Health Information Seeking and Technology Use in Harlem – a Pilot Study using Community-Based Participatory Research

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INTRODUCTION

Harlem is a well-known community with rich historical and cultural significance but also serious longstanding health and economic disparities. The Harlem Health Promotion Center is one of 33 Prevention Research Centers funded by the CDC. It is trusted in the community, has conducted research on health in Harlem for 10+ years, and was founded by McCord as a result of his now-famous 1990 study showing that a black man in Harlem had a lower life expectancy than a man in Bangladesh.[1] While average longevity in Harlem has increased, this statistic is still true[11].

The aim of this study is to do formative research to assess current health concerns and technology access, use, and attitudes in Harlem with a view toward creating a community health information and support website portal or other health and technology interventions aimed at improving the health of Harlem residents. The study is part of a CDC-funded Core grant. As mandated for all prevention research centers, it uses the method of community-based participatory research to ensure accuracy and accountability to the community in the direction and development of any interventions.

Community-based participatory research (CBPR)

This is a recently developed approach to health research that involves researchers and communities as equal and collaborative partners in research. In this approach, community-based organizations are important in the design and conduct of studies. They help involve community members as partners rather than as mere research subjects, use the community's knowledge to help develop interventions, and inform community members about how research is done and what its results are. Importantly, it is expected that research results provide immediate benefits to the community, rather than merely being published[2].

In CBPR, community members are also involved in getting the word out about the research and promoting the use of the research findings. This involvement can help improve the quality of life and health care in the community by putting new knowledge in the hands of those who need to make changes."[3]

Advantages of CBPR include increased validity, relevance and use of research results, decreased suspicion of community members who may have historically been only 'subjects' of research, ability to take advantage of local knowledge which may be important in ensuring success of interventions, better resource use, and bridging cultural gaps.[4] In the case of technology development, it may have the additional advantage of reducing development time and ensuring greater responsiveness to user needs, as concerns and factors unexpected by the development team (including answering the question of whether or not technological solutions are even appropriate), can be elicited before development begins. In addition, the creativity and varying perspectives of the participants contribute to the final design.

In this case the focus group study was also intended to inform the creation and specific wording of questions of a random-digit-dialed telephone survey of Harlem, that supplemented the focus groups with quantitative data on technology access, use and desired future developments by Harlem residents.

METHODOLOGY

Community board members and experts in the field of community-based participatory research and surveying were consulted as to the design and possible questions for focus groups. Six categories of participant were recruited, through flyers posted at local stores, churches, libraries, community groups, and street recruitment. Two groups were held for each category. The categories were:

English-Speaking: 1. Adolescent Internet users,
2. Adult Internet users, 3. Adult Internet non-users
Spanish-Speaking:1. Adolescent Internet users,
2. Adult Internet users, 3. Adult Internet non-users

There was no group for adolescent non-users as the vast majority of teens have Internet access and training at school [5]. This paper focuses on two of the groups, the English-speaking adult and adolescent Internet users, with demographics:

English-speaking adolescent users: n=11, (including 5 males, 6 females, 10 African-Americans, 1 Native American, 2 aged >18, 9 aged 15-18, 5 were in school currently; all but one (a GED graduate) gave 0-11 as highest grade of school completed).

English-speaking adult users: n=10, (including 8 females, 2 males, 8 African-Americans, 2 Hispanic, 1 aged 25-34, 5 aged 35-44, 2 aged 45-54, and 1 aged 55-64. One had completed graduate school, one college, four had completed some college, and the rest were high school graduates. A later random-digit dialed telephone survey of 800 Harlem residents was carried out and will be reported on in future.

