Race, Mistrust, and Cultural Incompetency: Barriers to Health Care Among African-born Men in Boston

Jennifer Foth Boston University School of Public Health International Health Culminating Experience The purpose of this photo essay is to illuminate the barriers African-born men face in accessing healthcare services in the greater Boston area and the impact that the African Initiative for Men's Health (AIMH), a program run by the Refugee and Immigrant Assistance Center (RIAC), is having on the African-born community in terms of addressing those barriers. The photo essay features photographs and excerpts from interviews conducted with African-born men directly involved in the AIMH program, as well as descriptive text presenting the African-born male perspective of the environmental and cultural factors that compromise their ability to access healthcare services in the US. To protect interviewee privacy, names have not been used and the quotes featured on each slide are not attributed to the men pictured.

The photo essay will be featured in digital format on the RIAC website, the AIMH Facebook page, and at future RIAC/AIMH consortium meetings to increase awareness of barriers to care among healthcare providers, religious and community leaders, and African-born community members. RIAC will also present the photo essay to the Massachusetts Department of Public Health and potential donors who could provide funding to sustain the AIMH program past 2011. "Why should I care about health care coverage? They explained to me my benefits in the HR orientation. But it enters here [points to one ear] and goes out here [points to other ear]."



Approximately 1.5 million African-born individuals live in the US today, over 17,000 in the metro-Boston area alone (1). Most of these individuals are men who enter the US as undocumented immigrants, asylum seekers, or refugees (2). Many of these men work in service industries for minimum wage and with low job security, making it difficult for them to afford health insurance or take time off for doctor visits (2). Though illegal immigrants in Massachusetts are eligible for what is called the Health Care Safety Net, this program only provides coverage for individuals under the age of 19, pregnant women, and emergency treatments, not routine check-ups (3). Even legal immigrants, asylees, and refugees, who are eligible for Masshealth, are often unable to afford copays for doctor's visits. And for those who receive health insurance through their employer, the real issue is often a lack of concern for health care coverage. Due to the high cost of copays, a lack of coverage, and a lack of concern, many African-born men choose to seek care at hospital emergency rooms only in the later stages of illness, which increases their risk of adverse health outcomes (4).

Studies have been done on healthcare knowledge, beliefs, discrimination, and access among minority groups and African immigrants more specifically (5, 6, 7, 8). However, little research has focused specifically on African-born men who are less likely to access care than their female counterparts, who are often introduced to the healthcare system via prenatal care.



The African Initiative for Men's Health (AIMH) is a program run by the Refugee and Immigrant Assistance Center (RIAC) in Jamaica Plain. Each year, RIAC serves over 400 clients from more than 60 countries. The majority are African immigrants from countries such as Somalia, Cameroon, Uganda, and Liberia. Through a health education and awareness campaign, engagement and training of religious and community leaders and healthcare professionals, the AIMH program aims to increase health literacy, access, and utilization of healthcare services among African-born men in Massachusetts. With 80% of the their staff of African origin, RIAC is well-positioned to understand and address the cultural, social, and economic factors that influence access to and utilization of healthcare services within this population.



Six AIMH participants and staff members were interviewed for this photo essay and asked to describe the barriers affecting access to healthcare among African-born men in the Boston area. Interviewees represented a wide variety of nationalities and professions and included an undergraduate student from Kenya; an NStar employee from Cameroon; a Nigerian psychologist and a Somali social worker who work directly with the AIMH program; and two AIMH community health workers (CHWs) from Cameroon and Liberia who work with the African-born community in the greater Boston area. Almost all interviewees cited educational opportunity as their primary reason for immigrating to the US.

When asked about their current health problems, several interviewees reported having diabetes, liver problems, and high cholesterol due to poor diet and lack of frequent exercise. The most common health concerns of African-born men include nutrition, physical activity, tobacco use, HIV/AIDS, cardiovascular disease, and diabetes to be the most common health issues of concern among African-born men (RIAC doc). Given the high prevalence of chronic disease in this population, their reluctance to seek out preventative care is of particular concern to AIMH staff members.

