Mechanics of Conducting Culturally Relevant HIV Prevention Research with Haitian American Adolescents: Lessons Learned, The

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OBJECTIVES: The purpose of this paper is to discuss how issues of recruitment, informed consent, and research incentives are viewed by Haitian Americans in a historical and cultural context and to identify implications for the ethical conduct of research. METHOD: The impact that Haitian history, culture, and experience with HIV has on current cultural attitudes regarding research participation are critically analyzed. Case illustrations from an HIV prevention research project involving Haitian adolescent girls are provided. Examples of how key informants and personal knowledge of both Haitian and research cultures were used to meet challenges of conducting ethical research with Haitian minors will be presented and discussed. DISCUSSION: Conducting culturally competent research may require nurse and health researchers to act as cultural brokers between members of the Institutional Review Board and members of minority and immigrant communities. Key words: adolescents, culturally relevant research, Haitians, HIV prevention, minority recruitment, research ethics

KEY WORDS: Adolescents; Culturally Relevant Research; Haitians; HIV Prevention; Minority Recruitment; Research Ethics.

According to the 2000 U.S. Census Bureau (2004), 548,199 Haitian Americans live in the U.S., predominately in Florida, New York, Massachusetts, New Jersey, and Connecticut (Migration Information Source, 2004). However, these data are probably underestimates due to undercounting and undocumented immigration (Raines, 2001). Currently, the rate of HIV is disproportionately high among Haitian Americans, and Haiti has the highest incidence of HIV in the Caribbean (Camara, 2003). Hence, it is critical that nurses and other health researchers develop culturally relevant HIV prevention interventions for Haitian people. We contend that understanding Haitian history and cultural values is critical at the beginning stages of developing any research initiative (i.e., at point of IRB application and review). Additionally, research regarding HIV requires appreciating the Haitian experience with HIV. We discuss these issues and identify implications for subject recruitment, informed consent, and research incentives using a pilot study for case illustrations.

HAITIAN HISTORY

The Politics of Haiti

Originally colonized by Columbus and later by French buccaneers, Haiti became a French colony in 1697. In 1804 under the leadership of Toussaint Louverture, a former slave turned general, Haiti became the first independent Black republic in the Western Hemisphere and the first country to outlaw slavery (Thomas, 1997). However, Haiti was not officially recognized by France until 1825 in exchange for an enormous indemnity (Douyon, Phillippe, & Frazier, 1993). The U.S refused to officially recognize Haiti until 1862, successfully pressuring Columbia, Venezuela, and other American states to exclude Haiti from the initial 1826 Panama Congress of American States (Haiti Program at Trinity College, 2003). This was a severe blow because Haiti had assisted the U.S. in the 1779 Battle of Savannah in this country's efforts to fight against the British for independence (Haiti Program at Trinity College, 2003).

Throughout the 19 century, Haiti struggled for recognition, against economic and political isolation that arose in response to officially outlawing slavery. Racial and social class differences created by colonization (e.g., the French granting more privileges to Mulattos than to Blacks) festered. Haiti split into a northern province ruled by the Black King Henri Christophe and a southern state governed by the Mulatto President Alexandre Petion but was reunified in 1820 under Jean-Pierre Boyer (i.e., Petion's successor). Boyer actively campaigned for African Americans to re-settle in Haiti, but this first wave of African American immigration ended with the collapse of his government in 1843, and Haiti fell under the rule of the notoriously corrupt and tyrannical, Faustin Souloque. Throughout the

20th century, Haiti experienced brutal and corrupt political leadership, financial indebtedness to wealthier Western nations, and internal strife with periodic U.S. intervention. In 1915, riots resulted in the death of the president and invasion and occupation by U.S. Marines until 1934. Jean Bertrand Aristide was deposed in a 1991 military coup d'etat but was reinstated in 1994 following a U.S.-led multinational, United Nations (UN)sanctioned, military intervention. UN peacekeeping forces remained in Haiti from 1995 to 2000. However, rioting again erupted in 2004, resulting in U.S.-led military intervention and Aristide being deposed. Noteworthy also is the progression of political leaders (i.e., "Papa Doc" Duvalier through Aristide) making promises to improve health care and other aspects of peasant daily life that were never kept, contributing to a sense of cynicism and distrust of government leaders.

