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BRIEF COMMUNICATION

A Pilot Study of Health Priorities of Somalis Living in Kansas City: Laying the Groundwork for CBPR

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Abstract African immigrant and refugee communities remain medically underserved in the United States. Formative efforts are being directed to address the local needs of communities by researchers, community agencies, and local populations. However, there is a paucity of data and sparse documentation regarding these efforts. The objectives for this pilot study were to identify the health priorities of the Kansas City Somali community and to establish a working relationship between an academic medical university and the local Somali community. Our team used community-based participatory research principles and interviewed Somali community members (n = 11). Participants stated that chronic and mental health conditions were of primary concern. Medical system navigation and literacy struggles were identified as barriers. Participants offered possible solutions to some health issues, e.g., using community health workers and Qur'anic readers. Preliminary findings will help guide future research and inform strategies to improve the health and well-being of this community.

Keywords Community-based participatory research · Formative research · Healthcare disparities · Refugee health · Somalis

Background

The Somali community has been in Kansas City for over 20 years, yet there is little information about the demographics, health needs, health care access and utilization, and the barriers to care faced by this underserved population. Lack of evidence about this growing population has impeded the abilities of researchers and community organizations to determine appropriate health interventions [1–3]. While it is reasonable to assume that the Kansas City

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Somali population (including the Somali Bantu) has similar disparities as other refugee or immigrant populations, some experiences and cultural practices are particular to this population.

There is no national, standardized database for African immigrant and refugee health. The majority of health literature concerning African immigrants has focused on infectious diseases, while little research has been conducted on chronic diseases [4–7]. For African refugees, the majority of research concerns infectious diseases and mental health. For Somalis settling in and outside of the United States (US), the majority of health studies have focused on mental health [8–24], female circumcision [25–30], and obstetrics [31–34]. Few community-based participatory research (CBPR) studies have been conducted with Somali communities, and most are in formative stages [35–37].

Somalia's civil war began in 1991 and Somalis have been coming to the US as refugees ever since. Somali refugees have sought asylum all over the world, most commonly in Kenya, Yemen, United Kingdom, US, and Ethiopia [38]. Worldwide, the estimated number of Somali refugees ranges from 700,000 to 770,000 [39, 40]. The number of Somalis who came to the US as refugees between 1996 and 2005 totaled over 280,000. In 2005, the number of Somalis admitted into the US was over 36,000 [38]. The number of Somali refugees admitted to the US has decreased, but due to recent sociopolitical situations in Somalia, refugees and asylum seekers are still being admitted to the US. Like other refugee groups, Somalis congregate in cities for a variety of reasons. Some cities host tens of thousands of individuals like Minneapolis-St. Paul, Minnesota, Columbus, Ohio, San Diego, California, and Atlanta, Georgia, while other cities may account for a few hundred individuals, such as Owatonna, Minnesota and Barron, Wisconsin [41]. Currently, the Kansas City metropolitan area hosts approximately 5,500 Somalis.

To address health in a meaningful, constructive way, our research team conducted this pilot study to identify the health priorities in the Kansas City Somali community. We believed the best way to accomplish this objective was to use a CBPR approach [42]. CBPR is defined as "a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision making and ownership"[42]. Meaning a partnership exists between researchers and the community, where all features of the research process (study design, data collection, data analysis and dissemination) are shared, including decision making and data ownership. Because we did not yet have a relationship with the community as a group, our second objective was to create a working relationship between the Somali community and the University of Kansas Medical Center (KUMC) in order to establish a CBPR team. The lead author has been working with the Somali community in Kansas City for 7 years and we wanted to build on this relationship. Future CBPR studies will be used to collaboratively strengthen it.

Methods

To better understand the health needs of the local Somali population, with the help of the Somali Foundation, Inc., we recruited 11 individuals through word-of-mouth and conducted semi-structured interviews with them (5 men and 6 women aged 22–71). These volunteers included a variety of people: community leaders, health professionals and students, interpreters, and health care recipients. Interviews were conducted by the lead author in English and native languages (Somali and Baraawe) with the help of a trained interpreter. Informed consent was administered orally because community members were more comfortable with oral rather than written consent. Study protocols were approved by the KUMC's Institutional Review Board and the Somali Foundation, Inc.