"That's the problem of the third world country. The health is not the primary thing. When you wake up in the morning, you think, 'Am I going to have enough to eat?"



Access to and utilization of preventative care is often minimal in the native countries of many African-born men, where health often takes a back seat to the daily struggle for survival. Moreover, the level of care in their native countries is often so poor that many men choose to seek care only when it is absolutely necessary. This mentality and behavior pattern surrounding healthcare services sticks with with these men long after they arrive in the US. This poses a significant challenge for the AIMH program since African-born men "still think of healthcare the same way we thought about it back at home - as terminal... They won't go for care because they are so afraid..."



Negative experiences with healthcare providers present significant barriers to healthcare access among African-born men. Rumors of "not-so-happy experiences" with doctors who prescribed medications that produced a near-fatal interaction circulate throughout the African-born community. Pervasive mistrust of the healthcare system makes African-born men more likely to "wait until they are terminally ill to go to the hospital," increasing their risk of adverse health outcomes.

"Perception is what works here. It's based on how you look. Where doctors look at you and you will feel that this man cares for me. You don't get that anymore. I don't trust."

Race and culture heavily influence the level of mistrust African-born men have for healthcare providers. Many, though not all, men would prefer to see an African-born doctor who shares their culture and language, who understands to some extent the circumstances they come from. As one man said, "Why don't we have an African medical doctor here? When you go to hospital, you find some people like you [white people], you find 50% trust..." Many men would rather delay seeking care until absolutely necessary than see a white or even African-American doctor.

"You go somewhere, you give your information, and you don't know where that information will end... They say, 'This is another set-up, another sting.' A lot of Africans think that."

As with many African-Americans, the Tuskegee Syphilis Study has fueled the belief among well-educated African-born men that healthcare providers want to "experiment [on them]" and use them as "guinea pigs for medications." As one man put it, "What happens now is just a symptom of the Tuskegee experiment. No matter what you tell us, most people would like to go...die at home than to go to hospital." Fear of personal data being reported to the authorities plays into feelings of mistrust as well. This fear runs so deep that some undocumented immigrants think that AIMH staff members - despite being African-born themselves - are "agents of the system" collaborating with immigration services.

"You're black, you're black." They [healthcare providers] don't see why they should pay special attention to Africans, when [the population is] actually completely different in terms of way of life, culture... everything is completely different."

African-born men tend to "think healthcare providers don't understand their culture." This has a major effect on doctor-patient communication. For these men, disease is "a personal, cultural, contextual thing. If a doctor has no idea how you talk about disease in your culture, they cannot engage with you in a way that you can collaborate..." Cultural competency has also impacted the AIMH program itself. African-born AIMH staff have found it difficult to develop partnerships with local healthcare providers who assume that African-born men are the same as African-American men in terms of their culture and health needs.



Already, the AIMH program has made significant strides in addressing the distrust African-born men feel toward the healthcare system and providers, and to make preventative care one of their top priorities. As part of their community awareness campaign, AIMH community health workers (CHWs) have been disseminating healthcare and insurance information to the African-born community via email, phone, and social networking sites such as Facebook. As a result of these efforts, "we've been able to change a lot of the stigma and distrust among African-born men to allow them to go to the hospital, to obtain health insurance, to make preventative health one of their priorities." As one CHW explained:

We conducted surveys, we conducted key leadership interviews, and we held a focus group. Just how the people responded we knew we were reaching a large African community. They were listening to us. So now you talk to them, you have feedback from them... they go to hospital now, they go to soccer fields where they have meetings. [You ask] "How often do you have your checkup?" Some will tell you "Every 3 months I go to my doctor." There is a big change.

A great deal of work still remains to be done, however. African-born men must be assured that their personal information and immigration status will not be used against them. At the same time, healthcare providers must be educated about the unique cultural context and health issues of African-born men as a population distinct from African-Americans. Addressing the mutual misconceptions inherent in this patient-provider relationship will facilitate the creation of effective partnerships between the AIMH program and Boston-area health centers where RIAC staff can refer African-born men and know they will be well taken care of. Ultimately, the goal is "to create a system that will stay even without the program running. To have a system in place in the churches or the mosque. To have something like a health ministry that can take over giving out education and information about some of these barriers and the common diseases... [and] what they can do to avoid stuff like that." The creation of such a system will have a positive, sustainable impact on the health outcomes of African-born men in Boston.

