ASSESSING KNOWLEDGE, ATTITUDE, BEHAVIOR, AND PRACTICES RELATED TO HUMAN IMMUNODEFICIENCY VIRUS INFECTION AND ACQUIRED IMMUNODEFICIENCY SYNDROME IN A UNITED STATES-BASED REFUGEE POPULATION

by

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ABSTRACT

Human Immunodeficiency Virus infection (HIV) and Acquired Immunodeficiency Syndrome (AIDS) continue to be major global health priorities. Although forced displacement is believed to fuel HIV/AIDS epidemic in countries affected by conflict, factors associated with forced displacement and HIV risk in conflict-affected populations are not well understood. The aims of this study were therefore (1) to describe factors that influence risk for HIV infection in a Utah-based Burundi refugee population and (2) explore relationship between Knowledge, Attitudes, and Behavior/Practices (KABP) in order design targeted HIV/AIDS prevention interventions for the population. We conducted a systematic review of studies on HIV/AIDS risk and protective factors and interventions that target HIV risk factors. Although the review found a plethora of data collection tools, there was marked shortage of culturally appropriate instruments with demonstrated reliability or validity. We therefore designed a valid, reliable, culturally appropriate questionnaire for use in assessing HIV/AIDS knowledge, attitudes, and behavior/practices. The questionnaire was administered in a cross-sectional study to a random sample (with replacement) of 215 Burundi refugees (n = 76 and age ≥ 12). The main outcome measure was behavior/practices. Predictor variables were: (1) knowledge; (2) Attitude; (3) self-efficacy. Univariate, bivariate, and multivariate analyses were performed. Regression models were developed to highlight significant predictors of HIV infection in the population. Results were controlled for known confounders. Questionnaire reliability was satisfactory (*Cronbach's Alpha* ≥ *0.70*). A 97.36% response rate was achieved. Significant predictors of protective HIV/AIDS behavior/practices were self-efficacy ($b = 0.248, p = 0.027$) and HIV/AIDS-knowledge ($b = 0.454, p < 0.001$). Attitude towards HIV/AIDS ($b = 0.5071, p < 0.001$) was a significant predictor of HIV/AIDS knowledge. Behavior/ practices were strongly associated with knowledge, attitudes, self-efficacy, gender, and household size. Overall, men were more knowledgeable than women

and had higher self-efficacy. Women had more positive attitudes and scored higher behavior/practices. These findings create foundational HIV/AIDS KABP as a basis for designing targeted, culturally-tailored HIV/AIDS interventions strategies for the population.

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CHAPTER 1

INTRODUCTION

Human Immunodeficiency Virus infection (HIV) and Acquired Immunodeficiency Syndrome (AIDS) continue to be major global health priorities. In regions affected by conflict, displacement is associated with increased HIV risk due to behavioral changes resulting from disruption of social-cultural networks, breakdown of traditional community support structures, lack of health infrastructure, socio-economic vulnerability, and increase in sexual violence particularly toward women and youth ([1-4]. Although displacement is not itself a risk factor for HIV, the circumstances associated with increased mobility such as inaccessibility of health services, socio-economic vulnerability or simply movement to higher HIV prevalence locations magnify risk for HIV transmission [5-7]. Other key factors associated with increased vulnerability to HIV infection include length of time in refugee camps, HIV prevalence in surrounding host populations and amount of interaction between refugees and host populations [1]. However, the common assumption that vulnerability to HIV infection translates into increased HIV incidence and consequently fuels the AIDS epidemic is not supported by data [7]. In the postconflict phase, context-specific factors that may contribute to increased risk of HIV transmission are less well studied [5, 8-9].

The purpose of this dissertation project was to assess knowledge about HIV infection and AIDS in the Burundi refugee population, investigate attitudes and beliefs related to HIV/AIDS, and identify behavioral factors associated with risk for HIV infection as a basis for designing targeted HIV prevention strategies. Data were collected using a structured, culturally and linguistically appropriate questionnaire designed for this study.

Specific Aims

The specific aims of this study were to conduct a systematic literature review of qualitative and quantitative studies on HIV/AIDS Knowledge, Attitude, and Behavior/Practices and HIV Behavioral Surveillance Surveys (BSS) undertaken in conflict and postconflict situations; (2) develop and administer a valid, structured, linguistically and culturally appropriate questionnaire to assess knowledge, attitudes, and behavior/practices in the Burundi refugee population; (3) conduct a cross-sectional study of HIV/AIDS knowledge, attitudes and behavior/practices among Burundi refugees (>12 years). The main outcome measure was HIV/AIDS behavior/practices. Predictor variables, designated as secondary outcome measures were (1) HIV/AIDS-knowledge; (2) Attitude; (3) Self-efficacy. Univariate, bivariate, and multivariate analyses were performed.

Methods

Specific Aim 1

Knowledge, Attitude, Behavior/Practices (KABP), Knowledge, Attitude, Practices (KAP) and Behavioral Surveillance survey (BSS) literature appearing in the period 1980 to 2010 were reviewed and evaluated based on methodological quality and use of internationally-accepted indicators for HIV/AIDS knowledge, practices and attitudes.

Specific Aim 2

A valid, reliable KABP questionnaire was designed for this study based on the literature review.

Specific Aim 3

A cross-sectional study was conducted to assess knowledge about HIV infection and AIDS in the US-based Burundi refugee population, investigate attitudes and beliefs related to HIV/AIDS, and identify behavioral factors associated with risk for HIV infection. Data were collected using the questionnaire developed in Specific Aim 2. Bivariate and multivariate analysis was conducted to highlight significant predictors of HIV infection in the population.

Summary

Detailed methodology for the three studies corresponding to each Specific Aim is described in detail in Chapters 2, 3, and 4.

