Original Report:
Social Determinants
of Health

ELICITING THE SOCIAL DETERMINANTS OF CANCER PREVENTION AND CONTROL IN THE CATCHMENT OF AN URBAN CANCER CENTER

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Objective: The objectives of this study were two-fold: 1) to engage community stakeholders in identifying the top three social determinant of health (SDOH) barriers to the early detection and treatment of cancer in their respective communities; and 2) to develop a tailored plan responsive to the potential social risks identified within the catchment of an urban academic cancer center.

Methods: Stakeholders from four neighborhoods in Brooklyn, New York with disproportionate cancer burden were recruited; the nominal group technique, a semi-quantitative research method, was used to elicit the SDOH barriers. Responses were consolidated into categories and ranked by points received.

Results: 112 stakeholders participated in four community-based meetings. The SDOH categories of economic stability, education, and community and social context were identified as the top barriers. The themes of lost wages/employment, competing priorities, and the inability to afford care embodied the responses about economic stability. The domain of education was best described by the themes of low health literacy, targeted health topics to fill gaps in knowledge, and recommendations on the best modalities for improving health knowledge. Lastly, within the category of community and social context, the themes of stigma, bias, and discrimination, eroding support systems, and cultural misconceptions were described.

Conclusion: The implications of our study are three-fold. First, they highlight the strengths of the nominal group technique as a methodology for engaging community stakeholders. Second, our analysis led to identifying a smaller set of social priorities for which tailored screening and practical solutions could be implemented within our health care system. Third, the results provide insight into the actual types of interventions and resources that communities expect from the health care sector.

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INTRODUCTION

The World Health Organization defines social determinants of health (SDOH) as the conditions in which people are born, grow, live, work, age, and a broader set of forces that shape daily life conditions.[1] Presently, there is a heightened awareness that these factors are responsible for most health inequalities.[2] While public health experts have long supported the critical need to address the SDOH's in health care settings, the actual implementation of SDOH screening is still a relatively new phenomenon. Recently, the Centers for Medicare and Medicaid Services (CMS) began to financially incentivize innovation in screening for and addressing SDOH, with the hopes of increasing its implementation and adoption in medical practices.[3] However, the barriers to this innovation lie in the fact that screening for patients' health-related social circumstances is profoundly different from screening for medical conditions for which validated screening and diagnostic tools are easily accessible in the health care sector. Therefore, as the field has evolved, so has a diverse array of SDOH screening tools with no current standardization in place.[4-6] In addition to the decision of which tools to use is the concern that "screening for any condition in isolation without the capacity to ensure referral and linkage to appropriate treatment is ineffective and, arguably, unethical."[7]

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As a result, recent evidence demonstrates that few US physician practices (15.6%) and hospital systems (24.4%) screen patients for multiple social needs (eg, food insecurity, housing instability, utility needs, transportation needs, and interpersonal violence).[8] To that end, we sought to take a community-engaged research approach to identify the critical social needs most relevant to closing the gap in disparate outcomes in four neighborhoods with disproportionally higher premature death (before age 65) from cancers amenable to early detection (breast, cervical, colon, lung, and prostate).

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In New York City, the burden of cancer incidence and death is unequally distributed by wealth, race, and ethnicity.[9,10] Black New Yorkers living in the poorest neighborhoods are the most likely to die from several cancers amenable to early detection.[11] Although Black and Hispanic New Yorkers may get screened for these cancers at the same rate, adequate screening rates alone are not sufficient to increase survival rates.[12] To fully tackle these disparate outcomes, we must address the social determinants of health. However, how best to prioritize these needs in the health care sector remains to be seen.

Hence, the purpose of this study was two-fold. First, to identify a set of social conditions that expert community members deemed to be the most significant barriers to the early detection and treatment of five cancers (breast, cervical, colon, lung, and prostate). Second, to develop a tailored approach to screening, and a community-based referral and linkage program responsive to those needs within the burgeoning cancer services program of an urban health care system.

