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Cancer Care in East and Central Harlem: Community Partnership Needs Assessment

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Abstract

In the largely African American and Hispanic communities of East and Central Harlem in New York City (NYC), health inequities are glaring. Mortality from cancer is 20–30 % higher than in Manhattan and 30–40 % higher than rates in the general population in NYC. Despite advances in risk assessment, early detection, treatment, and survivorship, individuals in Harlem and similar urban communities are not benefiting equally. Guided by community-based participatory research, this study serves as an important step in understanding cancer care needs and the range of factors that impact the disparate rates of cancer in East and Central Harlem. Forty individual interviews were conducted with community leaders and residents. Major themes included: need for appropriate supportive services; health care access and financial challenges; beliefs related to stigma, trust, and accountability; and the impact of the physical environment on health. Education was seen as a critical area of need and intervention.

Keywords

Cancer; Ethnic minority; Health disparity; Oncology; Community needs assessment

Introduction

In the largely Hispanic and African American communities of East and Central Harlem in New York City (NYC), health inequities—and the social inequities that contribute to them—are glaring (see Table 1). Harlem's mortality from cancer is 20–30 % higher than rates in Manhattan and 30–40 % higher than NYC's general population [1, 2]. Incidence rates for many diseases are not only higher in the Harlem communities, but are also interrelated. For example, in East Harlem 31 % of the adult population is obese (compared to 18 % citywide, with a national goal of 15 %), leading to extraordinary high rates of diabetes (15 v. 8 % citywide), a possible contributor to worse cancer outcomes [1, 2].

People's ability to lead healthy lives and improve their health is also related to their social context. East and Central Harlem are two of the poorest neighborhoods in NYC, where greater than 30 % of the population lives in high poverty [3]. Residents in low-income neighborhoods are 1.3 times more likely to die from cancer than residents in higher-income neighborhoods. For instance, disparities are particularly great in comparison to the Upper

East Side, directly south of East Harlem, known as one of the wealthiest communities in the USA.

One contributing factor to such disparate rates of cancer is participation in cancer screening and early detection. Such disparities could effectively be reduced through greater participation in cancer prevention efforts. For example, African Americans and Hispanics continue to have lower screening rates for the most common cancers in comparison to non-Hispanic Whites. In East and Central Harlem, 43 and 50 %, respectively, of adults aged 50 and older have had a colonoscopy in the past 10 years, compared to 54 % of Manhattan residents [1, 2]. Cancer screening and early detection have been shown to reduce mortality and, in the case of colorectal and cervical cancers, can result in the removal of precancerous abnormalities, effectively preventing cancer overall [4]. Despite advances in cancer risk assessment and early detection, individuals in Harlem and similar urban communities are not benefiting proportionately from these advances.

From a public health perspective, it is critical to explore how social inequities translate into cancer-related disease for Black and Hispanic populations in the USA. Guided by community-based participatory research principles and practices, the current needs assessment sought to work in partnership with East and Central Harlem community residents and leaders to identify cancer prevention, control, and care priorities in the context of community strengths and resources. This was done in an attempt to guide the development of strategies and interventions to improve the quality of cancer care and how it is communicated, coordinated, and delivered to patients and their families across the cancer continuum, in an effort to reduce the burden of cancer and eliminate cancer disparities.

Theory

The social ecological model served as the principal conceptual framework guiding this community needs assessment. This model asserts that the key determinant of health and illness is the degree of fit between an individual's biological, behavioral, and sociocultural needs and the environmental resources available to them [5]. A number of theoretical and research perspectives have been associated with this model, including the Person–Environment Fit Theory [6, 7], Community Health Promotion [8–10], and the Healthy Cities Movement [11, 12]. The social ecological model focuses on integrating behavioral and environmental health promotion strategies and emphasizes intervention development spanning the individual, organization, and community [5].

Methodology

Design

A qualitative research design was used to identify cancer prevention, control, and care priorities. A total of 40 individual, in-depth, face-to-face interviews were conducted between March and October 2010. Interviews ranged in duration from 25 to 91 min in length and followed a semi-structured approach, including open-and closed-response options. A conversational approach was used which enabled participants to voice other relevant issues; however, “must ask” questions were included to ensure that certain domains were addressed

uniformly. Approval for this study was obtained from the Mount Sinai School of Medicine Institutional Review Board.

