

Establishing a General Medical Outpatient Clinic for Cancer Survivors in a Public City Hospital Setting

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INTRODUCTION: Many cancer centers and community hospitals are developing novel models of survivorship care. However, few are specifically focused on services for socio-economically disadvantaged cancer survivors.

AIMS: To describe a new model of survivorship care serving culturally diverse, urban adult cancer patients and to present findings from a feasibility evaluation.

SETTING: Adult cancer patients treated at a public city hospital cancer center.

PROGRAM DESCRIPTION: The clinic provides comprehensive medical and psychosocial services for patients within a public hospital cancer center where they receive their oncology care.

PROGRAM EVALUATION: Longitudinal data collected over a 3-year period were used to describe patient demographics, patient needs, and services delivered. Since inception, 410 cancer patients have been served. Demand for services has grown steadily. Hypertension was the most frequent comorbid condition treated. Pain, depression, cardiovascular disease, hyperlipidemia, and bowel dysfunction were the most common post-treatment problems experienced by the patients. Financial counseling was an important patient resource.

DISCUSSION: This new clinical service has been well-integrated into its public urban hospital setting and constitutes an innovative model of health-care delivery for socio-economically challenged, culturally diverse adult cancer survivors.

KEY WORDS: adult cancer survivorship; primary care; racial and ethnic diversity; socio-economically disadvantaged persons; long-term follow-up.

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INTRODUCTION

Due to recent advances in cancer diagnosis and treatment, the population of cancer survivors in the United States has expanded to approximately 12 million individuals.¹ Although many survivors go on to lead long healthy lives after treatment, for some there are physical and psychological consequences that require surveillance, follow-up, and medical interventions.^{2,3} Therefore, it is critical that innovative approaches to delivering long-term, post-treatment care for adult patients be developed.

One of the most important drivers for improving survivorship care nationally is the 2005 Institute of Medicine Report, *Cancer Survivorship—Lost in Transition*.⁴ This report describes new survivorship care models, many of which include a collaborative relationship between the oncology team and the primary care physician (PCP).⁵⁻⁷ Each of these approaches recognizes survivorship as a distinct phase in the cancer care continuum, but leaves unanswered the question of how to address the challenges in caring for socio-economically disadvantaged survivors. These individuals face unique challenges compared to others who have more resources: they are more likely to be diagnosed at a later stage and are less likely to have adequate general medical care and to receive needed psychosocial services.⁸⁻¹⁷

Our public city hospital survivorship model combines oncology-related care with internal medicine services into one clinic staffed by medical internists with the goal of providing comprehensive long-term medical and psychosocial services to the multi-ethnic, low-income population of adult cancer survivors. Because of the late-stage diagnoses in our patient population and their complex non-cancer conditions, we chose not to limit the definition of “survivorship” to the post-treatment period as in the IOM report, but rather we incorporated the broader definition espoused by the National Cancer Institute and National Coalition of Cancer Survivors that defines survivors as all cancer patients from diagnosis forward.¹⁸

Aims

The objectives of this paper are to: (1) describe a new clinic model of survivorship care for culturally diverse, urban adult cancer patients and (2) present findings from a feasibility evaluation of the clinic.

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Setting

With a population of over 2.3 million, the Borough of Queens, New York, is the second most populous of the five boroughs that comprise New York City. The New York City Public Hospital system is currently the largest public hospital system in the nation.¹⁹ Within this system, the Queens Cancer Center of Queens Hospital (QCC) is the only clinically integrated, full-service cancer center in New York City's public hospital system; as such, patients can be treated regardless of their immigration status or their ability to pay. Over 80% of QCC patients fall below the national levels for poverty as defined by the US Census Bureau.²⁰ QCC provides services to a population that speaks over 138 different languages; 56% of patients speak a language other than English as their primary language. QCC has over 17,000 outpatient visits annually.

Program Description

The clinic was launched in August 2005 as part of a collaborative partnership between QCC and Memorial Sloan-Kettering Cancer Center (MSKCC). The current staff includes two internists who see patients within the cancer center, allowing close proximity to all of the oncology subspecialists. The internists see patients a total of 6 half days per week. The clinic has access to all of QCC's services, including financial counseling, nutrition services, pain management, social work, psychiatry, the smoking cessation program, and a patient

navigator. Any patient receiving care at the cancer center who does not have a PCP is referred to this clinic. The decision to include patients in active treatment in the survivorship clinic ensures continuity of care for the post-treatment period as well.