In summary, themes of exclusion, struggle for recognition, and betrayal of trust have predominated Haiti's political history. These political experiences set the stage for a diaspora of large proportions.

Immigration

Since the 1950s, there have been three waves of Haitian immigration reflecting the powerful social class hierarchy that exists within Haiti on the basis of education, language, economics, and culture (Boyd-Franklin, Aleman, Jean-Gilles, & Lewis, 1995). Well educated, French speaking, upper class Haitians immigrated first in the late 1950s, followed by urban, middle class, French speaking Haitians in the mid-1960s. The last wave began in the mid-1970s. These immigrants tended to be lower class peasants, unskilled with little or no education, who only spoke Kreyol (Creole). Immigration has preserved at least some classist attitudes (e.g., higher value and respect for French speaking Haitians) within the U.S. Haitian community (Chaney & Sutton, 1987; C. Guerrier, personal communication, February 2003).

The last wave of immigration is typified by chain migration where families pool resources to send the member most likely to get a job to the U.S. (Giles, 1990; Lassiter, 1998). Once in the U.S., this individual sends money back to Haiti to support the family and helps other members migrate (Giles, 1990; Lassiter, 1998). This arrangement goes awry when the next member in the chain arrives illegally, tests HIV positive, and then is unable to get a green card and gainful employment.

Individuals who test positive for HIV typically have an immigration experience shaped by their inability to procure a green card and acquire U.S. citizenship (Markel & Stern, 2002). Immigrants often learn that they are HIV positive inadvertently when applying for a green card. Already in the U.S., they elect to stay because of greater access to treatment in this country than in Haiti. However, because they are undocumented, they cannot be legally employed. These individuals fear being reported to Immigration and Naturalization Service (INS) and are typically uncomfortable signing forms but may view research participation as a rare and much valued work opportunity.

The Haitian immigration experience is also colored by race. Being Black, Haitians may be treated as if they are African American (Colin, 2001; Stepick, 1998). However, Haitians have a different political history, and their cultural tradition is European and African (Colin, 2001). A majority are Catholic (Lassiter, 1998), and their language is French or Kreyol, depending upon their social class (Boyd-Franklin et al., 1995). Furthermore, Haitian Americans see themselves as different and quite distinct from African Americans (Colin, 2001; Stepick, Grenier, Castro, &Dunn, 2002).

Finally, the acculturation process associated with immigration is different for children because they attend school and learn English (DeSantis, Thomas, & Sinnett, 1999; Jean-Gilles, 1996). In contrast, their parents either remain in Haiti (Colin, 2001; Suarez-Orozco, Todorova, & Louie, 2002) or live here but are typically isolated from the mainstream media and are limited in their ability to read because of their need to work, relatively low level of education, and lack of ease in speaking English (DeSantis et al., 1999). Thus, the worlds in which Haitian children and their parents live can diverge, leading to intergenerational conflict in expectations and values (DeSantis et al., 1999; Field, 2001).

Thus, immigration continues the theme of exclusion, adding issues of cultural identity, fear of deportation, and intergenerational differences in cultural values. It is to these cultural values that we turn next.

Haitian Culture

There is considerable intracultural variation within the Haitian community (Malow, Cassagnol, McMahon, Jennings, & Roatta, 2000). Many factors such as acculturation, socioeconomic status, education, gender, and age influence the nature of cultural values and the extent to which they are held (DeSantis et al., 1999). However, the following cultural aspects identified in the literature are ones we have noted in our work with the Boston Haitian community and suspect are generally present to some extent within most Haitian communities in the U.S. and Canada.

As a group, Haitians are achievement oriented and come to the U.S. seeking financial upward mobility, job security, educational opportunities, and better lives for themselves and their children (McEachern & Kenny, 2002). Both parents (DeSantis et al., 1999; Laguerre, 1984) and children (Colin, 2001) view education as key to upward mobility. Haitians have great respect for teachers and, based on our experience, university professors as well.

Haitian families are close knit (Lassiter, 1998) and children are highly valued "gifts from God" (Pape & Johnson, 1988; Stycos, 1964). Consistent with these values, Haitian parents strongly value preventive health care services and practice preventive health care behaviors for their children (Schantz, Charron, & Folden, 2003). However, many children born in Haiti did not have access to vaccinations and may need to be vaccinated when they present in emergency or primary care settings (Miller, 2000).