Interview questions were based on research aims (see Table 1). Interviews took place at the Somali Foundation, the Somali Bantu Community Association's *dugsi* (Islamic education) classroom, workplaces, and homes. No incentives were offered. Participants answered a short demographic survey (see Table 2). Interviews lasted between 30 and 60 min and were audio-taped and transcribed verbatim (with the exception of one interviewee who did not want to be recorded). Meticulous notes were taken and typed immediately after the interview. All transcripts were coded inductively by hand by the lead author, a trained anthropologist who has conducted qualitative studies for 12 years. Based on the interview guide and initial reading of the transcripts, topic areas and codes were identified, then re-evaluated after more transcripts were read. Standard text analysis was used to identify themes.

Results

Objective 1: To Identify the Health Priorities in the Kansas City Somali Community

We conducted 11 interviews. The 11 interviewees were from various regions in Somalia: rural, urban, inland regions, and coastal areas. These various environments relate to the diverse language and educational experiences the participants possessed. Our analysis of interview data revealed nine discrete themes around areas of health

Table 1 Sample questions

1. What are the health issues in your community? For men? For women? For children? Elders?
2. Under what circumstances do people go to the hospital?
3. How do Somalis access health information?
4. Describe a healthy Somali.
5. Where do people go for health problems?
6. Name anything you can think of that might make it more difficult for someone to access health care.
7. Do you think any of these problems are more common for Somalis? Is there any one thing that stands out as the biggest problem for Somalis? Why?

concern, barriers to access, and suggestions to improve well-being.

Health Concerns

Participants reported that diabetes, high blood pressure, and high cholesterol are health problems that need to be addressed. Overwhelmingly, diabetes was indicated as a health issue more than any other ailment. Participants indicated that before coming to the US, they had no experience with or had even heard of diabetes, but now it seems to affect everyone: men, women, and children. Participants offered reasons why. Most indicated it was due to a change of diet because in Somalia most people consumed fresh meats, fruits, and vegetables. A dietary transition has occurred since coming to the US and now people tend to eat more carbohydrates and saturated fats. Others talked about lack of exercise. Before coming to the US, people walked everywhere; now, people drive or find rides and do not go outside and move like they did before.

Following directions to administer medications properly was a concern. Interviewees indicated that people do not necessarily understand why it is important to follow specific directions and, as a result, do not do so. One participant who works in the health field stated, "They need somebody to come home and show them, it's more than, this is my morning (pill), this is night, this is noon, this is afternoon, this is dinner, this is breakfast. They don't know." Others stated the problem was more of literacy. Yet participants agreed that a significant portion of the population struggles with managing medications (when, how much, why, and in conjunction with other medications).

Community members viewed gender match with doctors and interpreters as especially important, particularly when addressing women's health issues. Generally, participants agreed that both men and women feel more comfortable with a provider and an interpreter of the same gender, due to religious and cultural notions. For example, a participant recalled taking her mother to the doctor and the interpreter was a Somali man. "She was like, 'Hell no. I don't want to treat this. No. Somebody needs to come treat me right, because I don't want an interpreter, Somali guy. Come on now.'" Her mother refused to have a male interpreter interpret sensitive information to the doctor. Even though there was some disagreement toward the extent of gender matching, participants viewed personal health topics as very uncomfortable and awkward if the opposite gender was present. The example provided was a typical description of why some community members are hesitant to seek health care.

Table 2 Demographic characteristics (N = 11)

Gender	
Male	5
Female	6
Age: median	40 (22–71)
Primary language	
Somali	8
Maay-Maay	1
Baraawe	2
Secondary language	
Somali	3
Maay–Maay	1
Arabic	3
English	10
Kiswahili	2
Average no. of years in US	13 (6–18)
Education	
Training program	1
Elementary	2
High school/GED	2
Trade school	4
College degree	2
Marital status	
Married living with a partner	6
Never married	1
Divorced/separated	2
Widowed	1
Other	1
Average no. of children[a]	4.7
Location growing up[b]	
Mogadishu	4
Baraawe	2
Kismayo	1
Rural	1
Urban	1
Nairobi	1
Mombaso	1
Ogaden	1

[a] Does not distinguish from number of births, survivors, and household members

[b] Does not show the diversity due to small sample size

Mental health issues are generally not discussed. Participants explained that a stigma exists for people who request or need mental health services. Thus, most people do not seek care. The types of mental health issues vary, but largely symptoms fall under the scope of anxiety and depression. Participants believed that issues from the past, i.e., war, forced migration, separated families, destruction of homes, camp life, and the present, i.e., struggles with literacy, employment, and education, and gaining citizenship status affect many people. Interviewees stated that few people seek help. "So that's what it is, that people do not want to talk about it, and when they come here, it's depression, untreated depression is gonna be …. you know, it's gonna go into mental illness, we know that, so it's the depression that they're not seeking help for, they are not addressing. They're hiding." Participants claimed there were some community members who had sought care for depression or anxiety symptoms via clinics, hospitals, and religious leaders, however, the majority of people who need help do not ask for it.