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CHAPTER 2

A SYSTEMATIC REVIEW OF HIV/AIDS LITERATURE IN CONFLICT AND POSTCONFLICT SETTINGS

Abstract

Widespread concern about high rates of HIV and AIDS globally has led to greater demand for effective HIV prevention programs. In recent years, researchers have turned their attention to a growing range of social and health conditions in complex emergencies that place affected populations at increased risk for disease including HIV/AIDS. To better understand the factors that affect HIV/AIDS risk among conflict-affected populations, we conducted a systematic review of studies on HIV/AIDS risk and protective factors and interventions that target HIV risk factors. The aim of this study is to summarize published scholarship in these areas. We searched both academic and grey literature for etiological survey studies of HIV risk and protective factors and HIV/AIDS intervention studies conducted between 1980 and 2010. We evaluated the studies under seven broad categories: title and background; year study was conducted; study setting; report type; study design; organization responsible for the study; and main findings from the study. A three-point screen was then applied to each study based on three methodological features: (1) Background and Objectives; (2) Methods; (3) Results/Discussion/Interpretation. We evaluated each study based on use of internationally accepted indicators for HIV-related KABP. One hundred ninety-one KABP and Behavioral Surveillance Surveys (BSS) surveys met our search criteria. We included 54 studies in the final review: 38 conducted in postemergency/camp situations and 16 conducted when durable solutions were secured. We found that sound, evidence-based research aimed on HIV/AIDS knowledge, attitudes and behavior/practices among conflict-affected populations is lacking; factors that affect HIV transmission in conflict-affected populations are not well elucidated; and

refugees are not sufficiently included in host countries' strategic plans for HIV/AIDS. Data on the HIV epidemic for displaced populations are scarce and HIV prevention programs are either not implemented or interventions are not effectively targeted. There is a great need for evidence based research to guide development of culturally competent interventions for displaced populations.

Introduction

Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) is the fourth-leading cause of death worldwide [3]. According to statistics from the United Nations Joint Programme on HIV/AIDS (UNAIDS), close to 60 million people worldwide have been infected with the HIV virus since the beginning of the pandemic in 1981, and more than 25 million people have died of AIDS [2]. In the United States, it is estimated that 1.4 million people are living with HIV and that the death toll in 2008 alone was approximately 25,000 [2-3]. The projected discounted cost of medical care for HIV-infected adults using current antiretroviral therapy (ART) standards from the time of infection until death is approximately $385,200 [10].The epidemic has spread to every part of the world and to all sectors of society and is expected to have a severe impact on many economies around the world [3, 9].

Conflict, displacement, food insecurity and poverty have the potential to make refugees and other conflict-affected populations more vulnerable to HIV transmission [5, 7]. At the end of 2009, there were more than 42 million people forcibly uprooted by conflict and persecution worldwide, including 16 million refugees outside their countries and 26 million others displaced internally [11]. The global number of refugees and displaced people continues to rise [11]. A significant proportion of people living with HIV/AIDS throughout the world (between 8% and 10%) are affected by conflict, humanitarian crisis and/or displacement [2]. In regions affected by conflict, displacement is associated with increased risk of HIV transmission among affected populations because of behavioral changes resulting from disruption of social-cultural networks, breakdown of traditional community support structures, lack of health infrastructure, socio-economic vulnerability, and increase in sexual violence particularly toward women and youth [5,

7]. Although displacement is not itself a risk factor for HIV, the circumstances associated with increased mobility such as inaccessibility of preventive and curative health services, socio-economic vulnerability or simply movement to higher HIV prevalence locations increase vulnerability to HIV infection [5]. Other key factors associated with increased vulnerability to HIV infection include length of time in refugee camps, HIV prevalence in surrounding host populations and amount of interaction between refugees and host populations [5, 7]. Although refuges are inherently more vulnerable to HIV during and after displacement, there is no evidence to support the claim that conflict-affected populations have a higher prevalence of HIV/AIDS compared to host populations [7].

United Nations High Commissioner for Refugees (UNHCR) seeks to alleviate situations of forced displacement and its aftermath by creating lasting solutions to the plight of displaced populations, asylum seekers and refugees [11]. The plan complements other international HIV and AIDS objectives and strategies, including the Millennium Development Goals (MDGs), the United Nations System Strategic Plan for HIV/AIDS (UNSSP) and the Unified Budget and Work plan (UBW). In support of UNHCR's strategic plan, data collection on refugee health in general has increased dramatically in recent years, and prevention efforts to promote changes in behavior are increasing. The Knowledge, Attitudes, and Behavior/Practices (KABP) methodology has been proposed as a means to establish baseline information on HIV/AIDS and to inform and guide the development of future programs on HIV and AIDS. Many surveys utilizing Knowledge, Attitudes, Behavior/Practices methodology seek to identify factors influencing behavior and, to some extent, explain why people practice certain health behaviors [12]. With regard to HIV/AIDS research, Knowledge, Attitude, Behavior and Practices (KABP) studies assess baseline levels of knowledge, examine attitudes towards HIV/AIDS and people living with AIDS, and identify behavior and practices that may influence HIV risk [1, 12-13]. Behavioral surveillance surveys (BSSs), an evolution from the KABP surveys are a tool to track trends in HIV/AIDS knowledge, attitudes and risk behavior among populations over time [1]. BSS surveys use reliable methods to track HIV risk behaviors over time as part of an integrated surveillance system which monitors various aspects of the epidemic [1]. Behavioral data can indicate which populations are at risk for

HIV infection, and can suggest the pathways the virus might follow if nothing is done to halt its spread [1, 14]. Both KABPs and BSS are especially useful in collecting data to inform local and national HIV/AIDS programming.

The aim of this study is to summarize published scholarship on etiological survey studies of HIV risk and protective factors and HIV/AIDS intervention studies that target these risk factors among displaced populations. A methodological critique of studies in this area is provided. We also identify gaps in the literature, and highlight areas where further research may be needed. Three interrelated research questions were developed to guide the literature search and to focus the review:

1. What methodological approaches are used to investigate risk factors for HIV infection among conflict-affected populations?
2. What factors affect HIV infection risk among conflict-affected and displaced populations?
3. To what extent are the methodological approaches suited for investigating risk factors for HIV infection among conflict-affected populations?

