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A Population Health Equity Approach Reveals Persisting Disparities in Colorectal Cancer Screening in New York City South Asian Communities

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Abstract

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Ethics Declarations

Informed consent was obtained from all individual participants included in the study, and participants were offered a $40 honorarium for their time. Data collection was approved as an expedited study by the NYU Langone Health IRB.

Conflict of Interest

The authors declare that they have no conflicts of interest

To assess colorectal cancer (CRC) screening among South Asians (SAs) and explore the challenges and facilitators to CRC screening among SA subgroups in New York City (NYC). Fifity-one semi-structured in-depth interviews and surveys were conducted among SA immigrants in NYC. Qualitative results suggested challenges to CRC screening were related to socio-cultural factors, such as a lack of knowledge on CRC and CRC screening, and structural factors, such as cost and language. A physician referral was the most cited facilitator to CRC screening. Participants reported culturally-and linguistically-adapted education and information on CRC and CRC screening would help to overcome noted challenges. Our findings support the development of targeted, linguistically and culturally-adapted campaigns for this population that facilitate access to health systems and leverage natural community assets and social support systems.

Introduction

Population health interventions, including policy, systems, and the environment (PSE) approaches, usually consist of upstream interventions for reaching the wider population and yielding broad improvements in outcomes. Often these strategies and interventions are based on research conducted in the majority population—largely White and middle-class [1, 2]. Efforts to increase rates of colorectal cancer screening in New York City (NYC) are frequently cited as a successful effort that integrated city-wide systems and organizational interventions. In fact, the Citywide Colon Cancer Control Coalition (C5) program, a multi-stakeholder coalition including the NYC Department of Health and Mental Hygiene, has noted that it not only improved colorectal cancer (CRC) screening rates at a population health level but also decreased disparities, citing that after14 years of implementation, all racial and ethnic groups are screened at par [3].

In contrast to large-scale population health approaches, a population health equity approach argues that population-wide strategies have had limited impact on eliminating the gradients in health and that targeted strategies are needed for a coherent and integrated paradigm for advancing both population health and health equity [1]. In this paper, we show the value of utilizing a population health equity approach using the specific example of CRC screening in NYC, demonstrating that despite large-scale health systems interventions supported by city-wide campaigns, disparities in CRC screening remain in particular racial/ethnic subgroups. Here, we focus on South Asians (SAs) living in NYC. South Asians, comprised of individuals from several countries including India, Pakistan, Bangladesh, and Nepal [4] are one of the most rapidly growing populations in NYC, reflective of the overall growth rate of the Asian American (AA) population in NYC.

Cancer, in particular, is a significant issue among the AA population as it is the leading cause of death for AAs in the United States (US) [5]. Colorectal cancer contributes significantly to cancer incidence rates among the AA population, especially for certain groups of AAs [6, 7]. For instance, a study examining data from the California Cancer Registry database found that although CRC incidence has been decreasing for AAs overall, rates are actually increasing among Koreans, SAs and Filipinos [6]. Results from both the National Health Interview Survey [8] and the Behavioral Risk Factor Survey [9] suggest CRC screening rates are lower for AAs compared to other racial and ethnic groups.

Similarly, population- and community-based studies that have disaggregated data for the AA population have found lower CRC screening rates, sometimes as low as 25%, for the SA population compared to other racial and ethnic groups [10–12]. A recent analysis conducted on the NYC Department of Health and Mental Hygiene's Community Health Survey indicated a low uptake of CRC screening among SA immigrants in NYC. Findings demonstrate that SAs consistently have among the lowest rates of CRC screening within NYC, between 45 and 58%, compared to non-Hispanic white (70.4%), non-Hispanic Black (68.2%), and Hispanic (71.7%) [13, 14]. Barriers and facilitators related to CRC screening in this population include social, acculturation, and access to care factors such as limited English proficiency, education, and length of residence in the US, which have been found to be stronger predictors of CRC screening for SAs compared to cultural and health beliefs [15, 16].