Medical care of the patients includes: treatment of comorbidities, cancer surveillance for a second malignancy, managing long-term and late effects of treatment, health promotion counseling, and referral to supportive services. Responsibility for managing short-term treatment toxicities and disease recurrence is the responsibility of the treating oncologist. Referrals to other oncologists and other medical specialists at QCC are made as needed. Communication with the treating oncologist is carried out by daily personal communication and/or weekly tumor board meetings.

Program Evaluation

To evaluate the feasibility of the clinic and for quality assurance purposes, a longitudinal database was established at the inception of the clinic to document basic information about each patient and each clinic visit. A waiver of informed consent was IRB approved. A customized form was used for entry into the clinic database (see online [Appendix](#)).

Over the 3-year period from September 2005 through August 2008, the clinic served 410 cancer patients, approximately a fifth of whom were post-treatment and presented with one or more general medical service needs (n=89, 22%). Most patients were in active treatment for their cancer (n=321,

Table 1. Selected Patient Demographics (Per First Visit to the Clinic)

Demographic characteristic		Active treatment		Post-treatment		Total	
		n=321	%	n=89	%	n=410	%
Gender	Male	92	29%	26	29%	118	29%
	Female	229	71%	63	71%	292	71%
Ethnicity	Hispanic	139	43%	35	39%	174	42%
	Non-Hispanic	137	43%	41	46%	178	43%
Race	Not recorded	45	14%	13	15%	58	14%
	Black	108	34%	23	26%	131	32%
	Asian	102	32%	28	31%	130	32%
	White	65	20%	16	18%	81	20%
	Other	32	10%	17	19%	49	12%
	Not recorded	14	4%	5	6%	19	5%
Primary language	English	170	53%	42	47%	212	52%
	Spanish	66	21%	23	26%	89	22%
	Other	56	17%	15	17%	71	17%
	Not recorded	29	9%	9	10%	38	9%
Education	No formal schooling	5	2%	–	0%	5	1%
	1 to 8 years	74	23%	16	18%	90	22%
	Some high school	27	8%	10	11%	37	9%
	High school or equiv.	60	19%	17	19%	77	19%
	Some college	23	7%	10	11%	33	8%
	Bachelors degree	31	10%	3	3%	34	8%
	Graduate degree	8	2%	5	6%	13	3%
Health insurance	Not recorded	93	29%	28	31%	121	30%
	Uninsured	140	44%	34	38%	174	42%
	Medicaid	84	26%	29	33%	113	28%
	Medicare	56	17%	12	13%	68	17%
Employment *	3rd party	41	13%	14	16%	55	13%
	Employed	68	21%	31	35%	99	24%
	Retired	80	25%	14	16%	94	23%
	Unemployed	151	47%	34	38%	185	45%
Not recorded	22	7%	10	11%	32	8%	

*Chi-square=10.9; df=3; p<0.05

Table 2. Stage of Cancer at Diagnosis by Cancer Site among Active Treatment and Post-treatment Patients