Methods

Search Protocol

All academic literature spanning a 30-year period from 1980 to February 2010 was searched without language restrictions to identify papers that deal with the topic of HIV/AIDS and conflict. The search activities comprised three main strategies:

1. A computer-based search of electronic databases (Medline, PsychInfo, PubMed, and Embase) using the following keywords, individually or combined, chosen to reflect different words and terms used in refugee-related literature: refugee, returned refugee, displaced person, or asylum seeker. To be eligible the title and abstract when available had to describe HIV/AIDS Knowledge, Attitudes, and Behavior/Practices of the populations studied.

2. Manual scanning of reference lists of articles identified through the first search to identify other potentially useful references within the data span.
3. Manual browsing through journals and books in order to retrieve relevant documents not detected by the previous two strategies. We searched through journals considered to be particularly relevant to the topic of HIV/AIDS: the American Journal of Public Health, the American Journal of Epidemiology, and the Journal of Health and Social Behavior.

To identify applicable quantitative or qualitative literature that was not reflected in the published academic literature, Web-based searches were performed on databases of agencies with operations in either conflict or postconflict settings. This review process began with a scan of local organizations that provide services to refugees, and expanding to national and international sources of gray literature. Local organizations identified or referenced in the initial search include the International Rescue Committee (IRC), Catholic Community Services (CCS), and the Asian Association of Utah (AAU). At the national and international level, several organizations were identified including the United Nations High Commissioner for Refugees (UNHCR), The United Nations Joint Programme on HIV/AIDS (UNAIDS), Centers for Disease Control and Prevention (CDC), and the World Health Organization (WHO) and United States Agency for International Development (USAID). We performed searches on the organizations' databases using the terms HIV, AIDS, behavioral surveillance survey, knowledge, attitudes practice, knowledge, attitudes behavior, practice, refugee, refugee returnee, internally displaced person, and conflict and postconflict in various permutations to identify papers, documentation, raw data, reports, newsletters, commentaries, editorials, and journal articles that deal with the topics of HIV and AIDS. Abstracts were read and appropriate articles retrieved for further review. When titles or abstracts were found but the complete articles were not available, authors and organizations responsible for the reports were contacted directly whenever possible.

Inclusion and Exclusion Criteria

We collected all available HIV/AIDS publications with a knowledge, attitudes or behavior/practices component in conflict and postconflict settings. Titles and abstracts were screened either manually or automatically by placing limits on subsequent searches using a specified inclusion and exclusion criteria. Inclusion criteria for article selection were as follows:

1. articles published in English;
2. articles including at least one conflict-affected population;
3. studies conducted in either developed or developing countries;
4. publications reporting quantitative epidemiologic data with reference to specific attitudes, behavior or practices regarding HIV/AIDS for the group(s) studied.

We excluded articles based on the following criteria:

1. publications in foreign language(s) where translation was not available;
2. abstracts for which full-length articles could not be retrieved from target databases or obtained from the authors;
3. studies conducted with one or more populations, but findings were not disaggregated to differentiate conflict-affected populations from other populations included in the study;
4. publications reporting quantitative epidemiologic data with no reference specific attitudes, behavior or practices regarding HIV/AIDS for the group(s) studied.

Data Abstraction

A data abstraction form was developed to capture and organize data from each eligible study. Studies were evaluated, categorized and entered into an Excel database according to Title and Background, Year when study was conducted, Study setting, Report type, Study design, organization responsible for conducting or funding the study and studies' main findings. A three-point methodological screen was then applied to each study based on recommendations from Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) on accurate

reporting of observational, cross-sectional studies [15]. Detailed evidence tables based on STROBE's recommendations were constructed for each study. The evidence tables include:

1. background and objectives
2. methods
    a. study design
    b. recruitment and sampling methodology
    c. ethical aspects/human subjects
    d. methods of assessment (measurement)
    e. conceptual and theoretical frameworks
    f. statistical analyses
3. results/discussion/interpretation

Table 1 presents methodological summaries of studies meeting our inclusion criteria.

Each study was also evaluated based on use of internationally accepted indicators for HIV-related Knowledge, Attitude and Practices/Behavior developed by the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), the Millennium Development Goal (MDG) project, and the US President's Emergency Preparedness Fund on AIDS Relief (PEPFAR) (Table 2). The indicators refer to 1) general knowledge of HIV/AIDS (prevention and misconceptions); 2) attitude towards HIV/AIDS and people living with HIV/AIDS; and 3) HIV/AIDS risk Behavior/Practices.

Results

Initial search using the specified keywords yielded a total of 132 academic publications and about 59 articles from grey literature. Grey literature articles consisted of seminar reports, field manuals and guidebooks, 'Best Practice Strategies', case studies, narrative commentaries, editorials, and informal reports. Searches for both academic and grey literature were further refined using specified inclusion and exclusion criteria, eliminating 137 publications that did not describe HIV/AIDS knowledge, attitudes, behavior or practices of conflict-affected populations. Of the 54 surveys included in the final review, 38 were conducted in postemergency camp situations

Table 1

Methodological Summaries of Studies Meeting Inclusion Criteria

	Number of Studies
Qualitative study design	17
Quantitative study design	14
Mixed methods study design	12
Study design not specified	9
Use of Internationally accepted key indicators for HIV/AIDS knowledge, attitude and practices/behavior	16
Results for HIV/AIDS indicators disaggregated by age or gender	11
Procedures for selecting samples discussed	39
Procedures for determining statistical power discussed	38
Explicit description of inclusion and exclusion criteria	34
Sampling procedures discussed elsewhere	6
Study monitored or reviewed by an Institutional Review Board or other similar ethics review committee	9
Utilized one or more behavioral models	9
Used validated questionnaire/survey instrument	2
Questionnaire/survey instrument back-translated	8
Questionnaire/survey instrument appended	14
Performed statistical analysis	17
Trained interviewers	2
Questionnaire/Instrument appended	8
Conducted statistical tests	17
Named statistical software	14
Performed descriptive analysis	48
Performed inferential analysis	2
Stated limitations and biases	14
Stated conclusions or provided recommendations	51