Despite these trends and emerging literature documenting the burden of CRC in this population, SAs remain an understudied racial/ethnic minority group in the US. Reasons for the lack of research on particular AA subgroups such as the South Asian community have been previously explored, and include lack of collection, reporting, and analysis of granular data at the local and regional level[17] and the persistence of the "model minority myth" which asserts that AAs are healthier than other populations [1, 18]. Given the lack of research on SAs and CRC screening, the growth of this community in NYC, and emerging community-based studies which have reported low rates of CRC screening in this population, it is important to determine if the gains in CRC screening in NYC are being equally experienced by the SA population. Here, we assess CRC screening and explore challenges and facilitators of CRC screening among SA immigrants in NYC using qualitative analysis, and discuss implications for achieving population health equity in CRC screening.

Methods

Data for this study comes from 51 in-depth interviews and surveys conducted with Asian Indian, Pakistani, Bangladeshi, and Nepali immigrants between 50 and 75 years of age who reside in the metropolitan NYC area and who had never been diagnosed with CRC between 2014 and 2015. A multi-pronged recruitment strategy was implemented across a coalition of partners of social service agencies, including a number of community- and faith-based locations serving largely SA immigrant communities around NYC using a modified snowball sampling technique. Specifically, bi-lingual outreach staff distributed recruitment brochures regarding the study and conducted in-person recruitment at events. A screening intake form was completed with participants during the recruitment process to assess eligibility. Participants were selected to ensure that there was a range in demographic characteristics (including gender and SA ethnicity), family history of cancer, and past receipt of CRC screening among sample participants. Interviews were conducted in the participant's preferred language (e.g., Urdu, Bengali, Hindi) by a trained bilingual, bicultural community health worker or graduate student intern, and lasted approximately 90 min; participants also completed a brief quantitative survey prior to engaging in the in-depth interview which assessed demographic characteristics and past receipt of CRC screening. Each interview was conducted in a private setting, chosen by the participant. The majority were conducted in the

office spaces of social service agencies, however a small number were conducted within the homes or worksite locations of participants (including 5 home visits and one work place). Informed consent was obtained from all individual participants included in the study, and participants were offered a $40 honorarium for their time. Data collection was approved as an expedited study by the NYU Langone Health IRB.

An interview guide was developed to gather key contextual information on participants' knowledge, attitudes, and behaviors related to CRC screening, potential strategies for increasing screening in the population, and content and venues for programing and messaging. All interviews were translated and transcribed into English by bi-lingual staff. A codebook was developed that used the interview topic guide as an initial outline for primary codes, and using an iterative process, secondary and tertiary codes were developed throughout the analysis process. Members of the research team collaboratively drafted definitions for the various cores and these definitions were also reviewed by project investigators. Four coders, advanced graduate students/members of the research team, coded the transcripts of the in-depth interviews for themes related to challenges and facilitators of CRC screening. Three independent coders reviewed five randomly selected coded transcripts each for consistency in coding. Discrepancies in coding were addressed via consensus building discussions. Analysis of the coded in-depth interviews followed techniques of narrative analysis [19, 20] and the "constant comparison" analytic approach [21], and utilized ATLAS.ti, a software package for qualitative data analysis [22].

Results

Sample characteristics

Table 1 presents information about the sample of 51 SA immigrants from the quantitative survey. In general, the socioeconomic status of the sample was low as about half of the sample had an annual household income less than $20,000 (45%), and 39% had less than a high school education. In terms of CRC screening, most of the sample had never received any CRC screening tests; only 39% of the sample had received a colonoscopy, and 35% reported ever receiving a fecal occult blood test.