METHODS

Setting and Study Participants

The four neighborhoods targeted in this study are within the cancer services catchment of the New York-Presbyterian Regional Hospital Network. The neighborhoods are represented by three United Hospital Fund (UHF) neighborhoods (Bedford-Stuyvesant/Crown Heights, Coney Island, and Flatbush) in Kings County. UHF neighborhoods are commonly used in research, including the New York City Department of Health and Mental Hygiene's Community Health Survey. UHF neighborhoods consist of multiple adjacent zip codes and specific city council districts. In 2016, among all Brooklyn neighborhoods, the UHF neighborhood of Bedford-Stuyvesant/Crown Heights had the highest age-adjusted death rate due to cancer (149.7 per 100,000), followed by Coney Island (145.4 per 100,000).[13]

Using a pre-written script, community stakeholders were recruited by the Meyer Cancer Center Office of Community Outreach and Engagement at Weill Cornell Medicine. The outreach staff purposively sampled stakeholders using the tenets of the Patient-Centered Outcomes Research Institute. As various members of a community have a stake in generating useful and relevant health care research evidence, we sampled members of constituencies based on professional experience, including clinicians, community members, health care purchasers, payers, industry, hospitals, and other health systems, policymakers, training institutions, and researchers. Dinner meetings for the recruited stakeholders were hosted at community-based organizations that could comfortably accomodate a minimum group of 50. Stakeholders were pre-assigned seating to ensure a mixture of constituencies was engaged at each table. The presentations and discussions were hosted in English only.

Conceptual Framework

We used the Kaiser Family Foundation's illustration of six categories of SDOH that have been shown to drive health outcomes as the guiding framework for the group discussions.[14] While health care delivery is essential to health, it is comparatively a weak social determinant. Rather, research has demonstrated that health outcomes are driven by an array of factors, including health behaviors, community and social context, and education, to name a few.[15] While there is currently no agreement in research on the scale of each factor's relative contributions to health, studies suggest that health behaviors, such as smoking, and social and economic factors are the primary drivers of health outcomes. Additionally, evidence shows that stress negatively affects health across the lifespan,[16] and that environmental factors may have a multi-generational impact.[17] Addressing social determinants of health is essential for improving overall health and reducing health disparities that are often deep-seated in social and economic disadvantage.