Traditional Haitian family values promote children's independence and respect for elders (Bibb & Casimer, 1996). Haitian children are socialized to be competent and self-reliant but are also expected to respect and obey parents and elders without question (Bibb & Casimer, 1996; Charles, 1986; Lassiter, 1998). Parents, especially fathers, clearly make the rules and have the last say (McEachern & Kenny, 2002).

Despite an emphasis on promoting children's independence, parents take an active role in their children's lives and view children as a life long parental responsibility. According to Fred Mombeleur, Executive Director of Caribbean U-Turn, an agency for youth and families involved with the juvenile justice system and youth deported to Haiti for criminal behavior (personal communication, May 2003), "Haitian parents don't turn their kids out at age 18 or 21 and say 'that's it' ." Consistent with this strong sense of parental responsibility, the first author in her counseling work with Haitian families has observed parents sending money to adult children living in Haiti as well as in the U.S.

Haitian parents are often shocked at the disrespectful behavior they observe in "American" youth (Field, 2001) and frequently find themselves living in urban, low income environments plagued by drugs and violence (Stepick, 1998). Consequently, parents may become strict and overprotective, severely limiting where their children go, with whom, and at what time (Colin, 2001; Field, 2001). Parents are typically even more strict with girls than with boys (Colin, 2001).

Religion and belief in God are important Haitian cultural values (Leininger, 1991). Haitians have strong religious beliefs (McEachern & Kenny, 2002) and high rates of church attendance (Stepick, 1998; Stepick, Stepick, Eugene, Teed, & Labissiere, 2001). A majority of Haitians identify as Catholic, the official religion in Haiti since 1860 (Weil et al., 1985). Vodun (i.e., Voodoo, Vodoun, Vodou), a union of Catholicism and African beliefs from Nigeria, Congo, and other enslaved colonies is practiced mainly by the lower or peasant classes (Bibb & Casimer, 1996; Colin, 2001). However, the belief system that underlies Voodoo has traditionally been an integral part of Haitian culture (Courlander, 1966). DeSantis and Thomas (1990) argued that voodoo shapes almost every aspect of Haitian culture and health practices. Vodouo, like the West African religions with which it shares a common heritage, asserts that gods and intermediary spirits may be appeased through sacrifice and manifested through spirit possession (Miller, 2000). Fate is pre-determined but can be altered with the aid of spirits and gods.

Finally, Haiti is a patriarchal society (Weil et al., 1985), and values with respect to gender and sexuality may have relevance for HIV prevention and other reproductive health related research. For example, sex is not discussed openly between parents and children

(McEachern & Kenny, 2002), and societal norms limit open communication about sex between partners (Holschneider & Alexander, 2003). Additionally, men are traditionally seen as dominant, and women are viewed as passive and obedient (Bibb & Casimer, 1996). These gender roles carry over into sexual relationships (Holschneider & Alexander, 2003; Ulin, Cayemittes, & Gringle, 1996).

As in other patriarchal societies, girls are expected to preserve their virginity for marriage (Centres pour le Developpement et al Sante [CDS], 1995; Ulin, Cayemittes, & Cringle, 1996). However, as with Latinas, this value can change as girls become more acculturated. For example, only 37% of the adolescents in a study by DeSantis and colleagues (1999) agreed that premarital sex was inappropriate for adolescent Haitian girls.

Meanwhile, early initiation of intercourse and having multiple partners is seen as important for male sexual prowess or as a sign of masculinity (Holschneider & Alexander, 2003). Consequently, having multiple partners (Adrien, Cayemittes, & Bergevin, 1993; Desormeaux et al. 1996; Pape et al., 1985), and engaging in premarital sex and unofficial polygamy have traditionally been accepted behaviors for men within the Haitian culture (Pape et al., 1986).

Cultural values may make Haitian people particularly vulnerable to HIV, but it is the Haitian experience with HIV that has profoundly shaped the community's response to the U.S. research community. The stigma created through this experience significantly impacts research participation and health care seeking behavior.

