI and WSHC for other outreach programs implemented over the past decade helped to build a foundation for the collaboration entailed in this intervention. However, it was still necessary to demonstrate the value of the clinical outreach program to WSHC. The WSHC providers were initially skeptical about the utility of the program and expressed uncertainty about the cancer center’s level of commitment. To address these concerns, multiple meetings were held over a ½ year period in order to establish trust, form a working partnership, demonstrate DFCI’s commitment to the WSHC patients, and incorporate input from WSHC staff into the business plan. The business plan stipulated that WSHC would provide support and training for the providers, and the oncologists and program nurse would perform their clinical duties under WSHC’s license. The clinical space was leased by DFCI as part of a previous agreement. To help offset the operating expenses for the program, WSHC would pay a flat fee for each day that clinical services are provided, but could recover these costs through billing for patient appointments. The remaining expenses incurred by DFCI, including staffing, would be covered through the philanthropic funding provided for the program.

4.3.4. Staffing

To staff the community cancer care facility (Fig. 5), medical oncologists representing a range of clinical expertise with the interest and willingness to commit the time and effort to see patients on-site at WSHC had to be identified, and a percentage of their time from DFCI had to be allocated to the intervention. In addition, since the conceptual model assigns several critical functions to the program nurse/nurse navigator, it was necessary to find a highly experienced nurse with the appropriate clinical, language and cultural skills.

5. Lessons for the field

Discussions around the clinical outreach intervention with institutional leadership and providers revealed that there was indeed interest and demand for this type of service, both from the cancer center and the CHC. Of equal importance, this conceptual model shifts the paradigm of oncology to assist with diagnosis rather than treatment only. Doing so brings the oncology practitioners closer to vulnerable communities and demonstrates the commitment of the cancer center to local communities with limited access to high quality cancer treatment, enabling us to assist the community in a more demonstrative manner. The intervention’s impact is currently
being evaluated according to several metrics, including time from initial appointment at the clinical outreach facility to resolution (treatment plan established, surveillance plan established, or return to primary care provider for negative diagnoses); utilization of DFCI by under-represented patients documenting an increase in absolute numbers over time; and no-show rates and the points at which they occur in the referral pathway. It is hypothesized that this model of care can decrease wait times for diagnosis and treatment of cancer, increase awareness and knowledge of cancer prevention and treatment, and foster trust with providers and patients from vulnerable communities. An upward trend in total clinical trial accrual numbers for unrepresented minority patients at DFCI is also expected through referrals of patients enrolled in the pilot program and will be monitored. Once performance measures are met, implementation of the intervention at other primary health care centers will be considered. Funding for this type of clinical innovation, however, is currently limited to institutional and philanthropic sources; therefore, a shift in the academic and public sector funding paradigms may also be required in order for the conceptual model to be implemented on a broader level, and to be sustainable in the future.

The impact of these sorts of collaborations on health care costs and access in the future is unclear. The Affordable Care Act offers some incentive to work with community health centers around cancer, but how this will manifest remains uncertain. The majority of patients are able to access the program, with very few insurance obstacles. Much of this has to do with the unique aspects of the Massachusetts health care system, as well as engaging on this issue early with leadership from all institutions. The DFCI Cancer Care Equity Program initiative forms the basis of this model demonstrating collaboration between tertiary care academic centers and a primary health care center, focused on eliminating cancer disparities and emphasizing a cohesive clinical service in a novel manner.

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References