Participants

Participants were chosen who reflected the various racial, ethnic, and geographic groups in East and Central Harlem and represented the community and its important social networks, sectors, and organizations. Participants included those individuals deemed to be influential leaders and members of their respective communities, as it was believed that these individuals would add a top-down perspective that would otherwise be missed without their participation. Participants were eligible to participate if they (1) lived or worked within the target communities, (2) were a member of a professional, community, or social organization interested in the health care needs of the target communities and/or had taken part in community-engagement activities, (3) were interested in the social and health priorities of the target communities, (4) were 18 years of age or older, and (5) were able to provide informed consent. A purposive sampling strategy was used, with the aim of achieving sufficient representation, saturation, and diversity of participants. Interviews were stratified based on gender (male v. female) and community (East v. Central Harlem).

Procedure

In 2009, a Community Action Board (CAB), with members representing East and Central Harlem, was formed to provide community input in governance and study planning, including survey questions. The initial pool of participants for the present needs assessment included these early CAB members (already meeting inclusion criteria for eligibility). Additional participants were identified using a modified snowball sampling method; each CAB member recommended additional community members to be interviewed. Through both formal (letter of invitation signed by a CAB member and investigators) and informal (telephone call) means, new potential participants were recruited for participation. Eligibility was determined prior to scheduling the in-depth interview. Several trained health educators conducted the individual interviews in a private environment, either in reserved rooms at the study site or other locations deemed convenient by participants, including coffee shops, apartment lobbies, or place of employment, with care being taken to ensure privacy. HIPAA and informed consent were completed before the onset of the interview. Participants were compensated with a \$25 gift card for participation.

Measures

A demographic questionnaire was created using questions developed from a previous assessment battery and assessed sociodemographic characteristics, including age, gender, race, ethnicity, education/income level, birthplace, as well as the participants' living and working history, measured in years lived or worked in the community.

The interview guide was created through a cooperative effort of the investigators (LJ, NB, BB, and CV) and then presented to the CAB, who provided valuable feedback and recommendations. This revised interview guide was pilot tested using five individual interviews to assess understanding, language, and ease. Feedback from these interviews guided revisions and the creation of the final interview guide (see Table 2). For this analysis,

participants were asked to describe: (1) their personal history and/or involvement in East/Central Harlem, (2) scope of cancer presence in East/Central Harlem, (3) support initiatives in East/Central Harlem, (4) cancer priority areas, (5) cancer interventions and programs in East/Central Harlem, and (6) personal experiences and thoughts about cancer.

Data Analysis

All interviews were digitally audio recorded with consent from participants. Each individual interview was professionally transcribed verbatim from the recorded audiotapes. Recordings were anonymized by digitally masking names of individuals and places. Two research team members (TE, JS), both trained in qualitative coding methodology, reviewed all transcriptions and conducted coding independently. Reviewers met multiple times to generate themes and resolve inconsistencies. An inductive approach to data analysis was undertaken, focused on eliciting main themes. Qualitative data analysis was performed using text analysis, involving a rigorous review and interpretation of interview transcripts. Coding and analysis was facilitated by the use of N'VIVO 9 software for qualitative analysis.

Results

Sociodemographic characteristics of participants are shown in Table 3. Interview results indicated nine major themes advocated by the respondents in terms of cancer care needs in East and Central Harlem. Themes are presented in order of occurrence from major to minor (see Table 4 for response rate).

Education

Greater than half of respondents noted lack of education to be a significant problem concerning cancer care in Harlem. Specifically, respondents noted that community members were unaware of “What to do, how to do it, and where they can access it.” Respondents were adamant that community members need to be better educated concerning available resources, lifestyle factors contributing to poor health outcomes, cancer symptomatology, and follow-up care. Many noted that community members “... need to understand that cancer can be dealt with if you have the right resources and they need to know that those resources are available and that the resources are respectful of their particular needs, be they cultural, economic, social, whatever.” Several spoke of the need for greater education concerning diet and nutrition, physical activity, and stress management. Education regarding symptomatology was also discussed, “I think we have to educate how people identify what symptoms are and what they experience, so that they can be better prepared and identify themselves that maybe something is wrong.” The need for educational efforts promoting the necessity of follow-up care was also emphasized, particularly for men in the community. Interestingly, many respondents alluded to educating youth as a key strategy in educating the community, “Education for all ages, outreach to our children is important, sometimes you can get to a child before and they’re the ones that can reach a parent.”

