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Chapter 2

HIV Knowledge Among Muslim University Women

Subha Singh

Introduction

The human immunodeficiency virus (HIV) is a growing threat among young people in the United States. Yet, there is scant research on the effects of HIV among minority groups, such as Muslims. About 1.2 million people in the United States were living with HIV at the end of 2011 and of those people, about 14% did not know they were infected. The young adult population (ages 19–29) is at the highest risk for getting infected, in part because they do not consider their behavior as “risky” (Hou 2004). What is more, at least half of all infections occur in individuals younger than 25 years old (Inungu 2009).

While studies have shown that HIV infections are increasing in Muslim countries, especially among the young population (Abu-Moghli et al. 2010), the prevalence of HIV infection among young Muslims in the United States is poorly understood. The United States has a Muslim population of 6.67 million and it is increasing every year. However, the CDC and other public health organizations do not include religious identification as a social category for which to gather statistics on risk behaviors and infection rates. Instead, health organizations disaggregate data on infection rates according to categories such as race, ethnicity, sex, social economic status, and transmission methods such as heterosexual contact, men who have sex with men (MSM) and drug injectors. This study (funded in part by the McNair Scholars Program) aimed to explore where young Muslim women and non-Muslim women in U.S. universities

obtain knowledge about sexually transmitted infections (STIs), namely HIV. Understanding how young Muslim women obtain information about HIV/AIDS will help to identify where to focus educational campaigns, and thus take an important step towards mitigating disease risks among this growing population.

HIV Knowledge Among Young Adults

Existing research shows that although students know how HIV can be transmitted and how it can be prevented, their education in safe sex and contraceptive use can still be improved (Davis 2006; Hou 2004). Hou's (2004) study found that U.S. college students knew that the HIV virus could be transmitted through blood, semen, vaginal fluids, and mother's milk; but they could not identify the ways in which the virus could *not* be transmitted (Inungu 2009). Outside of the US, recent studies have shown that HIV knowledge is lacking in many nations (Cherutich et al. 2012; Janssen et al. 2014; Ruud et al. 2014; Valadez et al. 2013), particularly in Muslim countries (Abu-Moghli et al. 2010; Mohtasham et al. 2009; Mor et al. 2010; Todd 2007). These studies raise the question of whether Muslims in secular nations such as the United States have a similar dearth of knowledge about HIV/AIDS.

Notably, within nations, HIV/AIDS knowledge varies among populations of different ethnicities. Kulwicki and Cass (1994) studied the knowledge, attitudes, and beliefs of Muslims living in the Detroit, Michigan area. They found that, in general, the population had less knowledge and more misconceptions than the general population of Michigan. Yet, the younger and more educated population had more knowledge about HIV than the older adults. Studies among male adolescents in Iran showed that most of them reported high levels of knowledge about HIV but many did not perceive themselves to be at risk of HIV infection (Mohtasham et al. 2009). Thus they continued to engage in high-risk behaviors, including unprotected sex, sex with

multiple partners, and sex with commercial sex workers (Mohtasham et al. 2009; UNICEF 2007). These studies signal the fact that knowledge varies among individuals from differently situated social groups. Given that HIV knowledge varies according to religious affiliation, ethnicity, age and education, this study (1) examined how younger, educated Muslim women in the United States obtain knowledge about HIV; and (2) proposed venues for delivering accurate information to this segment of the population in the most convenient way.