Our narrative analysis of the qualitative interviews yielded a rich description of the complex and contextual factors that influence CRC screening among older SA immigrants. Two overarching themes related to these influences emerged from the interviews, namely the role of (1) socio-cultural factors and (2) structural factors. Socio-cultural challenges to screening included, unfamiliarity with the screening test and process which resulted in themes around embarrassment or shame about CRC screening, and overall lack of knowledge about CRC and CRC screening. In addition, fatalism or the role of religion on a cancer diagnosis, and fear of a cancer diagnosis were often mentioned as initial or potential deterrents that were mitigated if structural barriers to screening were addressed. Structural challenges to CRC screening included lack of in-language or translated information or resources, and costs related to screening. Physician referral or recommendation, however, trumped the reported challenges and overall emerged as a key facilitator to CRC screening. The major factors are highlighted below with illustrative quotations drawn from qualitative interviews.

Challenges to colorectal cancer screening

Participants discussed a number of common and unique challenges faced by SA men and women to obtaining colorectal cancer screening. These various challenges fell into two broad categories: socio-cultural factors and structural factors.

In terms of socio-cultural factors, the most frequently cited challenge to CRC screening was a lack of information and knowledge on CRC, and unfamiliarity with the screening test procedure. “From my opinion, people don’t have any idea about colon cancer. They don’t know what they should do or not. They usually say no to the tests without exactly knowing what they are for,” (ID22: male, 63, unscreened). Further, many participants felt they did not need the test because they were “in good health” (ID30: male, 59, unscreened), and did not have any symptoms that would suggest CRC. “I’m a very healthy person, why would I do it?” (ID19: male, 55, screened). This appeared to be unique to CRC; the lack of familiarity with CRC compared to other cancer screening tests (e.g. mammograms) is highlighted by the following quote: “I think I’m okay, my food habits are okay, I don’t have any symptoms, I don’t have bleeding, nothing happens, I have no pain in the rectum. I don’t have anything. That’s why I think I shouldn’t do it. But for breast cancer, I think you have to do it, and every year I get a mammogram done.” (ID16: female, 66, unscreened).

Within this category of lack of knowledge about CRC and CRC screening, emerged several sub-themes related to socio-cultural factors. Almost half of the participants reported there was shame/discomfort and embarrassment associated with CRC and CRC screening in their community. As one participant noted when asked what made it difficult for people to get a colon cancer screening, “...it’s because they take off the pants and underwear so people get shy. First they check by finger, then insert tube, people get bothered that what kind of problem is that, then they don’t go for it.” (ID011: male, 74, screened). Further, participants noted CRC and screening tests associated with it were “shameful” (ID22: male, 63, unscreened). For instance, when asked what caused CRC, they responded “May be dirty things, dirty people…may not be clean back…” (ID41: male, 61, screened). Similarly, another participant stated, “A lot of people feel ashamed, for this reason they don’t do it.” (ID16: female 66, unscreened). A challenge specific to colonoscopy reported by 22% of the participants was the discomfort related to the preparation required to undergo the screening test and colonoscopy process itself, which participated noted was a “hassle” (ID16: female, 66, unscreened). “The process is very difficult. The reason is that is because the person has to fast for 36 hours, and their stomachs has to be completely empty, other than drinks, they cannot consume anything…because of these complicated processes, it’s a matter of someone’s time…because of this amount of time, people don’t want to give their time.” (ID27: male, 58, screened).

These feelings of embarrassment and shame were often coupled with fear of what the test would reveal about their health. Of the 25 participants who noted embarrassment and shame as challenges to CRC screening, 18 also noted fear of the test. For instance, when asked why their community members do not receive CRC screenings, one participant noted, “They are afraid, and also ashamed, both reasons.” (ID09: female, 65, screened). Participants stated they were afraid to get a diagnosis of cancer, and did not want to “hear they have a problem.” (ID033: female, 52, screened). Participants were fearful of the impact a diagnosis

would have on their individual health, but also the impact it would have on their family. Cancer in general was not discussed in the community, and if someone was diagnosed with cancer, they did not want to share information about their diagnosis because “the gossip just happens.” (ID33: female, 52, screened). As one participant noted, “I saw it in a lot of people, this thing, hiding it [cancer diagnosis].” (ID25: female, 58, screened).