Table 2

Evaluation on User of Internationally Accepted Key Behavioral Survey Indicators for HIV /AIDS Knowledge, Attitude, and Practices/Behavior

Indicator	Question
Standard prevention questions or similarly worded questions	People can protect themselves from contracting HIV by having sex with only one faithful, uninfected partner.
	People can protect themselves from contracting HIV by using condoms.
	People can protect themselves from contracting HIV by having sex with only one faithful, uninfected partner.
General questions	A healthy-looking person can have HIV.
	Standard misconceptions questions or similarly worded questions
	A person can get HIV from mosquito bites.
	A person can get HIV from sharing a meal with someone who is infected.
Standard attitudes questions or similarly worded questions	Would be willing to care for a family member who became sick with the AIDS virus?
	Would buy fresh vegetables from a vendor whom they knew was HIV/AIDS?
	A teacher who is HIV/AIDS/ but not sick should be allowed to continue teaching in school.
	Would not want to keep the HIV/AIDS/ status of a family member a secret?

and 16 were conducted after repatriation. Repatriation is the final phase, when durable solutions are secured, and refugees return to their home countries, are resettled in a third country, or are permanently integrated within their host country. The review of literature in this study used both academic and non-academic studies. We designed a strategy to retrieve studies that meet our inclusion criteria. Figure 1 represents the selection strategy for studies meeting the inclusion criteria. This report synthesizes the studies, organizes, and summarizes the conclusions of many researchers in terms of the three research questions stated above.

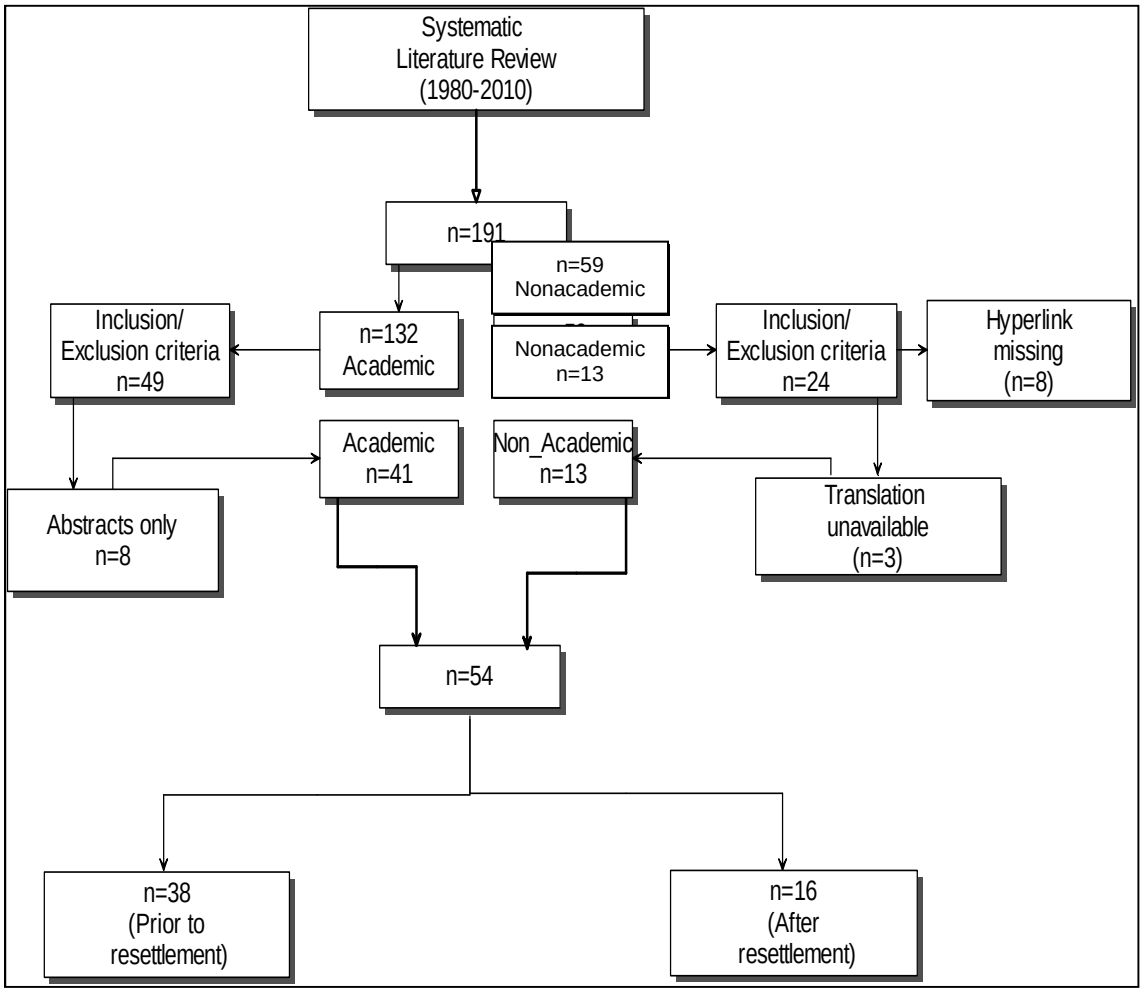

Figure 1. Selection Strategy for Studies Meeting Inclusion Criteria

Research Question 1: What Methodological Approaches Are Used to Investigate Risk Factors for HIV Infection Among Conflict-Affected Populations?

Since the advent of HIV/AIDS in the early 1980s, quantitative and qualitative methods have been widely used to gather data on HIV knowledge, attitude and practices. A wide range of quantitative, qualitative, or mixed-method approaches have been used to investigate HIV/AIDS Knowledge, Attitude and Practices/Behavior in conflict and postconflict settings.