In the United States, younger Muslims are exposed to a variety of sources of information about sexual behavior and risk, including the media, peers, and health providers. These sources of information exist alongside Qur'anic teachings, and may lead to different understandings of risk and STIs. In Jordan, "global cultural diversity creates considerable variability in cultural norms and represents a wide spectrum of beliefs and values" (Abu-Moghli et al. 2010, 660). Moreover, in Kenya, Maulana and colleagues (2009) found that religious leaders associate increasing unemployment, increasing divorce rates, high dowries, and substance abuse to "young people getting into trouble" (Maulana et al. 2009, 563). Furthermore, Maulana et al. (2009) reported that boys and girls who do not have a job tend to idle and increase substance abuse. These religious leaders suggested that rates of infection could be decreased if parents kept a closer eye on their children, kept them employed and, "[provided] directions on abstinence by boosting self-restraint" (Maulana et al. 2009, 563). Given the variety of information and social forces influencing sexual behavior, it is important to identify appropriate avenues for young Muslim university students to obtain accurate information on STIs. Such sources of information could influence their sexual behavior and reduce the rates of infection among this population.

In focusing on Muslim women, this research drew on existing studies, which show that females are more likely to get the HIV virus than their male counterparts (Hutchinson 2002).

Hutchinson's (2002) study of the influence of sexual risk communication found that daughters who talk to their mothers about sexual topics are more likely to use condoms as a safe behavior compared to daughters who mostly talked to their friends about sex. Communication with parents not only helps maintain a positive parent-child relationship, but it also offers an avenue to educate children in safe sex practices. It has been shown that parent-child communication can lead to less risky sexual behavior. Perrino et al. (2000) stated that if the communication is positive, broad, and open, it protects the child from sexual risk behaviors. It has also been shown that Muslim children in the U.S. have different risk behaviors depending on the types of communication they have with their parents (Henry et al. 2008). Therefore it is important to understand how young Muslims in the U.S. communicate with their parents regarding HIV and sexual risks. Drawing on ethnographic data, collected through interviews, this study investigates the extent to which young Muslim women look to their parents (specifically, their mothers) for information about HIV and other STIs.

When parents do not communicate with their children, adolescents tend to go to peers to get information and guidance. Perrino et al. (2000) found that adolescents who tend to go to peers for help have low levels of support from their families and high levels of parental authority. In such situations, the influence of peers on adolescent sexual behavior is greater (Perrino et al. 2000). In other words, both parent communication and peer influence contribute to sexual behavior (Whitaker and Kim 2000). Whitaker and Kim (2000) pointed out that parents tend to be a greater source for information about sex than peers; thus, when parents are not communicating with their child peers can have a greater influence on their behavior and beliefs. Such influence can lead to risky behavior that can increase the chance of being infected with an STI. Parental guidance provides a peer pressure buffer, helping young adults avoid dangerous

behavior, such as drug and alcohol abuse (Whitaker and Kim 2000).

Drawing on the above work, this study looked at the role that parents play in conveying information about STIs to their young Muslim daughters. This demographic is important to examine to two reasons: (1) because research suggests that sexual topics are not often discussed between parents and children in Muslim households (Merghati-Khoei et al. 2008); and (2) because studies show that the older generation of Muslims in the US has a limited knowledge of HIV/AIDS. Kulwicki and Cass's (1994) study stated that "there [was...] some confusion about the implications of AIDS for the Arab American community[...] The overall percent of [...] respondents who indicated that they had little or no knowledge was less than for other populations (Kulwicki and Cass 1994: 15)." This suggests that Arab Americans may be lacking information about HIV/AIDS and its implications for their communities.

This study also contributes to the scholarship on HIV/AIDS knowledge among university students, particularly women. Universities are a place for gaining independence and planning the future, but they are also places where young adults may be involved in reckless behaviors (Inungu 2009). The study also provides much needed information on Muslim women's knowledge and attitudes towards sexually transmitted infections. As the Muslim population grows, it is important to assess how young Muslim women learn about HIV/AIDS and how this knowledge compares to other, better-documented minority populations. By looking at minority groups in the US where STI risk is increasing, we can develop interventions that help to decrease the rate of infection among the young Muslim population in the US. Further, by investigating a younger, more educated segment of the minority population (such as the young Muslim segment constitutes), we can increase understandings of the roles that social media and peers play in influencing sexual behavior and attitudes towards STIs.