Groups were held at convenient times either at the HHPC offices or at other venues, typically community organization meeting spaces, and were timed to take 2 hours including introductions, food, and distribution of the movie tickets which were offered as an incentive. The interview guide[6] was first pilot tested on other Harlem residents among the staff or affiliated community associations, to establish question vocabulary, topics likely to be main concerns, and further probes. Questions were focused along two axes: 1) perception of health problems and health information seeking behavior in Harlem, and 2) technology access and use in Harlem. Final questions included showing participants pictures of various technology devices (e.g. desktops, notebooks, PDAs, gaming devices, cell phones) and asking them to identify the device, state its purpose, state how many Harlem residents (out of 10) they believe own or use one, what kind of people use the device, and so on.

Discussion was moderated by trained facilitators who are also Harlem residents, then recorded and transcribed. Facilitators reviewed the transcripts for accuracy and completeness, and researchers discussed the session immediately afterward to clarify any issues. Atlas TI software was used to code the transcripts, with a coding schema developed based on emergent properties of the discourse (i.e. ground-up development) which was discussed and refined among a group of 4 researchers/coders. Because a major purpose of the project is to inform technology development, double coding for health and technology features, source credibility, and similar themes was done.

RESULTS
Participants generally showed great interest in the topics of the groups and in at least one case discussion went overtime.

Emergent Themes
As expected, emergent themes followed the lines of the general questions. These will be discussed under the following headings: main health concerns and perceived determinants of health, health information sources and barriers, technology familiarity, access and use, and desired interventions.

Main health concern(s) and perceived determinants of health
Adolescents almost unanimously stated AIDS and related problems (harassment, ignorance, 'nastiness') as the main health concern in Harlem, and attributed this to a variety of social, environmental, and informational factors. These included lack of detailed, comprehensible and accurate information accessible to teens about HIV spread and prevention, lack of family communication, lack of disclosure about sexual orientation, street harassment of girls by boys and the attendant psychological stress, date rape, etc. Another factor was 'nastiness' on the part of peers, i.e. persons deliberately engaging in risky behavior which might spread the virus. Several teens described the social environment as less friendly than in their parents' generation. Adolescents suggested interventions at parties (where risky sexual and substance abuse behavior takes place).

Adults described a wider range of health concerns, including lack of affordable and accessible providers and insurance, asthma, diabetes, obesity and cardiovascular disease, hepatitis, substance abuse, and STDs. Among determinants of health, diet was mentioned by a majority of adult participants, and attributed to the difficulty of obtaining appropriate foods and diet information conveniently and affordably, and business practices which make doing so difficult (such as displaying low-quality foods prominently at lower prices in stores, or selling food with excess sodium or other additives). Environmental factors such as toxic waste dumps and the presence of several bus depots in Harlem were mentioned as contributing to the high incidence of asthma[7]. Physical access was also described as a problem: one participant said

"if I'm in the neighborhood and stop by for a visit …my perception is that the people inside the building have as their objective to frustrate me or to turn me away versus helping me to connect with that person or department or unit inside. The gatekeeper, with the gate shut and locked versus the gatekeeper with keys to open the door to get me in contact. And that's pan ethnic, red, yellow, black, white, brown."

Common to both these attributions is an emergent theme we have called 'hermeneutic of suspicion' (from the theological term).[8] Both adolescents and adults expressed suspicion of the motives and practices of government and industry. One woman said, "a lot of time FDA and the food companies work hand in hand so the FDA the Food and Drug Administration is supposed to be the watch dog to protect you to make sure you get good stuff in the market…But if they are working hand in hand all these things are hidden crap…that makes you sick that is snuck in there".

Another said,

"I think one of the keys is that there is money involved. It is all about greed".

A different participant elaborated,

"Then that leads me to conclude that there is just a lot of general information that we are not getting. There seems to be a mainstream level of information which gives you stuff to lead you into drugs different things like that…there is like a whole stream of other viable alternatives that could work but you don't even hear about because it will blow all the mainstream drugs out…").

Another man said,

.."those of us who are African-Americans are still grappling with the Tuskegee studies and the aftermath. So there are a lot of historical monsters with which we identify, when it comes to medical community treatment and medical residents here to, specifically to us."

Health information sources
Participants described a lack of information as one of the major causes of health difficulties, but also described multiple strategies and motivations they used to find health information.