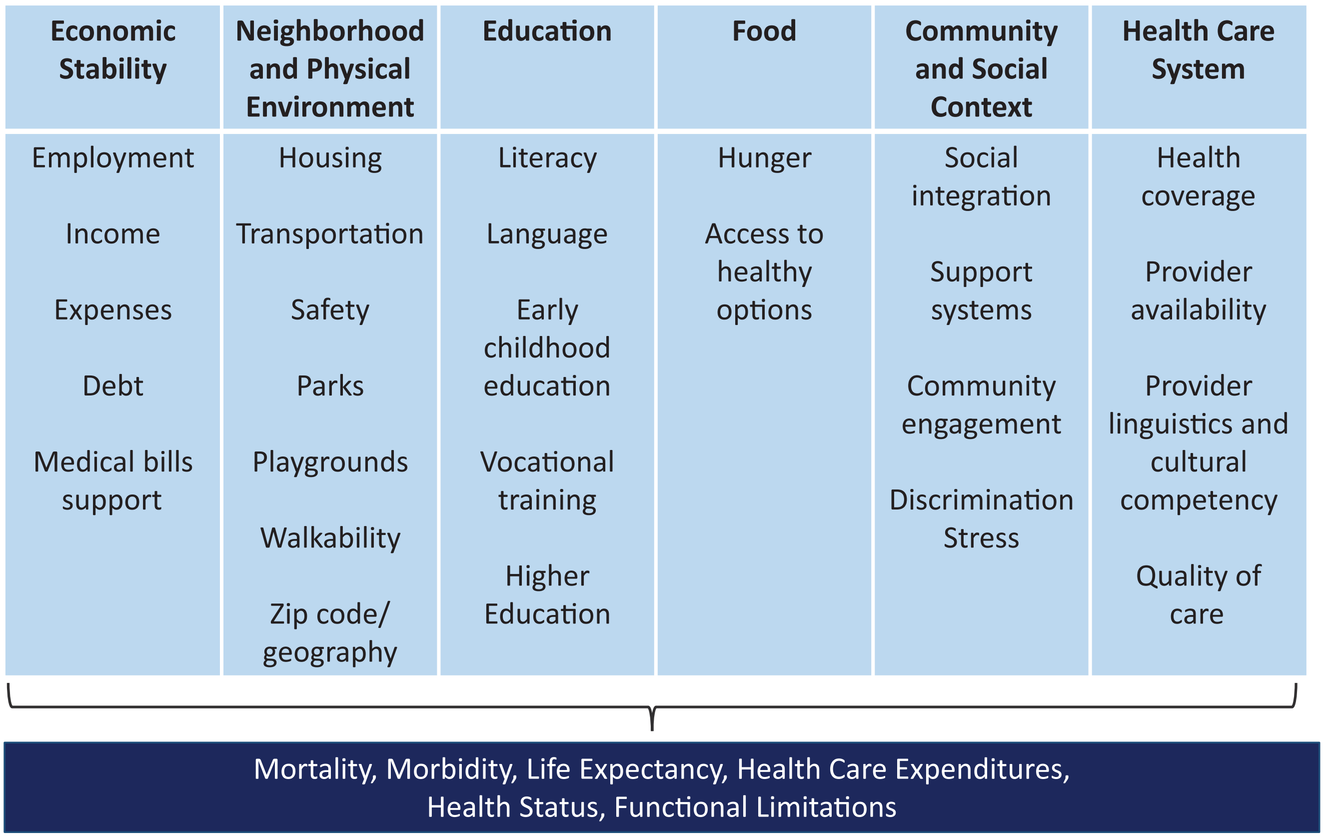
Data Collection

Nominal Group Technique

To elicit and obtain a consensus viewpoint on the social needs that should be prioritized in reducing cancer health disparities among the target communities, we used the nominal group technique. The nominal group technique is a structured, well-established, multistep, facilitated group meeting technique used to generate and prioritize responses to a specific question by a group of people who have expert insight into a particular area of interest.[18] The organized process gives participants an equal opportunity to contribute their personal views before inviting them to build on others' reflections and reach a consensus about the issues raised. In this study, we sought a response to one central question: "Among the six social determinants of health shown here (Figure 1), which three do you believe exert the greatest barrier to the early detection and treatment of cancer in your community?"

There was a total of four nominal group meetings, one in each of the target communities. The same experienced moderator led all sessions. At each meeting, participants were seated in groups of 6-8 individuals at a table. Each table had an assigned trained facilitator to ensure all participants were fully engaged, kept the discussion on track, kept a written record of the group's key points, and reported them after the group discussion. The same facilitators were used across the four nominal group meetings to maintain consistency. A research assistant kept written notes of the sessions and organized the data.

Participants received 40 minutes to discuss the primary question. Facilitators then reported their respective small group responses in a round-robin format to the larger meeting of participants. The moderator recorded every



Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment Income Expenses Debt Medical bills support	Housing Transportation Safety Parks Playgrounds Walkability Zip code/ geography	Literacy Language Early childhood education Vocational training Higher Education	Hunger Access to healthy options	Social integration Support systems Community engagement Discrimination Stress	Health coverage Provider availability Provider linguistics and cultural competency Quality of care

Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

Figure 1. Social determinants of health model

Table 1: Small group rankings of the social determinants of health domains for each neighborhood and cumulative ranking across neighborhoods

	Crown Heights, n=6	Bedford-Stuyvesant, n=8	Flatbush, n=5	Coney Island, n=5	Total, n=24
Economic stability	5	7	4	3	19
Education	6	4	3	4	17
Community and social context	4	8	3	2	17
Health care system	3	4	3	2	12
Neighborhood and physical environment	0	0	1	3	4
Food	0	1	1	1	3

n, the number of individual small groups at each neighborhood nominal group meeting.

response from each small group. All groups shared their ideas until no new responses emerged. The list of responses was then reviewed and discussed to ensure a shared understanding of each of the items generated. For individual groups where more than three barriers were reported, the research assistant reviewed the moderator's handwritten notes and the respective group notes (post discussion) and transcribed into an electronic format for coding.