Twenty-six out of the 54 studies reviewed used participant observations, interviews, surveys, focus group discussions, in-depth interviews, content analysis, or ethnographic accounts to gather data on HIV/AIDS. Qualitative research was especially effective in obtaining culturally specific information about values, opinions, behaviors, and social contexts of specific populations. Studies utilizing focus group methodology found that forming small, nonthreatening groups gave participants the courage and opportunity to discuss sensitive topics such as sexual behavior and share experiences that they had never before discussed openly [16-18].

Quantitative approaches consisted of cross-sectional KABP studies, rapid needs assessments, and field surveys. Thirty-nine studies were solely qualitative, 7 were solely quantitative, and 8 combined both quantitative and qualitative methods. Although quantitative methods were shown to produce potentially generalizable findings, processes for data collection, analysis, and interpretation were often called to question [14, 16-17, 19]. Furthermore, some variables used in the surveys were too complex to measure. For example, accurate assessment of individuals' socioeconomic status (SES) requires unbiased measurement of components that make up SES, such as income, residence, education, and occupation. Determining the relative weight of each of these components could be a daunting task in data analysis phases [14, 19]. Studies combining both qualitative and quantitative methods proved to be more effective in assessing HIV/AIDS needs than either method used individually. A combined approach was used in a rapid STI 'knowledge, attitudes, beliefs and practices' (KABP) survey, conducted among a random sample of refugee men and women from Rwanda and Ngara Districts in Tanzania [17]. First, a series of focus group discussions was held to determine the main topics to be explored and investigate the terminology that was used locally for HIV/AIDS and STIs. This

was then complemented by a community-based survey, in which a structured standardized questionnaire was administered to participants in the sample.

Anthropological techniques were also common in both conflict and postconflict settings. Conducting anthropological research however proved to be a difficult undertaking for researchers due to lack of collaboration. In the Rwandan refugee camp in Tanzania, suspicion of researchers' underlying motives, mistrust, manipulation, and, sometimes, outright deceit compromised validity of the data gathered [19]. Relief workers often lacked conviction helping people who had participated in genocide, and aid recipients were often suspicious of the efforts made to help them. In order to circumvent this persistent aura of falsehood, researchers were forced to make unprecedented revisions to their study methods; data collection strategies were expanded to include focus group discussions [17, 19].

Epidemiologic surveillance systems and antenatal-care sentinel sites were used to monitor health trends, keep abreast of events, and to safeguard human rights during conflict and in periods immediately following conflict [1]. Antenatal-care clinics provide the most accessible cross-section of healthy, sexually active women in refugee and general populations, and were the most common sites for sentinel surveillance in most developing countries [1]. Both epidemiologic and antenatal-care sentinel surveillance systems were used extensively to describe distribution and dynamics of HIV/AIDS and to track and report AIDS cases during conflict and during periods immediately following conflict [1, 7].

However, AIDS surveillance in these settings is not practical because of the delay between HIV infection and onset of clinical symptoms. Substantial under-reporting due to stigma attached to HIV diagnosis was noted [19]. Another limitation of HIV/STI surveillance methods is that HIV prevalence figures reflect a mix of old and new infections. Thus, their use for documenting recent changes in new infection rates is limited. Low prevalence in a population may signify fewer new infections, or it could mean more deaths. When prevalence is continually low, it may be because the virus has not yet reached a critical level in the target population or it simply may mean the target population does not engage in HIV risk behavior [1]. Where this may have been the case, the opportunity to plan preventive programs before the virus spreads

uncontrollably through populations with HIV risk behavior may have been lost. HIV surveillance is therefore not by itself equipped to record risk behaviors that may exist among conflict-affected populations. A new framework that uses behavioral data to plan programs aimed at reducing risk for HIV infection before the virus explodes through a population is warranted [1].

Informal, unstructured surveys were common in both conflict and postconflict settings. Refugees especially in postconflict settings were often subjected to multiple surveys and interviews, often without their consent or approval from Institutional Review Board or other similar ethics review committee [20]. Researchers' motivation and honesty have often been called into question. There is increased interest in research that aims to improve the health of disadvantaged populations, including conflict-affected populations. However, conventional research in these communities has a contentious history and offers limited opportunities to improve the health and well-being of these communities [19-20]. In order for communities to benefit from HIV prevention programs, effort should be made to obtain the support of community leaders when conducting needs-assessments and surveys. Effective methods that give conflict-affected people a voice in identifying and solving health problems affecting their communities are needed [20].

Community-based participatory research (CBPR), where researchers and community members work together in collaborative, nonhierarchical partnerships, show promise for improving the health of communities [20]. The CBPR process engages community members, employs local knowledge in addressing health issues, and involves community members in all research processes. A CBPR study aimed at exploring Somali immigrant women's attitudes, perceptions, and cultural values affecting their use of reproductive health care shows that engaging community members in all phases of the research process is critical to building trust and facilitating ethical conduct of research within communities [20]. A highly successful initiative, the Somali Women, Sexuality, and HIV/STD Prevention Project, created by the University of Minnesota's Program in Health Disparities Research (UMN PHDR) and School of Public Health, utilized the CBPR model to investigate health-related problems in the Somali, Latino, and Hmong communities [20]. The Somali Women, Sexuality, and HIV/STD Prevention Project was designed

to examine Somali women's knowledge of and attitudes about HIV and AIDS, and behaviors that might contribute to the transmission of HIV or prevent HIV infection, with the ultimate goal of developing culturally appropriate HIV counseling and testing services for Somali women.

A similar study on knowledge, attitude, and practices regarding HIV among Congolese refugees in Tanzania found that community-based outreach by refugee health workers was conducive to risk behavior prevention in the postemergency camp setting [21]. In general, programs utilizing a community-based approach and a system of outreach by AIDS educators selected and trained from the refugee population were shown to be effective in addressing HIV risk behavior in postconflict setting [20].