Methods

This research targets young Muslim populations because HIV/AIDS rates are increasing in the United States among this young adult population. The objectives for this research were to determine where Muslims and Non-Muslims obtain information about HIV. With this knowledge, we can determine how to focus educational campaigns geared toward this demographic in order to provide accurate information on STIs. This study also aims to understand the relationship between mothers and daughters in Muslim families and how those relationships influence risk behavior. The primary research question posed was: What sources of information on STIs do Muslim and non-Muslim women use, and how do these sources of information influence their knowledge about HIV/AIDS?

Data was collected by conducting eleven semi-structured interviews with women who identify as Muslim (seven) and non-Muslim (four) living in New Hampshire. The participants for the Muslim interviews were chosen by the following criteria: the participants had to be eighteen or older, they had to be Muslim and women, and they had to live in New Hampshire and be enrolled at a university. The non-Muslim participants were a convenience sample. All the non-Muslims participants were women attending universities in New Hampshire. The perspectives of these four non-Muslim were used to provide a basis of comparison between the two study populations. This comparison allowed us to investigate how knowledge, parenting styles and communication differed between the Muslim and non-Muslim women.

To recruit participants for this project we contacted a few students who were friends of the researcher majoring in many different fields and then used the snowball technique to recruit more people. The interviews lasted thirty minutes to an hour and took place either in person, over the phone or via Skype. Some were audiotaped so they could be transcribed later; in some

situations, the participant did not wish to be recorded and so the researcher handwrote the notes and responses during the interview. All protocol for this study was approved by the Institutional Review Board (IRB) at the University of New Hampshire.

Semi-structured interviews were used so that specific experiences and information from participants could be gathered. A general list of questions was used. Subsequent questions varied depending on the answers given by participants. Some example questions included: Are you aware of HIV? How is it transmitted? Where do you get most of your information about HIV/AIDS? Can you talk to one of your parents/family members about HIV/AIDS? The in person interviews took place in a private room. In each case, informed consent was obtained prior to the interviews by signing a form, and all participant data was recorded anonymously. As such, the names mentioned in this paper (Shya, Cami, Susan, etc.) are pseudonyms for the participants who were interviewed (Appendix A).

To analyze the data, the first step was to transcribe the interviews. Then information was divided into general categories represented by repeated key words or patterns. Differences and similarities between responses were sought, with a focus on the sources used to receive information about STIs and specifically HIV. Discourse analysis also helped to determine themes that the participants mentioned during the interview. The same analytical technique was applied to the non-Muslim interview data, facilitating comparison between the two study samples.

Results

The seven Muslim women that were interviewed were all university students. The four non-Muslim women were all undergraduates. The Muslim students were a mix of undergraduates and graduate students. All eleven participants knew about HIV and thought it

was a serious disease because it “shortens life and kills people” (Shya 2014). Common venues to learn about HIV/AIDS included the Internet (24%), school (20%), family (20%), doctors (16%), friends (12%), and the media (8%; Figure 2.1).