Data Analysis

The first step in the analysis was a tally count of each social determinant domain ranking at the neighborhood level. Then a cumulative tally across all four nominal group meetings was conducted as shown in Table 1. The written moderator notes from the individual groups were analyzed using thematic analysis and category coding approach.[19] The process commenced with the primary coder, a research assistant trained on the protocol, familiarizing themselves with the data by first reading through all the written facilitator and moderator notes from each nominal group meeting. Next, all data were coded in the order of occurrence of each of the nominal meetings. Patterns were identified among the codes and similar codes were collapsed into categories; categories were subsequently grouped into themes associated with each of the domains. The final categories and themes were reviewed for their usefulness and accurate reflection of the data by an independent corroborator. Disagreements were resolved by consensus. The data analysis process was done manually without the use of analytic software.

Table 2. Stakeholder groups represented at each neighborhood stakeholder meeting (n=112)

	Target Neighborhoods			
Stakeholders	Crown Heights	Bedford-Stuyvesant	Flatbush	Coney Island
Cancer advocacy organizations	4	5	2	3
Local social service organization or business	7	6	5	5
Hospital-based clinicians	2	5	0	2
Community-based clinicians	5	4	4	4
Community board members or residents	3	10	8	2
NYC department of health/ elected officials	0	6	1	1
Health system leadership	6	5	4	4
Total number of attendees at each meeting	27	41	23	21

RESULTS

Study Participants

As shown in Table 2, a total of 112 stakeholders participated in the nominal group meeting discussions. The table further depicts the distribution of participants per the four neighborhoods and the stakeholder groups represented. One neighborhood did not have representation from the policymaker constituency group (Crown Heights) and the hospital-based clinician constituency group (Flatbush). Across the four nominal group meetings, there were cumulatively 24 small groups. While 19 out of 24 small groups (79%) prioritized economic stability, an equal number of groups, 17 out of 24 (71%), identified education and community/social context as barriers. It is important to note that 50% of the groups prioritized the health care system over the less ranked barriers of the neighborhood/physical environment (16%) and food insecurity (13%).

Table 3: Qualitative themes for the top three selected social determinants of health barriers to the early detection and treatment of cancer

	Theme	Quote
Economic stability	Hidden impact on employment/wages	After you complete a screening test, you may receive a new diagnosis, then you have to stop working and tap into your savings, which then begins to deplete.
	Competing priorities	Prevention is secondary to survival; most people are just trying to keep their heads above water.
	Unable to afford medical expenditures or costs related to receiving care	Even employer-based health plans are inadequate now with high deductibles.
	Unable to afford items that promote wellness	Eating a healthy diet is important to prevention but healthy foods are not affordable
	Maladaptive behaviors	It's a vicious cycle people smoke cigarettes to deal with the stress of their finances, but cigarettes cost $10 a pack so it makes your finances worse and causes illnesses.
Education	Low health literacy	People must have some health knowledge to make informed decisions about their care.
	Health education topics	There is a need to educate people on how food relates to cancer and eating a healthy diet on a budget.
	Modes of health education delivery	We need to identify new ways of presenting the information beyond that of just standard print materials such as social media and public art.
Community and social context	Stigma, bias and discrimination in health care	When you lack the right education, are not economically stable, live in a specific neighborhood and you don't have the right immigration status you will not receive the same level of care.
	Erosion of support systems	We've lost our community building capabilities; we need stronger support systems.
	Deeply rooted cultural beliefs	Talking about illness is taboo. Our community is not open to sharing their personal or family history when it comes to health…. those topics are private.