Support

The need for greater supportive services was endorsed by more than half of respondents as being of vital importance. Concerning supportive care, one respondent described:

When I'm counseling people, they are really depressed. How am I going to face this? Those are the stories that haunt them in the dark—they come to us with their own stories of sadness, of the fight that they have to put up... not magnitude, it is the weight of the disease on the people.

Beyond the patient, support was also discussed in terms of the need for services for family and those in caregiving roles, "Where do the spouses go for support? ... at least for me, personally it has been on supporting my spouse, who do I go and talk to about what I'm going through?" In describing her role, one woman noted "They [patients] are real dependent upon us as healthcare providers to be sensitive to who they are and what they are doing and what they need. I see physicians get caught up in the medicine of it all and missing the patient." Respondents also spoke to the need of cancer-specific support groups in the community. Community members were described as needing to "...feel part of a community of other women and men that are going through that experience." Several respondents spoke to the need for support groups to be established locally, allowing for patients "...not to have to go downtown to have a group session with whomever." Although many spoke of the church as the primary place where many discussions of support take place, interestingly, several spoke about barber shops and beauty salons as "The premier spot for sharing of information and receiving information and tapping into it. The barber shops represent the point where a multitude of all generations interact."

Secrecy

Secrecy surrounding cancer was described by half of all respondents as being a significant challenge. One respondent noted, "Even though I've been here 30 years, cancer is not a subject that people just openly talk about." Another stated, "...it's disrespectful to find out too much information. Maybe cause I'm younger than the people who tell me, I don't think I've earned that right." Others commented on the lack of public discourse, "People don't talk too much about the type that they had or what the experience was. It was just that they had it, and they passed, and that's pretty much the end of the discussion." Secrecy was also discussed in terms of its impact on support, "You're not talking to other people about it, in which case you're not asking people for help." Lastly, several respondents mentioned the impact of secrecy on health-seeking behavior, noting "More often than not people who live in the area closest to the center will not go to that center, they will go to another, say like in the Bronx or someplace else," for fear that others in the community would see them seeking help.

Trust

Another common and pronounced theme expressed by half of all respondents was that of trust, largely in terms of its impact on physician–patient interaction, health-seeking behavior, and research participation. Several discussed mistrust of the intentions of health care professionals, "I feel it's quite unfair to have a teaching facility in this neighborhood, because we shouldn't be poked and prodded." Another commented, "I think it's a training ground frankly; a lot of misdiagnosis happens here more often than not." As often reported, many discussed medical mistrust, the underpinnings of this and its impact on participation in research studies and interactions with academics. One respondent differentiated issues of

trust between East and Central Harlem communities, noting "... in Central Harlem, there is the issue of trusting medical professionals because of the different studies that have been done in the past. And in East Harlem it's just the issue of the Hispanic community trusting anyone that doesn't really speak their language."

Beliefs

A little less than half of all respondents discussed the impact of beliefs on health-seeking and self-care behaviors. For example, many discussed the commonly held belief that "... cancer is a natural phenomenon controlled by unknown factors"; thus, many residents do not participate in prevention and screening efforts. Respondents also discussed how many in the community attribute illness to lifestyle factors, "I've seen family members say things like 'well he fooled around when he was younger' ... attributing it [cancer] to a person's lifestyle." Fear was also discussed as a major contributor to health care behavior, "People would rather live with not knowing than live [with] the fear of knowing." Stigma was discussed both in terms of person and place relevance. Respondents conveyed that community members continue to associate the word cancer with personal stigma, "People a lot of times still view illness as, you must have did something wrong, or you're being punished in some kind of way" or that "They've brought it on themselves or were prone to get it no matter what they did." Regarding place relevance, respondents commented on longstanding beliefs held about facilities, "...most of the community knows it as the place where you go when there is nothing left medically for you. And you are just there to spend your last few days... so for a lot of people, you mention.... [Ibid] and they just see you with like a morphine drip." This sense of place stigma was also discussed in terms of the use of the word "cancer" as a barrier to participation in community-supported programs of any sort; as one respondent noted, "... nobody wants to come to cancer programs."