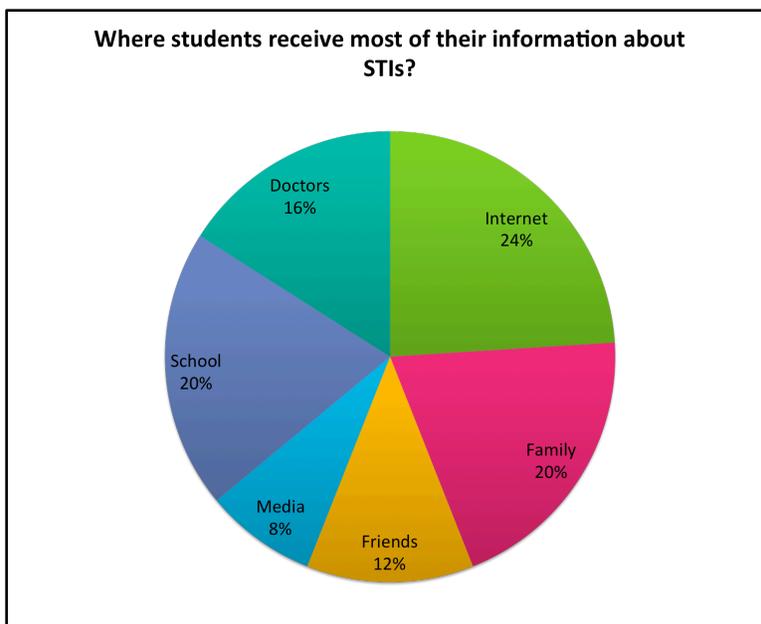


Figure 2.1. Where students receive their STI information.

The most common explanations mentioned by both Muslim and non-Muslim interviewees for virus transmission were unsafe sex, bodily fluids, needles, blood, open cuts, mother to child, and blood transfusion (Figure 2.2). All respondents knew that HIV affects the immune system although some participants thought that HIV and AIDs were the same. Of the eleven participants, six knew that AIDS is the symptomatic expression of the HIV virus. All eleven participants knew there was “no cure” for HIV/AIDS, and eight participants knew that there was medication available that stops the progression of the symptoms of the disease.

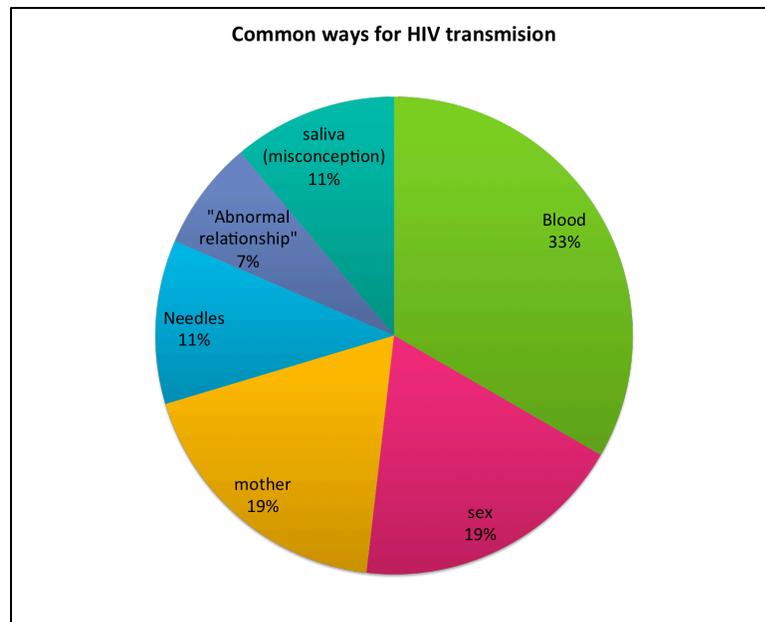


Figure 2.2. Common ideas about how HIV is transmitted.

When asked who was more likely to get HIV/AIDS, answers varied, and included: people who are not careful or are being promiscuous, homosexuals, “uneducated sexually active people” (Shya 2014), and young people between the ages of 20 and 40. Three respondents suggested that college students were among the people who were most likely to get HIV and AIDS. College students were described as irresponsible and reckless, considering themselves invincible. Preventing HIV/AIDS was not on the top of participants’ list of potential issues, and so they did not seek education on the subject. For instance, one participant said that contracting HIV was “not on my radar and so it is not something that I need to worry about” (Sophie 2014). This indicates that not all college students participate in typical college sexual behavior, or “hooking up.” Respondents were for the most part unconcerned about HIV/AIDS as a threat to their own health, and subsequently, they spend little time worrying about getting infected.

Below the key sources of HIV/AIDS information for the study respondents is delineated.