HAITAIN EXPERIENCE WITH HIV

Early events in the history of HIV have had lasting effects upon the Haitian community. Early in the epidemic when a small number of AIDS cases within the U.S. Haitian immigrant community became identified, the U.S. press speculated that HIV in Haitians was transmitted through bizarre voodoo rituals (Farmer & Kim, 1991) or sexual practices (Sabatier, 1988). The press, with the support of the scientific community, helped create a wide spread belief that AIDS originated in and was pervasive throughout Haiti (Viera, 1985). In 1982, Dr. Bruce Chabner of the National Cancer Institute announced that vacationing New York homosexuals brought "an endemic Haitian virus" back to the US (Farmer & Kim, 1991, p. 207), and the Centers for Disease Control and Prevention (CDC) included being Haitian as a risk factor for AIDS (CDC, 1982). The effect of these public statements by the scientific community and the misinformation in the press created a tremendous backlash against the Haitian community. Non-Haitians would not frequent Haitian businesses, allow their children to attend school with Haitian children, or wash their clothes in the same washing machine. Haitian families were evicted from their homes, Haitian workers were abruptly fired, able working adults were refused employment; and hospitalized Haitian patients were put into isolation (Casper, 1986; Farmer & Kim, 1991; Sabatier, 1988). To this day, some Haitians still harbor resentment over the allegation that AIDS was endemic to their country and communities in the U.S.

It is difficult for non-Haitians to grasp the depth of stigma regarding HIV that exists within the Haitian community because of the early politics of HIV. The Haitian community has internalized the stigma and rejection of the dominant society (Boyd-Franklin et al., 1995; Santana & Dancy, 2000). There is a tendency to assume that all sick Haitian persons are infected with AIDS regardless of their illness and to reject and distance from such people (Santana & Dancy, 2000). Haitians who are HIV positive hide their status (Martin, Rissmiller, & Beal, 1995), living in fear that someone will find out and tell their friends that they have the "little beast" (C. Calixte, personal communication, August 2004). Entire church communities, including the pastor or minister, may reject the individual once they learn that they are infected (C. Calixte, personal communication, August 2004).

Both HIV stigma and the circumstances that contributed to its development impact participation in HIV related research and treatment. Haitians may avoid participation in surveys and screening programs out of fear of being identified as being HIV positive (Adrien et al. 1994). They distrust members of the scientific, public health, and medical communities (Farmer & Kim, 1991). For example, Farmer and Kim (1991) described how a young HIV positive man questioned his diagnosis, believing his doctors gave him the diagnosis so he could be a "guinea pig for their experiments" (p. 203) and how a group of Haitian teens involved with a AIDS education project distrusted the intentions of state public health authorities when these authorities reached out to support their

efforts.

Haitian history, culture, and experience with HIV present challenges for developing culturally relevant and effective HIV prevention strategies and for conducting the ethical research needed to evaluate these interventions. Cultural values of respect for authority and for educators along with the poverty associated with being both Black and an immigrant in the U.S. create unique vulnerabilities with respect to voluntary participation. Family values call for different approaches to recruitment of children and obtaining a child's assent. The Haitian experience of research and science with respect to HIV and a historical sense of ill-use on the part of the U.S. government may recast research participation as an opportunity for institutional restitution.

CONDUCTING ETHICAL RESEARCH IN A CONTEXT OF HAITIAN HISTORY, CULTURE, AND EXPERIENCE WITH HIV

In July 2004, we conducted a pilot study of a potentially culturally relevant, six session HIV prevention intervention. The study involved asking Haitian adolescent girls ages 14 to 17 to complete pre- and posttest self-administered, paper-pencil and on-line questionnaires and to participate in focus groups about each intervention session. Questionnaire data were anonymous, and data were linked by having participants generate their own code names. Focus group discussions were audiotaped.

The first author had worked with a counseling program at a Haitian social service agency for over a year prior to the study. Colleagues at the agency became key informants providing input and guiding decisions regarding subject recruitment, informed consent processes, and participant incentives. They facilitated entrÃ©e into the community, publicly validated the intentions of the research team, and later assisted with conducting the study. Additionally, these key informants and other professionals in the Boston Haitian community provided important insights into the community's values and concerns.

Next, we discuss the challenges of conducting ethical research with Haitian minors that we encountered and our strategies for resolving them. Specifically, we review (a) strategies with respect to recruitment, informed consent, and participant incentives; (b) the relationship of these strategies to our prior discussion of Haitian history, culture, and experience with HIV; and (c) an Institutional Review Board for the Protection of Human Subjects' (IRB) concerns with some of our strategies and our resolution of these issues.