Themes Identified

Table 3 shows participant comments regarding the social determinant of health domains selected the most frequently.

Economic Stability

Participants generated 45 individual responses related to economic stability, serving as the greatest barrier to cancer screening and treatment. These responses led to five overarching themes. The themes of "impact on wages/employment," "competing priorities," and "inability to directly afford medical expenditure's or costs related to receiving care" accounted for more than half (69%) of participant responses. Although less reported in frequency, participants discussed additional economic barriers such as "unable to afford items that promote wellness" (ie, healthy food) and the use of "maladaptive behaviors" (ie, smoking) to treat financial stress.

Education

Participants generated 54 individual responses that pertained to education. Three themes were derived from the answers. The most discussed was that of "low health literacy" and its impact on making genuinely informed decisions about the health of individuals and their family members. Next, participants described the variety of "health education topics" that needed to be delivered and, lastly, the modalities in which they should be provided with an emphasis on moving beyond print material and seminars offered by health care providers. Social media and public art were mentioned as platforms most relevant to reaching younger populations and building health education into early childhood programs. These three themes accounted for 88% of participant responses.

Community and Social Context

Participants generated 85 individual responses about the community and social context; yet, their responses placed this domain in equal ranking with education. The themes of "stigma, bias, and discrimination in health care," "erosion of support systems," and "deeply rooted cultural beliefs" accounted for 67% of the overall responses. One participant shared, "There is a bias, lack of understanding, and the belief that bad things can happen (in encounters with health care providers); [it] can come from prior experiences with discrimination." Participants additionally focused on changes in existing support systems. Many endorsed that faith-based organizations such as churches are still a vital resource in the community as demonstrated by this comment, "support systems in the churches are some of the best in the country." There was equal discussion of eroding social support systems, which has led to community residents experiencing social isolation and neighborhoods where everyone is "doing their own thing." Lastly, deep-rooted cultural norms around "not sharing personal or family history" and "people hiding their illness in fear of burdening their family or just being ashamed of their illness" were discussed as critical factors to community residents not understanding their own increased risk for cancer.

Discussion

In this community-engaged study, our nominal group technique process elicited the social priorities of neighborhoods experiencing disproportionate rates of premature death from cancers amenable to early detection and treatment. In doing so, we identified three key areas (economic stability, education, and community and social context) for which our health care system and those similar to it should consider tailored screening approaches to assess social risk while simultaneously formulating linkage and resources that are patient-centered to address uncovered needs. Our findings have several important implications for social risk screening across different health care settings.

First, our work provides a model of a collaborative approach between health care systems and community stakeholders in identifying a smaller set of risk factors and priorities. In addition to identifying the priorities, community members also provided recommendations on practical solutions to address these real-life barriers. Few studies about the impact of social determinant screening have been published from the patient or community perspective. In one of the few studies to ask patients about their expectations regarding social risk screening, we find evidence that more than half of patients (64.5%) do not want help addressing their social risk from clinical staff.[20] We additionally see this viewpoint supported in work by Byhoff et al,[21] which reveals that although patients believe social risk screening is necessary and acceptable, they do not expect their health care teams to address the real-life social challenges they face. These findings underscore the importance of health care systems identifying solutions for needs that patients want, will accept and are in practical reach.

Second, our findings provide the foundation for demonstration projects that leverage existing systems and tools that may be more acceptable and aligned with what communities expect from the health care sector. One such example is the active role that health care systems in New York State could play in disseminating information that protects patients from lost wages due to seeking cancer preventative services. Currently, for employees of the public sector, New York state law mandates the right to paid, excused leave of absence from work duties for a sufficient period, not to exceed four hours, to undertake a screening for cancer of any kind.[22] While employers are mandated to inform their employees of this law, health care systems are not directed to do the same when referring and scheduling an individual for these services. New legislation to mandate nationwide breast density notification is a prime example of mandating health facilities to implement a law that addresses a well-established health disparity.[23] Similarly, national data demonstrates that employees without access to paid time off for preventative services are less likely to obtain recommended screening tests.[24] Thus, actively empowering communities with this information may have a more significant impact than screening for the inability to pay a utility bill or food insecurity.