Health & Educational Institutions

All eleven of the participants had heard about HIV in their educational institutions (Figure 2.1). One woman learned about HIV in elementary school, while four others learned about HIV in health class in middle/high school. All eleven girls had had a conversation with their mothers/aunts about HIV, which helped to enforce ideas of safe sex, and the importance of seeking knowledge and help about this issue. A Muslim participant reported that if her mother could not help her then she would go to a doctor or nurse for help. Nine women said that, in the event of an unsafe sexual encounter, they would go to a family doctor or UNH Health Services to get treatment, which they viewed as the most responsible course of action, despite reporting that they would be embarrassed and nervous to go.

Family & Friends

Family was a key factor impacting HIV knowledge for only nine of the eleven women (Figure 2.1). These nine women all reported having close family relationships. All of the eleven women said that they would rather go to a female member of their family to talk about HIV/AIDS to ask advice or gather information, even the two women who reported being closer to their father/male figure in their family. One participant described her parents as “not just my parents, my parents are not my friends; they are my *teammates*” (Cami 2014). Some Muslim women noted that in Muslim culture, the topic of sex is considered “taboo,” something that is considered a private affair and not openly spoken about. One Muslim participant said “where I’m from topics like that are somewhat taboo [...] Topics like that are generally really private” (Susan 2014). The participants that could not talk to their family reported that they would rather go somewhere else to get the information they needed, either from friends, the Internet or a doctor.

Two Muslim participants said that friends were a better resource to talk to about this subject, and that friends can be reliable depending on the information (Shya 2014). One woman noted, though, that information obtained from friends, needs to be doubled checked with a reliable source, such as a doctor or a website, such as the Center for Disease Control (CDC; Cami 2014). Two Muslim participants felt that going to friends was better than parents, describing their friends as more open, modern, non-judgmental and helpful (Susan 2014; Liz 2014).

Internet & Social Media

The reliability of the Internet as a source of information about HIV/AIDS was also commonly mentioned during the interviews (Figure 2.1). Respondents reported that “googling it” was the best way to gather information about HIV symptoms and treatment. Three women, Muslim and non-Muslim, said that they would start with the Internet to determine what was wrong with them and to gather more information. They would look at medical websites such as the CDC, which they noted are more reliable than others because they are evidence-based. Other websites, such as WebMD, were not visited because, according to participants, such distilled sites need to be double-checked for reliability and accurate information (Cami 2014).

Talking about Sex

Even though respondents freely reported on a rich array of sources for gaining information about HIV/AIDS and sexual behavior, these are difficult topics to discuss, especially with an unknown ethnographer. Thus, discourse analysis was used to identify additional topics that participants brought up but did not openly acknowledge. For example, some of the Muslim women were reluctant to be interviewed about sex, having grown up in what they described as “conservative families” where the word sex was never openly uttered. These Muslim women

used other words instead, such as “sexual relations” and “*abnormal* relationships.” After the interviews were finished, it was also noted that these women seemed more comfortable talking about HIV and sex when the conversation was not being recorded.

From Information to Knowledge

While respondents drew on a rich array of sources of information about HIV/AIDS and sexual behavior (Figure 2.1), many still held misconceptions about the risks of contracting HIV (Figure 2.2). A quote that came up repeatedly was “It will never happen to me” (Sophie 2014; Sarah 2014). This misconception is a result of the fact that most college students do now know anyone with HIV (at least that they are privy to). Although HIV testing is widely advertised and strongly encouraged among this age group, not many college students get tested (CDC 2014). In a 2010 survey done by the CDC, it was determined that only 35% of adults aged 18–24 had been tested for HIV (CDC 2015). Both the Muslim and non-Muslim respondents said that they believed they were unlikely to be infected. When Muslim participants state “It will never happen to me,” it may mean that they are following the Qur’an’s teachings about sexual abstinence before marriage, and thus are in a group with decreased risk. However, it was unclear from the interview data whether the Muslim respondents all abstained from sexual activity. Out of the eleven interviewed, three participants said that HIV started in the gay community, highlighting a misconception that many hold: that only homosexuals can contract HIV. In reality, many people who are not gay are also HIV positive (CDC 2014). These misconceptions derive from the media and peers. For instance, the media has provided statistics about HIV rates decreasing in some part of the world, such as Africa, while it is increasing in other countries, such as the United States (WHO 2005). Even when HIV/AIDS rates are increasing in the US, respondents did not seem concerned about becoming infected and some even noted that the virus can now be treated

(four responded in this way). Thus, while some of the respondents believe there is a treatment to cure HIV, thus far there are only treatments that suppress the symptoms of the virus.