Financial Challenge

Several respondents discussed financial challenges, including insurance and access difficulties, as well as the growing number of uninsured and undocumented community members, and their struggles "... to get access to care because of insurance and payment and not understanding the system that might be able to help them." Respondents also discussed difficulties among the working poor, stating, "...if they don't work they can't get paid which means they can't take care of their financial responsibilities, so health is not a primary factor in the household." One respondent discussed how financial challenges impacted health-seeking behavior, noting, "One might not necessarily want to go back if a type of screening or follow-up is required because then it's going to be costly and therefore people tend to worry about the cost more than they worry about the end result of wellness."

Accountability

Accountability was found to be a common theme, both from a patient and provider perspective. Several expressed unease that a concerted effort was lacking on the part of health care providers to truly understand the unique health care needs and concerns of the community. One respondent further asserted this point, "There is a cultural barrier to that, because if there isn't an understanding of how communities view disease and healthcare and

health maintenance from the cultural perspective it's very difficult to pinpoint an effective way of having some impact." More than a few talked about the need for patients and community members to "...feel empowered in their own health care in battling or preventing a disease." Although many residents were described as "advocates," others "...don't always have the ability to advocate for themselves... Don't have the literacy to understand and are embarrassed to say I don't understand." This segment of the community was described as being unable "To use the resources available, public and private, to make these things happen." This issue was mentioned as one in which health care providers need to "Be very sensitive to the fact that our patients come in all shapes and sizes and levels of literacy."

Environment/Pollution

Many respondents discussed the impact of the physical environment, both physical space and land use, on the health of residents. One respondent described the community as a "Dumping ground of different things that shouldn't be where they should be." Several cited the local bus depot and multiple highway exchanges as major problems in terms of pollution generators in the communities, "The highways on both sides of Manhattan, the constant cars going by... that rubber, that tread, its particle matter that goes in the air." One respondent commented on a problematic situation in her community related to pollution and the physical environment:

Where I live there is a high rate of cancer because there used to be, we believe, meaning the people that live in my development; that it came from a huge commercial laundry... We seem to have an astronomical amount of cancer in the housing co-op where I live, and we really think that it's environmentally related.

Access

Several respondents discussed access difficulties in relation to cancer care, specifically noting, "...you shouldn't have to leave your community for [care]. Whatever health institutions are in your community should be able to offer you the same thing that you can get outside." The lack of visibility of health care centers was also noted, "My cousin works in a clinic for elderly and it's behind a sky scraper, but it was in the back. And so my point is regarding cancer, I don't see any facilities, I don't." Another respondent noted that community residents should, "...not feel like they are just going to get the basics and that's it, or that the institution doesn't really have the time to dedicate to each individual person as they should." More than a few mentioned the use of satellite community centers as a possible solution to this. Access challenges were also discussed in terms of language and navigation difficulties, "People in the healthcare system outside of Federally Qualified Health Centers seem to struggle with the notion that patients are really having a hard time engaging in a healthcare system. It just isn't easy to access. So for somebody who is [from] out of the country, isn't sure of the language or the culture, and has no resources, it's that much more difficult."

Discussion

The current needs assessment sought to identify cancer prevention, control, and care priorities in an attempt to guide the development of strategies and interventions to improve the quality of cancer care and how it is communicated, coordinated, and delivered to patients and their families. A review of the major themes generated from individual interviews with community leaders and residents suggests that education and support were seen as critical areas of need and intervention in terms of strengthening cancer care in East and Central Harlem. More specifically, a significant need for education regarding available resources, including support services; lifestyle management; and follow-up care were expressed.