Barriers to Access

Literacy was perceived as the main obstacle to health care, information, and treatment. Overwhelmingly, participants agreed that lack of literacy impedes access to care. "The problem here is that people are illiterate… most of them are coming from not the big cities, from the villages and it's hard to make them come along and get into the dialogue and understand." Interviewees also discussed the need for better educational programs for both youth and adults. The issue goes beyond a lack of literacy, rather, possessing an analytical framework which is needed to engage in the process of building healthy communities. Some participants spoke of a changing climate in that the number of Somali youth attending post-high school educational programs had increased over the years. However, it is not clear how many complete post-secondary programs.

Other barriers to care included a lack of knowledge of the US health care system, cost, insurance, language, and transportation. Even though these barriers are not unique to Somalis, they pose access issues for the local community. It is estimated that 8–12 % of the adult Somali population in Kansas City is fluent in speaking and writing English [1]. According to participants, difficulties with English, compounded by medical costs or navigating the health care system, create considerable challenges for many individuals and families. These problems may be perceived as insurmountable by many. "Let me say they don't go (to the doctor), unless it's a serious case for emergency purposes, if they get in a car accident, or a very bad thing that they can't even manage it. That is for men. For women, most of the women even they don't go unless they are pregnant." Participants indicated that barriers to accessing care are not isolated factors; rather, they are a combination of obstacles that impede visits to health care providers.

Lack of knowledge impedes decision-making. Some participants thought that the lack of engagement in the community's health problems was detrimental for individual health. The lack of engagement or indifference to individual and community health needs may be attributed to a lack of knowledge. "It's just lack of knowledge, lack of input or insight as what's going on as far as disease process. You would see people who are suffering diabetes, or hypertension or even mental illness, not being (having) knowledge of the disease process. Medication, treatment regiments, diet guidelines, you know, all that kind of stuff, they are not grasping it. And it's getting worse and worse." Some participants saw the need for both general education and health specific education specific to community concerns.

Suggestions to Improve Wellbeing

According to participants, some community members used Qur'anic readers (i.e., Islamic healing) to aid health, especially mental health issues. Islamic healing, otherwise known as Medicine of the Prophet (*al-Tibb al-Nabawi*), is a body of knowledge that was conceived in the fourteenth century that merges religious and health information under the tenets of the Qur'an (holy book of Islam) and the sayings of the Prophet (*hadiths*). One aspect of Islamic healing is the use of Qur'anic readers, where individuals recite passages of the Qur'an to those who are sick. While consensus was not reached concerning the effectiveness of solely using traditional Islamic treatment for certain ailments, it was agreed that Qur'anic readers should remain an option for care. Some participants would like to see Qur'anic readers (or a more comprehensive approach of Islamic healing) incorporated into a system of care. Readers were consulted in the past and they are currently used today. They represent an aspect of positive health that resonates with community members; and, they provide care that is familiar and fits into a framework to which people relate.

Many participants believed that community health workers would greatly benefit the overall population. Generally, participants stated that there was a lack of health professionals who not only speak Somali, but are also competent in meeting cultural needs. Community health workers were viewed as a reasonable option for administering care to the community. References were made to other cities that use community health workers and that these individuals helped fill the access gap for many community members who would otherwise not seek or receive care. The recommendation participants gave was to

visit cities with successful programs intact and transfer an existing system of community-based care with appropriate modifications to fit local needs and interests.

Objective 2: To Create a Working Relationship Between the Somali Community and KUMC

To address our second objective, we have engaged in a variety of activities. The following activities describe community involvement that is consistent with CBPR goals and objectives in a formative stage. As part of the Community Partnership for Health initiative, Family Medicine's Research Division invited the executive director of the Somali Foundation to discuss the history of the agency, the population it serves, and programs that it offers to community residents. In addition, the lead author showed a video that was produced in a prior project in which the two had participated [43]. The meeting was attended by 26 research faculty and staff and began initial discussions among a larger group of faculty about the needs of the Somali population.

A team of KUMC researchers met with members of the community to report results of this study. The meeting was attended by five research staff and 14 community members. The data presented at the community meeting were well received with positive feedback from community members. First, community members were happy that researchers had an interest in improving basic health within the local population. Second, community members agreed that the themes presented were consistent with how they perceived health needs and conditions. Third, community members gave suggestions for further investigation. The meeting facilitated a discussion of health concerns and needs; community members voiced the need for better education and training opportunities (for adults and children) and community health workers. In addition, researchers were receptive to the recommendations and recognized the limitations of the pilot data presented. Researchers emphasized the need for a larger study to obtain community-wide baseline data. These data are needed to design effective interventions. The meeting proved invaluable as the team and community members met face-to-face and shared interests in working with African immigrant and refugee populations. Both community members and researchers who were present wanted to continue a dialogue and a working relationship to tackle these health disparities.