Adolescents
Adolescents described school and related programs, family members, television, and the 'street' as primary sources of information on AIDS. However doctors, clinics and hospitals were preferred sources of information due to their credibility and ability to provide immediate treatment and prevention. They also described the Internet as a variably credible source of information, (rating it as between 25% and 70% credible depending on topic) and mentioned specific sites and search strategies they would use. Major motivations for health information seeking

among adolescents included desire to protect oneself from STDs, 'because people are nasty,' as well as to aid family members with a health problem. Other motivations included media reports, and required health classes. Specific desired features of Internet health information included diagnostic criteria, graphics or photos, and information on prevention, treatment, and side effects.

Youth exhibited an attitude of self-efficacy with regard to searching for health information and the skill of Internet use in general. One teen said,

"It's just plain easy for our generation because we are computer savvy, so all we have to do is just type in key words and we are good. Like, the old timers are not kinda, they understand or don't like know how to use the Internet properly, so they kinda get it wrong easily, but I think our generation we just know what to do and automatically come up with answers, even if they are not what we want, we still come up with some kind of result."

Folk or alternative medicine, home remedies handed down through the family, and mothers' care, were favorably mentioned by several adolescent participants as the first-choice measure, followed by provider contact, and Internet searching. The ability of Internet searching to provide different points of view, including information on alternative treatments, was mentioned as an advantage by several participants.

Barriers to online searching for health information included the use of medical vocabulary, literacy level, frustration at difficult navigation, and inability to find relevant information. Adolescents also displayed persistence in the face of these: "and even it was a little difficult, I could figure it out …Dictionary dot com".

Adults
Adults' motivations for health information seeking were similar to adolescents' but more broadly focused on a range of health problems which they or acquaintances experienced (e.g. stress, thyroid, prostate, fibroids, ulcers, bird flu, bronchitis, meningitis). Sources of health information included professionals and/or relatives who are health professionals, acquaintances, health fairs, libraries, hospitals, and the Internet. Two adult users said they would not use the Internet for searching for health information, stating their belief that it would take too much time compared to seeing a provider, or that they simply had a preference for books. Internet search strategies included using URLS from radio

programs, just typing a disease name, (e.g. asthma.com), visiting news sites, using search engines with keywords, progressive searches ("you always start on an easy level and then you progress yourself into another areas where there is more information").

Barriers to searching included inconsistent Internet access (e.g. dial-up access which was too slow or unreliable to make searching worthwhile, or long wait times at library facilities). Lack of immediate relevance was also a factor (several users said they would not use an advertised URL unless it pertained to an immediate health problem). Lack of Internet access at home was considered a particularly common and frustrating barrier.

Desired Interventions
Many participants expressed ideas for interventions, both technological and organizational, to improve health in Harlem. Using the Internet for social and/or activist organization to improve conditions, inform community members about events, and provide health information were the most common. Teens stated that this must be paired with other attractions, such as famous people conveying the message, or music availability and 'cool design'.

Technology Access, Familiarity and Use
Participants were able to identify all the devices shown in the technology part of the focus group and knew their general uses. Estimates of at-home computer availability ranged from 5 to 6 out of 10. PDAs were felt to be the least-used by Harlem residents, with an estimate of 1 out of 10. They were perceived to be only for 'important people' or wealthier people from other neighborhoods. Cell phones and handheld game devices were perceived as much more common; participants estimated that 6 to 9 out of 10 Harlem residents own one. Broadband Internet access was felt to be important but not necessarily widespread.
Participants were generally open to using some devices, such as cell phones, to transmit or receive health information (particularly to and from their doctors) provided privacy and security issues were adequately handled. Cost and unpredictability of charges for Internet and cell phone service were sometimes mentioned as a significant barrier to consistent availability. Cost of computers was also sometimes misperceived as higher than current actual prices; this was sometimes declared a barrier to computer ownership. Older people (described by one participant as 'those over 60') were perceived as being more afraid and less knowledgeable about computing in general.