Type of cancer	Total	% of total	Stage of cancer at diagnosis									
			Stage 0		Stage I		Stage II		Stage III		Stage IV	
Breast	141	34%	7	5%	29	21%	54	38%	29	21%	22	16%
Digestive system	93	23%	–	–	9	10%	20	22%	19	20%	45	48%
Colorectal	68	73%	–	–	4	6%	13	19%	14	21%	37	54%
Stomach	16	17%	–	–	4	25%	3	19%	3	19%	6	38%
Other digestive system	9	10%	–	–	1	11%	4	44%	2	22%	2	22%
Female genital system	69	17%	–	–	27	39%	9	13%	17	25%	16	23%
Cervix uteri	37	54%	–	–	14	38%	5	14%	8	22%	10	27%
Corpus uteri	23	33%	–	–	10	43%	4	17%	6	26%	3	13%
Other female genital system	9	13%	–	–	3	33%	–	–	3	33%	3	33%
Male genital system	42	10%	–	–	9	21%	21	50%	2	5%	10	24%
Prostate	38	90%	–	–	8	21%	19	50%	1	3%	10	26%
Testis	4	10%	–	–	1	25%	2	50%	1	25%	–	–
Lymphatic, hematopoietic	20	5%	–	–	3	15%	8	40%	2	10%	7	35%
Respiratory system (lung)	14	3%	–	–	–	–	2	14%	6	43%	6	43%
Melanoma of skin	9	2%	2	22%	2	22%	1	11%	1	11%	3	33%
Head and neck	8	2%	–	–	–	–	1	13%	1	13%	6	75%
Urinary system	8	2%	–	–	3	38%	2	25%	2	25%	1	13%
Other ¹	6	1%	–	–	3	50%	–	–	2	33%	1	17%
Total	410	100%	9	2%	85	21%	118	29%	81	20%	117	29%

¹Brain/CNS, sarcoma

78%). Time since completing primary treatment for cancer as of the date of first visit to the clinic ranged from 9 months to 17 years (average=4.5 years). Demand for services grew steadily, both in terms of the number of patients per quarter and the number of patient visits. On average, post-treatment patients had 4.2 visits per year, and patients in active treatment had 2.8 visits per year.

In addition, the clinic provided cancer prevention services to 255 family members and caregivers. Since preventive care patients were not the intended target population of the new clinic, they are not included in the data presented below.

Demographics of the clinic’s cancer patients are shown in Table 1. Our cancer patients were primarily female (n=292, 71%) and racially diverse (64% were Black or Asian). Forty-two percent of all patients were Hispanic or Latino (n=174). Primary languages spoken by our patients included English (n=212, 52%) and Spanish (n=89, 22%), as well as a host of other languages. Half of our patient population (n=224, 50%) had no more than a high school diploma or its equivalent, with 1% reporting having had no formal education (n=5). Clinic patients were approximately 59 years old (SD=12.4 years) and ranged from 24 to 96 years old.

Table 3. Common Medical Diseases and Conditions

Effect	Active treatment		Post-Treatment		Total	
	n=321	%	n=89	%	N=410	%
Anemia*	53	16.5%	4	4.5%	57	13.9%
Pain	35	10.9%	11	12.4%	46	11.2%
Depression	22	6.9%	10	11.2%	32	7.8%
Psychosocial distress	26	8.1%	4	4.5%	30	7.3%
Bowel dysfunction	18	5.6%	5	5.6%	23	5.6%
Cardiovascular disease*	10	3.1%	9	10.1%	19	4.6%
Pulmonary function deficit	13	4.0%	4	4.5%	17	4.1%
Osteoporosis	13	4.0%	1	1.1%	14	3.4%
Lymphedema	10	3.1%	3	3.4%	13	3.2%
Hyperlipidemia*	6	1.9%	6	6.7%	12	2.9%
Fatigue/muscle wasting	10	3.1%	1	1.1%	11	2.7%
Malnutrition	9	2.8%	1	1.1%	10	2.4%
Nerve damage	6	1.9%	4	4.5%	10	2.4%
Sexual dysfunction	6	1.9%	3	3.4%	9	2.2%
Bladder dysfunction	6	1.9%	1	1.1%	7	1.7%
Infection	6	1.9%	–	0.0%	6	1.5%
Diabetes mellitus	3	0.9%	1	1.1%	4	1.0%
Cognitive deficits	1	0.3%	1	1.1%	2	0.5%
Infertility*	–	0.0%	2	2.2%	2	0.5%
Renal failure	1	0.3%	–	0.0%	1	0.2%
Weight gain	1	0.3%	–	0.0%	1	0.2%
Premature menopause	–	0.0%	1	1.1%	1	0.2%
Other late side effects	42	13.1%	14	15.7%	56	13.7%

*Chi-square is significant; df=1; p<0.05

At the time of their first visit, 42% of the clinic's cancer patients were uninsured (n=174), 45% were receiving Medicaid and/or Medicare (n=181), and 13% had some form of private, third-party health insurance (n=55). Nearly half (n=185, 45%) were unemployed, and 23% were currently retired (n=94). Patients on active treatment were more likely to be unemployed than post-treatment patients at the time of their first visit (47% vs. 38%, respectively; chi-square=10.9; df=3; p<0.05).