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Culminating Experience Reflection Paper

Introduction

For my Culminating Experience (CE), I decided to combine my interests in both photography and international public health to create a photo essay that would bring greater awareness to the health issues facing a specific segment of the population in the Boston area. As an International Health concentrator completing my last semester of classes, I wanted my photo essay to be as internationallyfocused as possible without requiring that I leave the country. I therefore decided to focus my essay on a refugee/immigrant population in the Boston area. I had taken many courses on refugee health during my time at BUSPH and thought that by examining the health issues faced by refugees and immigrants after resettlement, this photo essay would help broaden my understanding of refugee health beyond the disease burden, morbidity, and mortality rates found in the refugee camp or country of origin.

The experience of researching, interviewing, photographing, and creating this photo essay was extremely rewarding, though not without its frustrations and complications. What follows are a few recommendations, based on my own personal experience, for BUSPH students interested in pursuing an independent project of this sort for their CE.

#1: Get the support of a partner organization early on

It was only towards the beginning of the Fall 2011 semester that I decided to pursue this photo essay as an independent project for my CE. Unfortunately, this gave me very little time to determine the topic of my photo essay and write up the project proposal. In order for this project to be successful, I knew that I would have to partner with a refugee/immigration organization that could provide me with access to members of this population. I sent emails to five or six organizations introducing myself and explaining the purpose, scope, and timeframe of my proposed project, yet I received only two responses. The first was from a refugee health organization claiming they did not have the capacity to support my project at that time. The second was from the Refugee and Immigrant Assistance Center (RIAC) in Jamaica Plain saying that they were very interested in my proposed project. RIAC responded positively to my request for support because they believed the photo essay would provide them with a means of advocating for increased funding from the Massachusetts Department of Public Health for their African Initiative for Men's Health (AIMH), a program designed to increase health literacy, access and utilization of healthcare services, and build capacity to address health disparities among African-born men in Massachusetts.

Given their already limited financial and human resources, I do not think RIAC would have agreed to support this project had it not provided the added benefit of a potential fund and awareness raising tool. Without that added benefit, I would have spent considerably more time struggling to find a partner organization and may not have found one in time to complete the photo essay by the end of the semester. For me, this experience highlighted the importance of securing a partner organization early on and communicating the ways in which this type of project could potentially benefit that partner organization, something which I did not communicate in my initial emails to the various refugee and immigrant organizations I contacted.

#2: Link the CE to a BUSPH course

One of the best, most helpful decisions I made regarding this project was the decision to link the photo essay to my final project for SB818: Qualitative Research Methods. The final project for this class required that I conduct semi-structured, in-person interviews with at least four individuals concerning a health-related topic of choice, which correlated perfectly with what needed to be done for the photo essay. The SB818 syllabus provided submission deadlines for the research question, interview questions, interviews, and components of the final paper which helped keep me focused and on track for completing my photo essay on time. By linking the photo essay to this course, I was also able to get frequent and substantive feedback from the professor regarding the structure and content of my interview questions, which helped elicit richer responses from the African-born men that I interviewed.

2

Without the external structure provided by the SB818 course, it would have been much more difficult to keep up with all the work that needed to be done on the photo essay, particularly given the extensive amount of work required for all the other courses I was taking that semester. I would therefore recommend that BUSPH students considering a project of this sort try to link it to a course that will complement and provide structure for the project.

#3: Cross-campus collaboration can be tough

When I first approached my CE advisor with the idea for this photo essay, she expressed concern over the fact that she would only be able to provide feedback concerning the written text that would accompany the photographs, not the photographs themselves. She therefore recommended that I contact a professor at the Boston University College of Communication who could lend a critical eye to the composition and sequencing of the photographs I would be using in my photo essay. Following her advice, I contacted Peter Southwick, an Associate Professor of Photojournalism and the Director of the Photojournalism Program at the BU College of Communication, who agreed to meet with me over the course of the semester to provide constructive criticism of the photos I would be taking.