Recruitment

We used three strategies to recruit 20 Haitian adolescent girls for the study:

* The first author participated in a community-based Kreyol radio show.

* An evening parent information session was held.

* Information packets were distributed to girls who attended an after school program.

On the radio show, during the information session, and in informal interactions with parents and their daughters at the agency, we used our first names but clearly identified ourselves as nurses and professors. We did this to help decrease any tension that might arise from our study's challenge to the cultural taboo against talking openly about sex. We also created a flyer for the study that was included in the information packet that we distributed to parents or adolescents who were interested in participating. It was our impression that the flyer was not needed as much for recruitment as it was for legitimacy in the community (i.e., "serious" or "good" researchers have a flyer).

The IRB initially questioned the need for "our aggressive subject recruitment" but came to understand that while this type of recruitment might be aggressive for some ethnic groups, it was culturally appropriate for Haitian Americans. To recruit Haitian adolescent girls, we needed to directly recruit their parents out of respect for and recognition of their authority role in the family and because parents view themselves as the ones who decide what activities are and are not acceptable for their daughter. Meanwhile, we needed to recruit the daughters directly to avoid being caught up in any intergenerational conflict arising from different acculturation

rates between Haitian parents and their children. Finally, we needed to use different recruitment strategies because of the "different worlds" in which parents and children live. Hence, we chose the after school program as a point of contact for the girls and the Kreyol radio show as a point of contact for the parents.

Both parents and daughters were actually invited to the "parent" information session, but the purpose of this session and the radio show was to reach out to parents in a way that would not only allow them to ask questions but (also) give them a personal sense of who we were. We thought that this was particularly important given the community's history with respect to HIV and the level of distrust of the scientific community that has been engendered, and our key informants concurred. Moreover, given the cultural taboos against talking openly about sex, we wanted the parents to feel very comfortable with who we were as professionals. Additionally, the parent information session provided concrete opportunities to show parents how we would treat their daughters. For example, we provided a meal and discussed the foods we would serve their daughters at the focus groups.

Following our key informants' recommendations, we intentionally used Kreyol phrases in our recruitment materials. For example, we used Kreyol names for different parts of the study. Our key informants encouraged use of Kreyol to emphasize that the study was for Haitians and to indicate our appreciation for Haitian culture. We did not translate our recruitment materials (i.e., letter, flyer) or consent forms into Kreyol because our key informants explained that many Haitians cannot read and write in Kreyol. When we raised concerns about parents who could not read and write in English, we were assured that if this was the case, there would be a friend or family member who could translate materials. Additionally, our key informants were available to provide translation for any parents who needed assistance, a common service provided by the agency.

Informed Consent

Although we used written assent and consent forms for girls and their parents, we also used various verbal strategies to ensure that participation was truly voluntary and that participants understood that they could choose not to answer questions. We used these strategies in response to two concerns arising from our understanding of Haitian culture that we feared might limit the girls' ability to freely assent to participate in the study activities:

* The girls would perceive us as authority figures deserving of respect (i.e., teachers) who they should obey.

* Parents would strongly encourage the girls to participate because of a desire for them either to acquire preventive health care information or to interact with a college professor who might help them with their academic goals.

Hence, we used a verbal consent procedure to review information on the consent form and made sure the girls had no questions. We then verbally repeated our consent process prior to asking the girls to complete study questionnaires or participate in a focus group. And perhaps most importantly, in our verbal presentation, we used examples to illustrate how research participation was different from a job:

If this was a job, I could tell you to scrub the floor with a toothbrush, and you would have to do it if you wanted to be paid, but this is a research study. In a research study, if I tell you to scrub the floor with a toothbrush, you can refuse, and it's okay.

Then we related the idea behind the example back to what the girls were being asked to do:

So since this is a research study, it means that if you don't want to answer a question on the questionnaire, you don't have to. You can just skip it. And we will never know because your name is not on this questionnaire anyway.

Providing tape recordings of someone reading the consent form information in Kreyol is a strategy we did not use, but one which might be particularly useful for a study involving adults or recent immigrants (Martin et al., 1995).