These expressed areas of need can be understood and addressed from both an individual and community system perspective. Given that several themes dealt with individualities in relation to beliefs, trust, and accountability, the potential impact of education, as it relates to empowerment, self-efficacy, and advocacy, on health outcomes is enormous. Increased knowledge through improved education may lead to greater “resident power” in that it has the potential to build social power and reduce feelings of isolation. Related education which serves to impact the capacity of the community to address social determinants of health is as important as health outcomes themselves.

What and how this information is communicated to individuals and the community at large are fundamental and should be mindful of the needs and culture of the community as approaches and methods of delivery for patient education are key. The use of multiple teaching strategies, including targeted and structured approaches that are culturally appropriate, has been found to be effective [13]. Several unique interventions have been created in an attempt to strengthen both individual and community members’ health-related self-efficacy and empowerment. For example, the use of a community radio to facilitate and encourage sustainable change [14], the use of a caregiver empowerment model [15], and the use of telehealth to promote disease self-management and promote empowerment [16] are valid options for improving community health outcomes. Accordingly, the development of programs and interventions that build and strengthen community involvement and capacity to increase sustainable change is essential.

The results of this needs assessment also highlight the importance of place with respect to health and health outcomes, particularly for members of East and Central Harlem communities and is consistent with that suggested in previous work [17, 18]. Several respondents discussed the detrimental impact of environmental conditions, including land use, pollution, and food access and availability, on the health of residents. Freudenberg and colleagues label this as “urban health penalty” and describe it as the appalling health conditions of inner cities and the resulting inequalities in health [19]. Effective programs and policies addressing environmental conditions must provide opportunities for community involvement. Investment must be made to improve the social and psychological structures that exist within these communities, including acknowledgement of “third places,” those important social spaces for informal public life [20].

From this assessment, we are not attempting to undermine the influence of the larger cultural, social, political, and economic systems which impact the health-related behaviors and health outcomes of these communities. Rather, results from this study show that the individual- and community-system-level factors and the interplay between them are equally important in impacting the health of these communities. While we realize that some would argue that providing education and resources pertaining to individual-level factors are narrow in scope and argue for more short-term solutions, we also advocate for efforts addressing the social and economic realities of these communities. According to the social ecological model, the interplay of factors across multiple system levels serves to impact the health and health outcomes of communities and society at large. Efforts to intervene across multiple levels through improved education can significantly impact cancer care needs and related health outcomes found within these and similar communities.

Limitations

Several limitations of the present study must be acknowledged. First, the generalizability of the results may be somewhat limited, as our sample was fairly analogous to our study population, consisting of individuals living and/or working in East and Central Harlem. These communities may present with unique health-related challenges and protective factors given their unique history and geographic location. Nevertheless, results may be generalizable to other communities characterized by low-income, un(der)insured, and large racial and ethnic minority populations. Second, this study relied on information garnered from a unique subset of individuals, namely those deemed influential members of their respective communities. Their insights and opinions may not align with those of other members of the same or similar communities. However, in our selection of this sample, we attempted to move beyond the generic definition of community member, in an attempt to add a top-down perspective and to add diversity of voice to the literature.

Implications

This study serves as an important step in understanding the cancer care needs in East and Central Harlem communities, as expressed by influential community members including healthcare and organizational professionals. Addressing these needs could serve to enhance a number of cancer care priorities, for example, improved patient-provider communication, social and emotional support, participation in screening and follow-up care, and dissemination of more accurate information and resources available. As has been shown in previous research, full engagement of the community, at both the individual and collective level, is vital to effective and sustainable change. Acknowledgement, understanding, and appreciation of the various environments, including service, social, and physical, and their presence within the political and economic climate are of the utmost significance in impacting the health home of the community.