Several participants also reported feelings of fatalism or the role of religion associated with failure to get CRC screening, which was cited by 37% of participants. Many participants initially stated they did not need to get screened because they had no control over whether they got cancer and/or when they were going to die. As one participant noted, “If it’s God’s will that someone is to die then has to die. Right? That time is set…” (ID39: female, 61, screened). On the other hand, participants did not consistently express fatalistic views and expressed the ability to prevent cancer through behavior change. As one participant stated, “It’s this. We need to abstain from different foods. Smoking, drinking, or whatever are they called. Sleepless, eating habit, not to eat everything. Such as not to eat a lot (sic) of chili peppers. If you control the things like these, we may prevent cancer, I think.” (ID49: male, 66, unscreened).

Structural factors included financial challenges and a lack of in-language or translated information and resources to facilitate CRC screening. Twenty-seven percent of the participants reported cost of care and lack of insurance as a reason why their community members were not getting screened: “Money is the biggest barrier, without money, no treatment is possible. Those who have insurance, they are the ones who do it, those who don’t have it, without money, they can’t.” (ID23: male, 73, screened). Some participants also noted language, mostly due to low levels of English proficiency among SAs, as a challenge to CRC screening. “For some people, there is language problem. They become little shy in going, because they think how would they speak to doctor?” (ID13: female, 58, screened). Participants, however, were generally able to receive care from a provider who spoke their language. Similarly, participants noted that they preferred to receive care from a provider of the same gender, but did not report this as a challenge as they were generally able to find a gender-concordant health provider or were comfortable seeking care from a doctor of the opposite sex.

Strategies for facilitating CRC screening

The narrative analysis revealed the most significant facilitator to CRC screening was a physician referral. Over half of the participants (65%) noted similar comments as this participant. “If the doctor said, I would get it (CRC screening) done.” (ID01: male, 73, screened). “I really feel that the doctor understands best whether you need this test, if you are going from the start to the doctor.” (ID008: female, 57, screened). “See, I would say doctor is the good source. When people go to the doctor and people have insurance here, and if doctor tells them that you are more than 50 years of age and you should go for it, I think that will be more useful, people will give that more weight., Instead of you or I tell them that.” (ID14: male, 64, unscreened).

In fact, the lack of physician referral was a barrier cited by many participants. When asked why they did not get a CRC screening, one participant responded, “I didn’t do it because

the doctors never told me to…" (ID36: female, 55, screened). Another participant was asked what could be done to prevent colon cancer and he responded: "I don't know this, the doctor hasn't given a suggestion and I also don't know." (ID 28, male 60, unscreened). In some cases, a physician recommendation was often tempered by a lack of familiarity with the test and thus a fear associated with lack of knowledge of the test and outcomes related to CRC. "Doctor keeps telling me to do colonoscopy I don't do it I say… I am scared.." (ID06: female, 65, screened). "It should be explained to them like it's not something to be fear of, it could be treated well…" (ID13: female, 58, screened). For most however, fatalism appeared as an initial barrier that could be overcome by a physician recommendation. In response to a question regarding cancer prevention, a participant noted, "I don't know this, I won't be able to say if anything can control it. That Allah himself knows. All the cancers, all the things, he's the one in charge.... Whatever things that can be done to prevent, there might be something, but the doctor knows better." (ID 33: female, 52, screened).

When asked about strategies or programs to overcome challenges to get a CRC screening, participants thought their communities needed more culturally- and linguistically-adapted education and encouraged opportunities for more open dialogue and discussion in the community. "Some don't understand too, we are Gujarati with little English…They talk about such things amongst own relations/family. It's not right to talk about this outside home." (ID06: female 65, screened). "Yeah, it should be talked with others; it's not something to be ashamed of. If we tell others about it, they could take the precautions; they can go to the doctors. Rest, telling others is not shameful. It's not something to hide…. For some people, there is language problem. They become little shy in going, because they think they don't know English…" (ID 13: female, 58, screened).