This review draws attention to the need for more scientific-based evidence to guide the development of targeted HIV prevention programs for conflict-affected populations. Effective methods to assess HIV risk in populations affected by conflict are needed in order to characterize the HIV epidemic and provide a rational basis for designing HIV prevention programs for this population.

Research Question 2: What Factors Affect HIV Infection Risk Among Conflict-Affected and Displaced Populations?

Complex socioeconomic and cultural factors unique to displaced populations have been shown to impact HIV risk behavior in conflict and postconflict settings, for example, sexual violence and abuse, destruction of families, loss of homes and income, deterioration of social structures, unraveling of social mores, and commercial sex trade within refugee camps [1, 5, 7]. Other factors that have been shown to increase vulnerability to HIV infection during these phases include lack of health infrastructure and inaccessibility of treatment and support services [1, 17]. While public health interventions can help to reduce HIV risk, prevention efforts are greatly constrained by prevailing social-cultural norms, beliefs, myths, taboos, and misconceptions about HIV transmission and prevention [14, 19].

A baseline survey on Knowledge, Attitudes, Beliefs and Behavior (KABB) among Rwandan women found that parents do not discuss with adolescents matters related to sex [16]. The same study reported high level of awareness of HIV/AIDS prevention and transmission,

largely due to aggressive anti-AIDS campaigns before the onset of conflict in Rwanda. However, AIDS prevention efforts did not lead to increased condom use as more people sought treatment and counseling for STIs in the 12 months following the campaign. Although more than 50% of the respondents perceived themselves to be at moderate or high risk for HIV infection, only 16% of the men reported using a condom during their most recent casual sexual encounter. This study also revealed reluctance of women to suggest condom use to their partners because condoms were often associated with promiscuity.

According to a KABP study among Congolese refugees in Tanzania, HIV risk behavior, particularly transactional sex, increased significantly in the period following displacement [21]. Although radio broadcast messages were thought to promote awareness of HIV transmission within the refugee community, use of condoms remained low even among those living with AIDS. However, refugees involved in transactional sex used condoms through their own health initiatives, under the influence of peer refugee health workers. Among women, a common myth suggests that condom use provokes caesarian section and abnormal child birth. Despite ever-increasing awareness regarding the importance of HIV prevention for conflict-affected populations, as well as the consequences of unprotected sex, inattention continued to place these individuals at risk for HIV infection.

A study on Women's Adaptive Behavior at Benaco Refugee Camp in Tanzania reported postmigration increase in HIV risk for women due to gender based violence, rape, torture, abduction, forced marriage, slavery, trafficking and forced pregnancies [19]. Women in refugee environments found themselves in high risk situations where they faced constant threats of violence and potential exposure to HIV/AIDS [5, 19]. Gender violence in the camps, including domestic violence within households, prevented women from being able to protect themselves. War erodes traditional practices that promote respect and gender balance in societies, engendering a culture of violence that permeates the society [5]. Abusive behavior in the camps was often excused as "cultural practices" with the rationalization that such behavior is part of the culture [5]. Cultural taboos against women speaking out, coupled with shame and fear of not being believed prevented many women and girls from reporting rape or other human rights

abuses [19]. Even when women were not victims of domestic violence or sexual assault, they often felt powerless to negotiate safe sex or suggest condoms to their partners because condom use was associated with promiscuity [19]. Other factors shown to increase vulnerability to HIV infection among conflict-affected populations include language and cultural barriers, misconceptions about HIV/AIDS, and intense stigmatization [22-23]. These findings demonstrate a need for innovative, culturally-sensitive, gender-specific strategies to avert HIV/AIDS for conflict-affected population.

Refugees are more vulnerable to HIV not only due to lack of access to medical services, but also due to discrimination and stigma associated with HIV/AIDS within both the refugee and host populations. According to a study on communicable diseases among displaced Afghans, lack of resources and services in health, discriminatory practices, stigma and negative attitudes towards people with HIV contributes to increased susceptibility to HIV infection [24]. A study conducted among refugees in Egypt found that HIV-positive refugees' access to health care in Egypt is impeded by discrimination and intense stigma associated with HIV/AIDS [25]. The study reported that refugees were denied access to national HIV/AIDS services, and were left to depend on Nongovernmental Organizations. Although HIV/AIDS information may help to increase knowledge levels of HIV prevention and transmission, knowledge alone is not sufficient to promote HIV protective behavior or address the stigma and discrimination surrounding not only HIV/AIDS but also refugees [21, 26]. HIV prevention programs must go beyond simply increasing HIV knowledge levels and creating awareness [27]. Along with providing factual, easy-to-understand information, HIV/AIDS programs need to address the stereotypical attitudes that create xenophobia [25]. It is equally important that the programs be culturally sensitive and appropriately tailored to the needs of conflict-affected populations [20].

Positive attitudes towards AIDS or towards persons living with AIDS were shown to predict HIV protective behavior or behavior change among conflict-affected populations. A behavioral surveillance survey conducted among refugees and surrounding host communities in Uganda reported a relatively lower HIV/AIDS prevalence among refugee populations compared to surrounding host populations [28]. Although HIV was typically perceived as a severe disease, the

study uncovered a great deal of variability regarding attitudes towards the disease. Refugees were shown to be more-accepting and compassionate towards people living with AIDS, suggesting an association between HIV prevalence and positive attitude toward HIV/AIDS. Knowledge has also been shown to influence risk behavior among conflict-affected populations [17]. However, the link between knowledge and behavior is moderate [1, 19] and correlations between information level and overt behavior remain weak [17, 21]. According to the some studies, refugees who have been exposed to programs supported by Nongovernmental Organizations (NGOs) and host governments may have higher knowledge of HIV/AIDS, and their behavior may be less risky compared to that of nondisplaced persons and IDPs in their country of origin [7]. Refugees living in camps may actually have more opportunities for HIV prevention education than other conflict-affected populations because they are relatively easily targeted by NGOs for HIV/AIDS prevention education, and have easier access to information and services on HIV /AIDS compared to more stable populations [23]. Refugees participating in NGO-sponsored programs acquire important and valuable HIV/AIDS information and skills that can be used after repatriation to their countries of origin. However, translating the knowledge and skills acquired into practical HIV preventive behavior was reportedly challenging [17, 19].