On a broader level, health care systems must play a critical role in advocating for policies that alleviate the financial toxicity of cancer treatment and directly meet the needs of their communities. Our findings highlight the need for weekend or late practice hours to help reduce the cost and inconvenience of leaving work to seek screening without paid leave, although we acknowledge that flexible practice hours may not entirely offset the lack of paid leave.

In the context of patient-centered cancer care, medical oncologists are central to the delivery of high-quality treatment. They also serve as a focal point in helping contain the financial burden and distress to their respective patients. They most certainly can leverage their role in the front lines of cancer care toward promoting quality cancer care that involves avoiding low-value treatment as described by the

Choosing Wisely campaign.[25-28] Providers can also play a significant role in the inclusion (or exclusion) of cancer drugs as part of their accountable care organizations' bundled treatment.[29]

Lastly, our results illuminate areas in which health care systems can partner with communities to respond to social risks such as low health literacy, social isolation, and cultural misconceptions. Low health literacy is an under-appreciated factor in cancer control communication and patient decision-making.[30] It is often also unrecognized that low health literacy affects all communication types—written, oral, and visual. Patients with low health literacy skills develop different communication skills and often rely far more on radio, television, verbal explanations, and direct health advice from family and friends.[31] The use of friends and families as trusted decision-makers regarding cancer control decisions further supports the need for expanding and financially supporting robust evidence-based lay health education programs. Lay health educators trained in specific health topics have been shown to effectively deliver community-based interventions, including cancer control. In response to these findings, our cancer services program has designed and implemented an 8-week lay health education cancer preventative program in the communities targeted by this study. The curriculum incorporates personal stories, short videos, a workbook developed at a 7th-grade reading level and can be taught in person or via a virtual platform.

Lay health educators can also directly play an essential role in diminishing social isolation, a need that can be easily screened for in the context of an office visit. In a systematic review of peer-supported interventions for health promotion and disease prevention, lay health educators had a positive effect on social outcomes such as connectedness, as well as individuals level outcomes such patient activation and self-efficacy.[32]

Limitations

Our study has several limitations. Although the purpose of the nominal group technique is to brainstorm and allow for quick agreement for specific topics, groupthink can lead to problems in the accuracy of responses gathered. Groupthink can overshadow the individual differences in opinions in favor of a group consensus; however, this was mitigated by trained moderators and facilitators. While the composition of the stakeholders in each group differed, those viewed by others within the small group as an authority in the subject matter may have created a bias in the discussion. Similarly, varying interpretations of the question posed could have led to the differences in responses, as the scribes recorded notes based on what he/she heard from the conversation. Since many social determinants of health domains had overlapping components (especially between the community and social context and the health care system), stakeholders may have comprehended each determinant's aspects differently.

CONCLUSION

The implications of our study results are three-fold. First, they highlight the methodological strengths and ease of using the nominal group technique as a quick and structured form of a qualitative consensus methodology for engaging diverse community stakeholders. Second, the analysis of the written group meeting notes led to identifying a smaller set of social priorities for which tailored screening and practical solutions could be implemented by the cancer services program of our health care system. Third, the results provide insight into the actual types of interventions and resource linkages that communities desire and expect from the health care sector.

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Conflict of Interest

No conflicts of interest to report.

Author Contributions

Research concept and design: Phillips; Acquisition of data: Jou, Ramos, Antoine, Nanus, Phillips; Data analysis and interpretation: Jou, Sterling, Ramos, Phillips; Manuscript draft: Jou, Sterling, Nanus, Phillips; Statistical expertise: Phillips; Acquisition of funding: Phillips; Administrative: Jou, Ramos, Antoine, Nanus, Phillips; Supervision: Sterling, Phillips

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