Conclusion

This study identified a lack of information on HIV risk and treatment among Muslim women university students, but found that a students' religion had little influence on their level of education or understanding of HIV/AIDS.

Education and family environment, rather than religion, were shown to be the most important influencers of HIV knowledge among the women interviewed (Figure 2.3). A Muslim participant said, "religion is not always the foundation of all families," meaning that not all families follow the Qur'an's teachings and some Muslim families do talk to their children about sexual education (Susan 2014). Susan's family was "conservative" but she was very open to talking about sex and HIV knowledge since she had grown up in the United States and was highly conversant with American cultural norms and values (Susan 2014). In another interview, a participant said that her "education would influence [her] risk behavior more than [her] culture. But [her] culture led to [her] education. So it is all intertwined" (Cami 2014). Cami defined culture as the way she was raised by her family and her beliefs, which were also shaped by society and her education. Education is considered something that is very important to all participants, as each one brought up education as a critical influencer of their sexual behavior. "When one is more educated, then they have more knowledge about HIV and STIs and thus open to talk about it" (Kim 2014). Knowledge about how to protect yourself sexually can help a woman make smart decisions when considering whether to engage in sexual activity. A better understanding of HIV/AIDS and STIs can also eliminate the misconception that HIV is unimportant and therefore not a serious issue facing today's young adults.

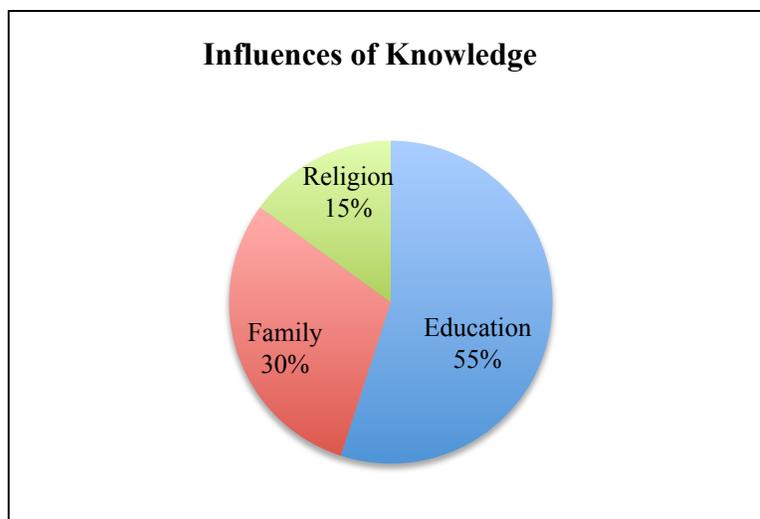


Figure 2.3 Influencers of HIV knowledge.

Despite popular beliefs that sex and STIs are taboo subjects among Muslims, this study suggested that not all Muslims consider these topics unmentionable. Respondents' willingness to discuss these topics depended upon their family background (social status, economic status, political/religious views) and their views on education. One Muslim participant said "it is ethically wrong [to have premarital sexual relationships]" (Kim 2014), emphasizing that having some contact to her "homeland" was an important factor for her as she began to teach her children about matters like sexual education. Kim said "Some cultural aspects you leave and some you are proud of and keep it. It helps to deal with situations and teach children values" (Kim 2014). Another Muslim participant reiterated Kim's concern, stating "Culture and religion gets you out of trouble. Religion is discipline, while...culture...teaches you respect and manners" (Liz 2014). Even though the Muslim women interviewed for this research were all open to talking about HIV, they did mention that not all Muslims were open to discussing HIV since it is often considered a taboo subject. Yet, the fact that these women were open to talking

about HIV suggests that other factors work alongside religion to shape HIV/AIDS knowledge and behavior.