Research shows that HIV risk is influenced by a constellation of interrelated social ecological factors, and that the most effective approach leading to behavior modification involves a combination of effort at all social ecological levels[8]. The socio-ecological framework assumes that people's health is shaped by environmental, intercultural, community, organizational, interpersonal and individual factors [29]. Barriers to healthy behaviors are shared among the community members [27]. As these barriers are reduced or eliminated, behavior change becomes more achievable and sustainable [27, 29]. Behavior change comes slowly in any environment, but in a refugee camp where people struggle with survival issues far more real to them than the mysterious AIDS virus, the process of behavior change can be painstakingly slow [28]. In camp environments, complex power relationships shape social interactions and permeate every facet of camp life, ultimately affecting project outcomes [19, 23]. In order for HIV/AIDS

interventions programs to be effective, it is therefore essential for program planners to understand the cultural and social context in which refugees operate [8].

Although factors associated with forced migration and displacement greatly increase the risk of exposure to HIV and other sexually transmitted diseases (STDs), a systematic review of HIV infection in conflict-affected and displaced people in seven sub-Saharan countries did not find sufficient data to support the assertions that conflict, forced displacement, and wide-scale rape increase HIV prevalence at the population level among populations affected by conflict, and that refugees have a higher HIV prevalence than surrounding host communities [7]. The review found the opposite to be true in many circumstances. Much of the research behind the assertion has not been rigorously tested, and seems to have overlooked elements during conflict that might help to reduce HIV transmission [5, 7].

Once the emergency and postemergency phases are over and populations enter the final phase of disaster recovery where refugees are repatriated, permanently integrated within host countries or resettled in another country, individuals' health status and needs continue to evolve. Although risk factors for HIV infection among refugees in emergency and postemergency phase are well documented, factors that affect risk for HIV infection after resettlement are less well understood [5, 22]. It is however widely recognized that AIDS is far more than a medical and biological problem because of behavioral and psychological factors associated with HIV infection [30]. Some studies, albeit a limited number, highlight factors associated with HIV risk during the final phase. Other than vertical transmission from mother to child, HIV risk-related behavior such as unprotected sexual intercourse with an HIV-infected partner and sharing of hypodermic needles are the primary means of HIV transmission [27]. In the absence of efficacious vaccines, prevention interventions focus mainly on altering human behavior, in particular, sexual behavior [29-31]. The postemergency phase in particular provides critical opportunities for targeted HIV/AIDS prevention programs. To be effective however, programs must be tailored to specific needs of target populations [32-36]. Creating integrated, versus parallel services for refugees may help to reduce stigma and discrimination by addressing the misconception that conflict-affected population have a higher prevalence of HIV infection than do the surrounding host

communities, and that refugees spread HIV infection in host communities. Given high mobility and frequent interactions between refugee and host populations, prevention strategies that are integrated with host populations' programs would be of great benefit [1].

Research Question 3: To What Extent Are the Methodological Approaches Suited for Investigating Risk Factors of HIV Infection Among Conflict-Affected Populations?

Forty-eight of the 54 studies that met our inclusion criteria exhibited one or more methodological limitations (Appendix B). These limitations potentially detract from the studies' usefulness with respect to generalizability and applicability of the findings. The deficits relate to

1. recruitment and sampling;
2. ethical considerations;
3. conceptual and theoretical frameworks;
4. survey methodology;
5. measurement/assessment issues; and
6. data analysis.

Recruitment and Sampling

A majority of the studies reviewed used either probability or nonprobability samples, with sample sizes ranging from 148 to 7,484. Purposive sampling techniques, where participants are selected based on the purpose of the study or some other specified criteria, were common in conflict settings and during periods immediately following conflict. Procedures for selecting samples and determining statistical power were omitted in 15 studies. Twenty studies did not describe explicitly the inclusion and exclusion criteria. These omissions made it difficult to determine the sufficiency of the study sample. Six studies discussed sampling procedures elsewhere, with 3 reporting the use of household replacement and only 5 reporting the number of households or persons refusing to participate in the study. Two out of the 14 studies that reported sampling strategies addressed the issues of retention and attrition. Without sufficient clarity of sampling methods, generalizability of study findings may not be possible, and the benefits of research might never be fully realized. In order to generalize research findings to the larger

population, selecting random samples of sufficient size is recommended. Use of the same or broadly similar sampling and data collection methods could greatly increase comparability of risk behavior across time and in different locations [15].

Ethical Aspects

Nine studies were approved, monitored or reviewed by an Institutional Review Board or other similar ethics review committee. Although there was no evidence of participants being deceived in any way, appropriate consent procedures were not implemented in 30 out the 54 studies. Documentation of appropriate steps taken to safeguard participants' privacy was not provided in these studies. It was not clear from study procedures whether the research purpose and objectives were fully understood by participants.

Conceptual and Theoretical Frameworks

Since the advent of HIV/AIDS, strategies based on psychosocial theories and models of behavior have been used widely in Social Science research [8, 29]. These theories focus on cognitive variables as part of behavior change, and share the assumption that attitudes and beliefs, as well as expectations of future events and outcomes, are major determinants of health related behavior. Nine out of the 54 studies reviewed utilized one or more psychosocial theories in planning, implementing, or evaluating health promotion programs. Majority of the studies, however, lacked a clearly specified theoretical foundation and were limited in their application to non-Western contexts [30-32, 35]. Questions related to the adequacy, or lack thereof, of the theories in contexts different from those where they were initially developed and tested have been raised [29].