Unfortunately, this arrangement worked better in theory than in practice. Between coordinating and conducting interviews, and trying to keep up with coursework for my other classes, it was very difficult to find the time to meet and communicate with Professor Southwick throughout the semester. In fact, we met only once at the beginning of the semester so that I could introduce myself, the project, and set up a meeting schedule. After that, communication was limited due to both of our busy schedules. I would therefore caution students interested in pursuing this kind of project against relying too heavily upon collaboration with and support from faculty outside BUSPH. Conflicting schedules and the extensive amount of time and effort required to schedule and conduct interviews made cross-campus collaboration very difficult. However, this may be less of an issue for future BUSPH students given the growing relationship between COM and SPH.

#4: Be flexible and patient

The biggest lesson I learned from this experience was the importance of remaining flexible and patient when working with another organization and a population that is already hesitant to discuss health-related issues. Originally, I envisioned my photo essay focusing on the health issues facing one particular refugee population in the Boston area. However, in order to secure the support of RIAC, I had to adjust my vision and agree to focus on African-born men, a population which I had not originally considered for my project and of which I had no prior knowledge. A considerable amount of patience was required when it came time to schedule the interviews with the African-born men. Before putting me in contact with potential interviewees, the RIAC staff asked to review my interview questions, a process which took several weeks due to the heavy workload of the three to four staff members whose feedback was deemed critical. Initially, the RIAC staff and I had agreed to try to do all the interviews and photographs during a meeting of the AIMH participants on October 15. Though I was able to take some candid group photos at the meeting, the timeframe for the interviews was pushed back significantly since the interview questions had not been approved by the time of the meeting.

Further patience was required even after the interview questions were approved by the RIAC staff. It took a great deal of time and effort to contact and arrange a mutually agreeable time and place to meet with and photograph each interviewee. Several interviews were rescheduled over the course of the project and one potential interviewee never showed up to the initial meeting or any of the subsequent meetings that we rescheduled. With so much of the scheduling out of my control, it was challenging to adhere to the deadlines laid out in the SB818 syllabus and remain on track to complete the project by the end of the semester. Moreover, during the actual interviews I could sense some reluctance on the part of the interviewees to discuss personal health-related issues with a young, white female, despite my assertions that their responses would not be linked to their photo. Though the interviewees seemed more comfortable responding to questions as the interview progressed, my

4

background and presence may have influenced the content and depth of interviewee responses relating to their health-seeking behavior. This "interviewer effect" could have been mitigated by involving a fellow African student in the interview process.

Conclusion

Despite the numerous delays and setbacks that occurred throughout this process, overall I found working on this project to be a very valuable experience. Over the past couple of years, as my interest in photography has grown, I have been contemplating ways in which to marry my love of photography with my passion for international public health. This was my first real foray into the world of photojournalism and it taught me a great deal about the challenge of playing the role of both journalist and photographer simultaneously, of getting the great shot while still conveying to the interviewee your interest in their response and not just their image. The camera has an amazing ability to alienate and it was a difficult but rewarding experience trying to capture these images without sacrificing the depth and richness of the interviewee responses.

This project also exposed me to a subpopulation and a complex set of social and cultural factors of which I had no prior knowledge or experience. As cliche as it may sound, I really enjoyed engaging with the interviewees, hearing their life stories, and getting a brief glimpse of the US healthcare system through their eyes. To hear that racism and discrimination still persist in racially discordant doctor-patient relationships was disheartening and surprising for a young, white female for whom such issues have never been a problem. For all our claims of equality, these interviews showed that racism and discrimination, both overt and unconscious, still have a lasting effect upon the health-seeking behavior of African-born men in the US who, despite their foreign origin, are still aware of what happened at Tuskegee. For me, this project demonstrated the powerful effect even long-past and indirect experiences can have upon current behavior, and that longstanding misconceptions and distrust must be addressed in both patients and providers in order to truly improve health outcomes among African-born men.