Most eye-opening was this study's finding that the female students interviewed overwhelmingly reported that they do not think they are at risk for contracting HIV and furthermore, do not consider it important to obtain information on STIs. During the interviews there were some non-Muslim participants that said that they did not think that they would ever get HIV. "AIDS is not something I talk or think about. I am not ignorant about it, but I just do not need to think about it right now" (Susan 2014). During another interview, a participant exclaimed, "I am realizing that I do not know anything!" (Cami 2014). The participant realized how important it was for any college student to obtain this information before considering sexual or other risky behaviors (such as needle usage). This participant had thought that she knew a lot about HIV and its transmission, but subsequently realized how little she knew. This study also impacts the medical community. Since the medical community is trying to educate the younger generation there seems to be a lack of education indicated by this study. There seems to be a sense of security among students in the United States, leading them to believe that they will not be infected. The rate of infection was high in the 1980s and after that there was much influx of education and safe sex promotion that it impacted the behavior of students at that time. Since then the promotion of safe sex and testing has decreased and thus there are fewer students concerned about being infected.

According to this study, the Internet is the most commonly used method for receiving information. While Muslim women tend to get information about HIV from their friends, mothers and the Internet; on the other hand, non-Muslim women get their information from the Internet, doctors, and mothers. Thus, more accurate information should be made accessible to

them via the Internet, such as online health classes. The younger, more educated segment of the minority population can increase their understanding and knowledge of STIs even more by understanding the influence that social media, peers, and parents have an influence on their sex behavior and attitudes towards STIs.

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Appendix A (all of the names below are pseudonyms. Interviews were conducted informally during the summer and fall of 2014).

Pseudonyms	Muslim/Non-Muslim
Shya	Muslim
Susan	Muslim
Liz	Muslim
Kim	Muslim
Sarah	Muslim
Cami	Non-Muslim
Sophie	Non-Muslim

Note from the Editor:

The next two contributions are project proposals written by students in *ANTH 612: Applied Anthropology*, taught by Prof. Sara Withers during Spring 2015. As part of this class, students were asked to develop a three-part applied project proposal that focused on three key questions: *What area of applied anthropology interests you the most? What issues or problems—on either a local or global scale—are the most relevant for applied anthropology to tackle? If you were working as an applied anthropologist, what type of project might you want to design and/or be interested in working on?*

To accomplish this task students first researched the historical background of an issue or topic of interest, the history of anthropological involvement in their chosen subject, and drew on real-life examples of other relevant and related applied projects. Using this background research as a starting point, students then outlined their own proposed applied project, and gave an explanation of not only the process and methods, but also the importance and relevance of their project: Why is a project like this needed? What methods will be used? What are the desired outcomes or goals?

Then, students were asked to explore the specific roles of real-world anthropologists and social scientists working in organizations with similar interests, and/or on similar applied projects with whom they could conduct an informational interview. The goal of these interviews was for students to describe their project ideas to seasoned professionals, people with a first-hand knowledge of the issue, in order to get feedback and advice about their proposed design, as well as to gain a deeper understanding of what has worked—or not...and importantly, why—in the past.

Finally, using the knowledge gained from the background research and interview, students created a final project proposal of their own. As part of this final proposal, students were asked to provide a more critical assessment of their proposed project: What are some potential challenges or issues you foresee in this work? Lastly, students addressed the reality of its future potential within applied anthropology: What is the role of anthropology in this project? In what ways does applying anthropology offer a unique lens through which to do this work, think about this problem, and/or address this real-world issue?