For health education materials and campaigns to be impactful, many participants cited the need for the materials to be disseminated in-language and in community sites such as faith-based organizations, community centers, and ethnic grocery stores. "Well, normally they're in English, but if you really want to help people and raise their awareness, they should be in the home language of the people in the area. Like here, they should in Punjabi, and if the posters/pamphlets are posted in an area where mostly Gujarati live, then they should be in Gujarati." (ID44: male, 56, screened). "Grocery stores are good as many people visit it and can read it and then we can place it in temples too... If in Guajarati it would be better as most of the people will understand." (ID05: female, 52, screened). "If they have the language, it's very good. Most of the people from where I am from, Bangladeshis, there's a lot of people who don't know English, so they can't understand. So if it's Bengali, or the language, then they can clearly understand the language… You can put it in mosques, grocery stores, in senior centers, like these…. The best, well nowadays everyone comes to mosques and senior centers, it depends because, if its older people then for them the mosque and senior center is the right place." (ID 16: female, 66, unscreened). "If they write it in Bangla, we are mostly Bangladeshis, if you write it in Bangla, we will be able to understand everything," (ID 25: female, 58, screened). "It should state that whatever language is spoken by the onlooker, that language is available…Language is most important," (ID08: female, 57, screened). "Language, if you want to conduct in our community, mostly there would be older men and women, so it would better if you do in our language, because if you explain

in our language, they would understand better. Rest, like there posters are mostly in English and most people don't even know English." (ID 11: male, 74, screened).

Many participants also preferred family and friends as a source of instrumental and social support, and vehicle for dissemination and enhanced uptake of CRC screening. "I asked a friend, and the friend advised me that it was good to do this, so I felt more assured. Then I went and did it (colonoscopy)." (ID27: male, 58, screened). By providing education on the topic and being able to speak about it with family and friends, one participant noted others would feel like CRC and CRC screening is "not shameful. It's not something to hide." (ID13: female, 58, screened).

Discussion

Our qualitative study results are aligned with findings from the NYC Department of Health and Mental Hygiene's Community Health Survey [13,14]. The lower rates of CRC screening seen among SAs in this population do not reflect general population trends across the US, which demonstrate increases in CRC screening across most racial/ethnic groups. Targeted and tailored efforts to promote screening have been credited with the general increase in CRC screening [23]. For instance, the C5 program carried out screening campaigns targeted to black and Hispanic New Yorkers and saw dramatic increases in screening in these populations. The elimination of disparities, however, was not seen among the Asian American population.[3]

The qualitative data suggest structural challenges, such as poor access to healthcare, language barriers, as well as cultural and social norms, influence CRC screening disparities among SA immigrants. There are very low levels of knowledge and familiarity with CRC, CRC screening, and the CRC screening process among this population, which may manifest as embarrassment and shame associated with CRC screening. This is exacerbated by the lack of culturally relevant and translated education materials and campaigns, which was identified as a key challenge to addressing the low levels of knowledge. Recommendations from physicians and opportunities for open dialogue and communication from families, friends and community networks were reported to be important sources of trust and information [24]. Similar results have been noted in studies of SA populations across the US. For example, a study of SAs in California found that barriers to screening included low levels of information on CRC screening, stigma and fatalism, and lack of health insurance. This study also noted the strong role of physicians to promote CRC screening and the need for culturally and linguistically adapted services and information [25]. Another study of SA immigrants in Chicago, IL identified perceived risk, income, and level of acculturation as predictors for endoscopy screening [16].