In addition, the Somali Foundation requested KUMC's help with a health fair. Family Medicine's Research Division and the Center for American Indian Community Health offered flu vaccines, BMI, cholesterol, HbA1c, and glucose screening. Other organizations attended the fair, including: Samuel U. Rodgers Health Center and American Red Cross. Forty-eight community members attended the event and received screenings. Community members who attended the health fair were grateful for the free screenings and researchers were happy to assist in a community event.

Discussion

The themes discussed are couched within larger structural conditions, including education, socioeconomic concerns, and migration processes. Future studies and collaborations should acknowledge these conditions and incorporate them into a model that accounts for multi-level roles from individual providers to institutional support to economic realities.

Overall, our results indicate a greater focus on chronic conditions is needed. Few studies have addressed chronic disease such as diabetes care [4], cancer screening [44], or behavioral health concerns in the Somali community [6, 7, 45]. These studies and our results do not coincide with common research agendas geared toward African immigrants and refugees which highlight infectious diseases.

Mental health was discussed at length. Participants mentioned that more people need mental health services. Mental health services may reach community members better if they were culturally tailored to this population. This may include using Qur'anic readers or other socially acceptable approaches that address mental health needs. Even though many research studies have focused on Somalis and mental health [8–24], only one [35] engaged a pan-refugee population (including Somalis) using a CBPR approach.

Participants rated literacy as the number one barrier to care. Basic language and communication skills were seen as imperative to better care. Studies have addressed communication between providers and Somali patients [46, 47] and better communication makes a difference in the quality of care received.

In addition, our data indicate that more exploration is needed to address the fears and expectations of this community about going to a health care provider. Many individuals have little experience being seen by a health care provider and their goals may not be congruent with those of providers [48]. Implications of this include frustration and discouragement when they do see a provider and encouragement of using the emergency department for medical care [49].

We have identified some areas for improvement as we move forward with future CBPR studies with this population. First, we may modify the questionnaire to include, "how does the community come together for those in need (i.e., paying medical bills, emergency health info)?" There are indigenous structures that are used to solve community

problems. If researchers can better understand these systems, future interventions may be more specific and culturally tailored to fit this community's needs. Also, these assets would enhance our working relationship and better enable us to serve the community at large. Second, we will modify the demographic survey to include "citizen status versus non-citizen status" and "length of stay in Kansas City." These items are important as they relate to benefits, security, community involvement, acculturation, and migration patterns.

We acknowledge limitations to this study. The first limitation is the small sample size. Therefore, the generalizability of this study is restricted. Due to the diversity of the population, e.g., length of stay in the US, education levels, and English acquisition, stratifying the sample by gender, age, and citizenship status, may have provided more in-depth information. In addition, the sample we interviewed contained many English speakers. This high percentage of English speakers in our sample does not reflect the population; it is estimated that 60 % of adults are non-literate in English and 55 % are not functional in spoken English [1]. In addition, we used an etic perspective (an outsider's view) in the collection and analysis of the data. We did not include an emic perspective (an insider's view). Both perspectives are important because a reliance on one view will invariably cause an omission or oversight in the data. However, even though we did not offer any incentives, child care, or a meal to compensate interviewees for their time, people felt compelled to participate and be involved in the process.

As we continue to build relationships, we are looking for ways to encourage future collaborations. We plan a thorough community health assessment that will better incorporate community members in all stages of the research process. The 11 interviews provide a snapshot of what may be happening in the Somali population in Kansas City and we are investigating ways to enhance this relationship. From this formative, pilot study, we have learned that we need to (1) explore participants' suggestions and potential program development through a thorough community health assessment; (2) develop effective, culturally-appropriate intervention programs to increase care within the Somali community; (3) compare and contrast health experiences to other immigrant and refugee populations in and outside of Kansas City; and, (4) develop programs that will be appropriate for all refugee populations in Kansas City, not just Somalis.

New Contribution to the Literature

Researchers and community members must work together to address pertinent health topics in a culturally sensitive manner, especially in underserved populations. CBPR harnesses the experiences and knowledge of community members and engages them in the research process. This formative, pilot study provides a snapshot of what may be happening in the Kansas City Somali population. We plan to develop a community health assessment and expand community members' roles in the research.

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