Research Incentives

Research incentives were problematic in this study because the IRB's recommendations were directly at odds with those of our key informants. Each group was concerned about exploitation but had opposing definitions of what constituted coersion. Additionally, IRB members saw their role as protective, but the key informants perceived the IRB's recommendations to be paternalistic and racist. We realized that the cultures of the two groups were at odds and found ourselves translating the concerns of each group into cultural terms that the other could understand. Through this process of familiarizing each group with the other's culture, we were able to reach an acceptable compromise.

Our key informants initially recommended that we pay our participants in cash: $50 per on-line questionnaire ($100), $100 for completing the intervention, $20 for focus group participation. They based their recommendations on what they were accustomed to seeing in non-biomedical HIV-related research involving adults and HIV outreach programs targeting adolescents that used a train the trainer model.

Our initial proposal to the IRB included our key informants' recommendations. The IRB immediately expressed concern about the use and amount of cash incentives proposed; members did not approve of the use of cash and questioned how it might be spent. IRB members felt the amount was exploitive because teens, especially low income teens, would have difficulty refusing to participate. They suggested offering a smaller incentive in the form of a $50 gift certificate or a compact disk and/or providing a pizza party and special t-shirts as incentives and gifts.

Our key informants were shocked by the IRB recommendations. They felt that the girls should be given money so that they could spend it as they wished. They were perplexed by the idea of giving out t-shirts and food as incentives. They did not view such goods as incentives and thought that it was "unjust" to ask Haitian girls to be in a study and only offer such things. When the first author prompted, they readily agreed that science had ill-used the Haitian community in the past with respect to HIV, and they did not want this to happen again.

Because we had a foot in each culture, we were able to explain (a) the concerns of IRB members regarding voluntary assent to our key informants, and (b) the meaning of IRB recommendations within a context of Haitian history, culture, and experience with HIV to members of the IRB. The first author's close relationship with the key informants enabled her to see past the key informants' initial polite response. Using knowledge of Haitian culture, she translated the IRB's concerns regarding voluntary assent into the IRB's desire to protect the girls from being exploited. The key informants could then appreciate the sentiment behind the IRB recommendations, even though they did not agree with the recommendations. In the end, a compromise was reached. Girls received a $20 gift certificate each time they completed an on-line questionnaire, attended an intervention session, or attended a focus group. Instead of cash, girls were given a list of gift certificates to choose from, and we soon learned that the flexibility of shopping mall gift certificates made these incentives desirable to Haitian adolescents.

DISCUSSION

Conducting culturally competent research challenges researchers to communicate to IRBs an appreciation of a particular group's historical and cultural context gained from months to years of work within a particular community. At the same time, researchers are challenged to communicate information regarding the historical and cultural context surrounding human subjects research to members of cultural communities. The stakes are high. If all involved do not understand context, the protection of human subjects could be ineffective as well as incongruent with a community's history and culture.

The core values of autonomy, beneficence, and justice in protecting human subjects are essential for all research, regardless of the research population. It is crucial to engage researchers and IRBs in a process that ensures these core values are followed in a manner that is culturally relevant for members of particular immigrant or minority communities. We suggest three ways to accomplish this goal. First, research teams may want to submit a brief historical and cultural review that helps IRB members understand the use of particular recruitment approaches. Second, researchers should either be invited to speak at IRB meetings or to meet with a

designated member of the committee before the meeting to explain rationales behind unique approaches. Lastly, we suggest that members of minority or immigrant communities be invited to sit on IRBs to help identify research procedures that are both culturally relevant and consistent with the core values of autonomy, beneficence and justice. Such active participation of community members directly brokers cultural relevance and is consistent with the spirit of current National Institutes of Health (NIH) recommendations related to IRB membership:

Membership should be diverse regarding race, gender, cultural heritage . . . If the IRB regularly reviews research that involves a vulnerable category of subjects such as children, prisoners, pregnant women, or physically or mentally disabled persons, consideration shall be given to the inclusion of one or more individuals who are knowledgeable about and experienced in working with these subjects. (NIH, 2004 Â¶3-2)

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ACKNOWLEDGMENTS: We wish to thank Colbert Calixte, Claudine Guerrier, and Fred Mombeleur for their information regarding Haitian culture and Haitian families and our key informants, Carolle A. Millien and L. Oswald Neptune, without whose invaluable assistance and insights the pilot study discussed here could never have been done.

FUNDING SOURCE: Support for this study was provided by a Boston College Research Incentive Grant.

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