As shown in Table 2, breast cancer patients were 34% of the patients seen at the clinic and accounted for the highest proportion of post-treatment patients (46%). Colorectal, prostate, and cervical cancers were also frequent diagnoses. Nearly half (49%) of all patients served had been diagnosed at late stages (stages III or higher). Among lung, head and neck, and colorectal patients, more than three-quarters had been diagnosed at late stages.

For the four cancers with known screening interventions, patients were more likely to have late-stage disease at diagnosis than is reported nationally. For breast cancer patients, 37% were diagnosed at late stage versus 6% nationally; for prostate cancer, 29% were diagnosed at late stage compared to 5% nationally; for colorectal cancer, 75% were diagnosed at late stage compared with 54% nationally; for cervical cancer 49% were diagnosed at late stage compared to 43% nationally.²¹

Co-morbidities for new QCC patients were determined through patient self report of known medical conditions and a review of previous medical record information. The most common medical co-morbidities treated were: hypertension (n=155, 38%), adult onset diabetes (n=56, 14%), mixed hyperlipidemia (n=45, 11%), morbid obesity (n=26, 6%), and coronary artery disease (n=18, 4%). Nearly two-thirds of patients (n=254, 62%) presented with one or more co-morbidities at the time of their first clinic visit, with patients in active treatment significantly more likely than post-treatment to present this way (65% vs. 49%, respectively; chi-square=7.5; df=1, p<0.05).

Medical problems most commonly identified among post-treatment patients receiving care at the clinic included pain (12%), depression (11%), cardiovascular disease (10%), and hyperlipidemia (7%) (Table 3).

The most common referrals included financial counseling (20%), nutrition (5%), pain management (3%), and patient navigation (2%). Patients in active treatment were significantly more likely to be referred for financial counseling.

DISCUSSION

QCC's cancer survivors' clinic offers a unique opportunity for providing long-term care to medically underserved cancer patients in a public hospital setting. Thus, by revising our focus and applying an expanded definition of "survivorship" to include individuals and their families from the time of diagnosis, we have been able to establish a plan for ongoing care. Although the original clinic plan was to focus on the post-treatment patients, it became evident that offering medical services to patients as soon as they entered the cancer center was an important way of assuring access to medical care and that it might better assure continuation of care in the post-treatment period.

Because these patients have few resources to navigate back and forth between their PCP and an oncologist, the model provides "one-stop-shopping" for a wide range of health-care services in a single setting and establishes the PCP as the coordinator of survivorship care. Given that the clinic exists within a comprehensive cancer treatment facility, subspecialty referral and provider communication are facilitated, thus reducing the barriers patients would otherwise face in navigating the services of multiple facilities and practices.

This model is well suited for other public hospitals, even those that don't have all the needed services in the same physical location. With the ongoing cooperation of and communication among all the key providers of these health services, a virtual cancer center could be set up to meet the multiple, complex needs of the patient population.

At this juncture we have been able to demonstrate the feasibility of establishing a clinic with a focus on post-treatment cancer care. Going forward, we will need to assess whether patients continue to attend the clinic, and if not, to understand the barriers preventing their attendance. In addition, there are numerous clinic infrastructure challenges to be addressed. The significant turnover of support staff creates inefficiencies because of the need for repeated training and quality review of clinical data collection. Because of limited infrastructure to support the clinic, the physicians are required to spend considerable time performing non-clinical tasks. This reduces efficiency, adds to wait times, and limits patient volume.

The next steps in improving clinic function and survivorship care delivery include: conducting a health literacy assessment as the initial step in developing a tailored health education program to increase patient adherence to post-treatment follow-up care; assessing compliance with surveillance and screening recommendations; identifying and evaluating improved linkages between providers to better facilitate patient referral to the clinic. In the long term, we need to apply specific metrics to evaluate the delivery of services in this type of clinic and whether those services reduce morbidity and translate into improved health outcomes.

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