The idea of an Internet portal specifically geared to Harlem health needs was met with enthusiasm and suggestions for topics and features to be included, as part of a general Harlem-oriented site. These extended to other community services, such as assistance with housing, jobs, event calendars, coordination of efforts to change unhealthy aspects of the environment, and tailored health information.

DISCUSSION
The focus group participants were all Internet users, many of whom had been using the Internet for a variety of purposes for years, though a few had not used it to search for health information. Differences between adolescents and adults were related primarily to topics of interest. All expressed some degree of technology and health self-efficacy, describing how they would tackle problems of access to either Internet resources or healthcare providers.

Implications for technology development.
It is clear from our findings that use of Internet and other technologies holds promise for improving health in Harlem, but that this must be implemented in such a way as to address some very specific problems, which range from large scale societal issues to addressing individual user abilities and interfaces.

The cost of access (to computers, Internet, other devices) is a significant problem to be solved. Lack of consistent at-home access means that either measures to improve access must be undertaken as part of the project (for example, by cooperative computer purchasing initiatives, increasing library access, and better advertisement of existing services), or that delivery of information on devices people already have and find affordable, such as cell phones and game devices, is more likely to be successful. Measures now being discussed, such as neighborhood or city-wide wireless Internet access (as is happening in Philadelphia and Washington, DC[9]) may present partial solutions to some of these problems. This has important implications for health promotion advocates and community members.

It is also apparent that for individuals to have knowledge about health problems is not enough. Simultaneous delivery of health information in conjunction with methods of delivering care itself is seen as having particular value, suggesting a need for more sophisticated information delivery at clinics, or e.g. Internet sites which permit online drug purchase when the need for them is established.

All participants recognized the significance of lifestyle, psychological and social factors in overall health and chronic disease, and many had made personal efforts to improve these, seeking serious practical solutions to the practical problems of diet, nutrition, exercise, and stress. While technology can assist (for example by facilitating food access, coordinating exercise clubs, chronic disease management, service delivery, and support groups), this must be done using a literacy level and interfaces which permit progressive learning about health and technology as well as user engagement to address the extremely varied levels of user ability and interest. Preliminary examination of the non-user focus group results reveals that literacy level and interface design which make the would-be user feel 'confused' or overwhelmed are significant reasons why they do not use technology to find health information.

The emergent 'hermeneutic of suspicion' theme has several implications for health and technology improvement. Participants were acutely aware that serious health concerns are often related to the larger societal structures which are not controlled by community members, such as the placement of bus depots in the neighborhood, policies relating to building access, prices and food access, access to parks, the practices of drug manufacturers, and so on. Solutions must take into account the community's historical suspicion of researchers, government, and like structures. Interventions must be convincing and ideally permit control by the community as well as community organizing to address the larger society. At the same time, this awareness can be a motivation for health behavior change: it was successfully exploited in the federally-funded anti-tobacco Truth Campaign,[10] which used television and Internet ads which encouraged youth to question the motives and claims of tobacco advertising. It can also lead to more rigorous health information seeking and evaluation.

One advantage of CBPR is that it broadens the horizons of the academic researchers and brings to light factors which might not have been considered by them alone. Examples of this in our study include the significance of street harassment for girls' health, the belief that some youth may in fact be well-informed about AIDS but engage in risky behavior deliberately, and the priority given to alternative or home therapies for the cure of minor problems.

CONCLUSION

Harlem is a unique community with many similarities to underserved populations elsewhere, and has both great needs and great possibilities for health improvement. The CBPR approach has provided valuable insight into specific problems and preferences which will inform the development of health technology interventions, as will supplemental quantitative data collected in the telephone survey. Some focus group respondents indicated keen interest in continuing to assist with resource development; continuation with a small group which meets regularly will be part of our development process. As lack of convenient access to providers and Internet are two of the most important themes in this work, projects to map healthcare and technology resources in Harlem to facilitate access have also been completed.

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