Many of these challenges have also been noted in other racial/ethnic populations and settings. For example, a recent study of CRC screening within the Hispanic population in El Paso, Texas, found that barriers included "cost, fear, and embarrassment," while facilitators included "in-person health education and physician recommendation." [26]. A focus group study of Somali immigrant men in Minnesota reported similar themes, the most prominent being lack of knowledge [27]. Additional themes included emotional barriers, such as fear

and suspicion; acculturation, in that more recent immigrants appeared to be less engaged with their physicians; accountability of physicians to relay information; and fatalism. This study noted that Somali men with limited English proficiency had much lower rates of CRC screening and the authors concluded by recommending the use of patient navigators and community health workers to lessen the disparity [27]. In contrast a 2018 paper on CRC screening among AAs who were members of the Kaiser Permanente health plan in California reported similar screening rates between AAs and non-Hispanic whites and across Asian subgroups [28]. The authors suggest these results may reflect the general higher level of acculturation among the Asian population utilizing this health plan, and the benefits of "integrated and organized" screening and the use of language tailored outreach materials and interpreters [28]. Overall, the results from existing studies suggest the importance of CRC recommendation, an integrated approach or navigation to accessing screening, and the need for culturally and linguistically tailored materials to achieve recommended CRC screening rates. Our study results reiterate the need for these types of strategies to address the disparities SAs in NYC are facing in regards to CRC screening.

Our study has a number of limitations which should be noted. First, data are based on self-reported behavior, which may overestimate screening uptake [29]. Second, generalizability may be limited due to the focus on SA immigrants in NYC, which may be a unique setting compared to other areas in the US. Similarly, the SA immigrant sample included in this study may not be representative of the general SA population in NYC or the US as our sample is representative of low-income, limited English proficient SAs. Finally, although efforts were made to ensure data saturation in our qualitative sample, the study results may be limited by the sample size. Nonetheless, the study makes a unique and important contribution to the public health literature through a qualitative exploration of challenges and facilitators to CRC screening among a diverse SA sample who are often under-represented in research.

Our study findings also support the growing literature that posits a fundamental shift in public health approach is necessary to enhance health equity at the population health level. Despite aggressive city-wide efforts, our analysis reveals that South Asians – one of the fastest growing immigrant populations in NYC – have not benefitted equally from campaigns to increase colorectal cancer screening. The use of the qualitative data provides contextual reasons for why this disparity exists and how it can be remedied. Our findings support the development of targeted, linguistically and culturally adapted campaigns for this population that facilitate integrated access to health systems and leverages natural community assets and social support systems. Indeed, similar programs have demonstrated a significant impact in improving CRC health disparities for other vulnerable populations [30].

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Table 1.

Demographic characteristics of qualitative sample of foreign-born South Asian adults 50–75 years, New York City 2014–2015 (n=51)

Gender	**N (%)**
Female	27 (52.9)
Male	24 (47.1)
Age	
50–59 years	17 (33.3)
60–69 years	20 (39.2)
70–75 years	14 (27.5)
Ethnicity	
Indian	14 (27.5)
Pakistani	16 (31.4)
Bangladeshi	17 (33.3)
Nepali	4 (7.8)
Education	
Elementary school (1–8) or less	20 (39.2)
Some high school (9–11)/high school graduate (12/GED)	14 (27.5)
Some college (1y-3yrs)/college graduate (4 years or more)	16 (31.4)
Missing	1 (1.96)
Household annual income	
<$20,000	23 (45.1)
≥$20,000	11 (21.6)
Do not know	17 (33.3)
General health	
Excellent/ very good/ good	29 (56.9)
Fair/ poor	21 (41.2)
Missing	1 (1.96)
Type of insurance	
Insured	44 (86.3)
Uninsured	5 (9.8)
Do not know	2 (3.9)
Colorectal cancer screening (ever)	
FOBT	18 (35.3)
Colonoscopy	20 (39.2)
Barium enema	14 (27.5)