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Table 1

Rates of disparities in East and Central Harlem

	East Harlem	Central Harlem	Upper East	NYC
% Black and Hispanic ^a	88 %	86 %	9 %	51 %
% poverty level ^a	38 %	35 %	7 %	21 %
No high school degree ^a	46%	33 %	5 %	28 %
Avg. adj. death rate (100 K) ^a	1,084	1,003	573	718
Cancer mortality (100 K) ^a	208	222	153	161
% Adults who smoke ^b	27 %	26 %	12 %	18 %
% Obese adults ^b	31 %	27 %	8 %	20%
% Adults with diabetes ^b	13%	12%	3 %	9 %

Percent age adjusted. Obesity is defined as a body mass index of 30 or greater

^aBureau of Vital Statistics, NYC-DOHMH, 1995–2004; US Census 1990 and 2000/NYC Department of City Planning^bNYC Community Health Survey 2002-03-04

Table 2

Interview questions

Construct	Sample questions
Personal community involvement and history	<p>How long have you lived or worked in East and/or Central Harlem?</p> <p>Could you describe your involvement with the East and/or Central Harlem community?</p> <p>Have you been involved in community-based activities? Please tell me about them.</p> <p>What are some of the strengths and/or challenges of East and/or Central Harlem?</p> <p>What are some of the strengths and assets in East and Central Harlem in the area of health? In the area of cancer services?</p>
Cancer presence	<p>Is cancer a big problem for the people of East and/or Central Harlem?</p> <p>If yes, how big of a problem?</p> <p>What kinds of problems with cancer do the people who live in East and/or Central Harlem face?</p> <p>Do you think this is different from other communities? If yes, how is it different?</p>
Support initiatives	<p>Who do you think people in the community [East and/or Central Harlem] go to with problems related to cancer? Or to get help?</p> <p>What kind of help do people need?</p> <p>Do you think these differ by different types of cancer? How?</p> <p>Where are the places in the community [East and/or Central Harlem] that people feel comfortable to gather and talk about issues related to cancer?</p>
Priority areas	<p>Please name the 5 top cancer issues affecting East and/or Central Harlem. If you had to put them in order with 1 being the most important and 2 being slightly less important, and so on, how would you rank these 5 issues?</p>
Cancer interventions and programs	<p>If I wanted to do a cancer-related health program with yours or other community organizations [East and/or Central Harlem], what are the things I would need to know? Who are the people I would need to know?</p> <p>What have you heard and/or what stories are told about types of programs related to cancer in the community [East and/or Central Harlem]?</p> <p>What types of programs do you think might be useful for your community? Why?</p> <p>As we think about programs, where do you think we should focus our initial energies? And why?</p>
Personal experience	<p>Can you tell me about your own experience with cancer? [if no personal experience, then family member's experience]</p> <p>What were some of the key problems you [your family member] faced with regard to your [their] cancer?</p> <p>How do you think this is different from the experiences of residents in other communities?</p>

Table 3

Participant sociodemographic characteristics

	Number	Percent
Gender		
Male	13	32.5
Female	27	67.5
Mean age (SD)	56.2	13.7
Marital status		
Married/living with partner	16	40.0
Separated/divorced/widowed/never married	24	60.0
Education		
8th–11th grade	1	2.5
Some college or university	6	15.0
Bachelor's degree	14	35.0
Graduate degree	19	47.5
Income		
Less than \$39,999	9	25.6
\$40,000–\$79,999	15	38.6
\$80,000 or greater	14	35.8
Race ^a		
Black/African American/Afro-Caribbean/West Indian	25	59.6
Hispanic	12	28.6
Other	5	20.9
Hispanic origin		
Yes	16	40.0
Country of origin		
USA	36	90.0
Other	4	10.0
Mean years in the USA (foreign born only) (SD)	35.8	18.3
East Harlem		
Resident	24	60.0
Length of residency in years (SD)	16.7	21.01
Employment	23	57.5
Length of employment in years (SD)	8.3	14.04
Central Harlem		
Resident	16	40.0
Length of residency in years (SD)	15.6	24.51
Employment	12	30.0
Length on employment in years (SD)	4.3	9.94

^aNot mutually exclusive

Table 4

Interview themes and response rate

Theme (sub-themes)	Number of referents (%)
Education (resources, lifestyle, symptoms, follow-up care)	24 (60 %)
Support (emotional coping, support groups, discussion)	23 (57.5 %)
Secrecy	20 (50 %)
(Mis)trust	20 (50 %)
Beliefs (fear, stigma, fatalism)	18 (45%)
Financial challenge	17 (42.5 %)
Accountability	15 (37.5 %)
Environment/pollution	14 (35 %)
Access (facilities, language, navigation)	13 (32.5 %)