The most frequently cited theories (AIDS risk reduction model, cognitive–social learning theory, diffusion of innovation theory, empowerment theory, harm reduction model, health belief model, theory of social change, theory of gender and power, and theory of reasoned action) may not capture all the elements necessary for behavior change in every culture or population [29, 32]. Although evidence shows that culture is a central feature in health behaviors, particularly in

the context of behaviors that may predispose individuals to HIV/AIDS, the role of cultural contexts in program implementation was often overlooked [20, 23].

A general lack of scientific rigor combined with a shortage of theoretical frameworks upon which to base methodology choices limits the interpretation of many studies carried out to date in conflict and postconflict settings and raises questions about the validity of the results. These deficits potentially limit the usefulness and applicability of HIV/AIDS programs for conflict-affected populations. To address this gap, theories of behavior could be adapted to work in various cultural contexts. A pilot study on alcohol/HIV prevention curriculum adapted from an American model and delivered to ninth-grade students in five South African township schools successfully demonstrated that behavioral interventions developed in Western countries may be adapted to work in other cultural contexts [33]. Rather than implement the entire curriculum, one intervention in South Africa adapted specific modules from several effective interventions implemented in America and South Africa [33]. Adaptations were accomplished through both qualitative research and participatory action research with the target audience. Cultural adaptations in intervention planning were also shown to be effective in studies that where existing models of behavior were expanded to include socio-cultural factors [8].

Survey Methodology

Data were typically gathered through various types of cross-sectional surveys, the most popular and widely used method being the knowledge, attitude, behavior and practice (KABP) survey [12]. Behavioral Surveillance Surveys were used in the more stable, postconflict settings to track trends in HIV/AIDS-related knowledge, attitudes and risk behavior among populations and to monitor HIV risk behaviors over time [1]. The study design was not identified in 11 studies, making it difficult for readers to assess whether the study designs were suited to investigate the stated hypotheses.

Data collection methods were either qualitative or quantitative. Quantitative data gathering approaches included face-to face interviews with either structured or unstructured questionnaires. Twenty-nine studies provided training for interviewers, and the remaining 6

recruited interviewers based on interviewers' prior experience in conducting surveys. Fourteen out of 54 surveys were solely quantitative, 17 were solely qualitative, 12 combined both qualitative and quantitative components, and the remaining 9 did not specify a study methodology. Because of the urgency of HIV/AIDS immediately following armed conflict and forced evacuation, unstructured, rapid needs assessments were conducted to help identify and prioritize immediate health needs of populations affected by conflict. Rapid needs assessments often lacked the resources necessary to support the development and implementation of interventions. Although rapid needs assessments are relatively fast and inexpensive, the methodology utilized is demanding in terms of logistics and time, lacks scientific expertise, and suffers from lower degree of validity [37].

Use of Internationally Accepted Key Indicators for HIV-Related Knowledge, Attitude and Practices/Behavior

Over the last few years, a great deal of work has been put into developing standardized indicators for HIV-related knowledge, attitude and behavior [1]. The indicators define aspects of behavior and practices that affect risk of HIV transmission. HIV prevention programs generally try to change these behaviors and practices, and provide a convenient way to compare levels of risk behavior between different population groups, so that decisions can be made about the efficient allocation of prevention resources. Standardization ensures comparability of HIV risk behavior over time and between population groups [1, 6]. Sixteen out of the 54 articles included in this review used at least one internationally-accepted or similarly worded indicator for HIV-related knowledge, attitude and behavior. Nine studies failed to report an indicator for HIV-related knowledge, attitudes, or behavior. Out of the 54 studies, 11 reported disaggregated HIV/AIDS indicators according to age or gender.

Disaggregating specific HIV/AIDS indicators by age and gender helped to provide useful pointers to gaps in knowledge, attitude or behavior among the socio-demographic groups surveyed [6]. Although indicators for HIV-related knowledge, attitude and behavior should be tailored to specific needs of populations and subgroups studied, effort should be made to conform

to internationally accepted standards in order to allow for progress tracking and comparability of HIV risk between populations over time [1, 6].

Measurement/Assessment Issues

Assessment of population's level of HIV/AIDS- knowledge, attitude and behavior/practices is an important first step to developing targeted interventions. Although a number of valid, reliable needs assessment instruments were found in the literature, they were neither specific to the topic of HIV/AIDS nor tailored to the unique needs of conflict-affected populations. The instruments were designed for use with large-scale nationwide surveys that require large samples and demand significant technical expertise [1]. They were thus deemed unsuitable for assessing HIV/AIDS-related knowledge, attitudes, and practices among conflict-affected populations as they may present undue burden with HIV needs assessments in emergency settings.

We found that little or no effort went into translating, back-translating or pilot testing questionnaires that were not written in commonly spoken languages. Measurement instruments were translated in 9 studies. In some cases the questionnaires, despite being translated, were neither back-translated nor pilot-tested. Some items were incorrectly worded and lacked cultural relevance, potentially leading to biased findings. Data collection during conflict, although possible, is fraught with difficulties and interpretation should be cautious [15].

Data Analysis

Descriptive statistics in the form of percentages and means were reported in 45 studies. For studies that performed quantitative analysis, statistical significance was set at p less than or equal to 0.05. Seventeen studies used one or more software application for data analysis, i.e., EpiInfo, STATA, SAS, SPSS, and SUDAAN. Of the 17 studies, only 2 reported inferential statistics and 3 studies described categorization scheme in qualitative analysis. Ten studies reported findings in a manner that was difficult for readers to assess whether the stated objectives were met. Seventeen studies assessed more than one outcome. With 2 exceptions, results were reported for the same outcomes that were assessed in the study. Out of the 54

studies, 14 acknowledged limitations of the studies, taking into account the limitations while interpreting results and reporting findings. Fifty-one studies stated conclusions or provided recommendations.

Discussion

There is a critical need to strengthen and improve HIV/AIDS research in conflict and postconflict settings. Findings from this review draw attention to the need for scientifically sound, evidence-based research aimed at investigating HIV/AIDS knowledge, attitudes and behavior/practices among conflict-affected populations. Based on this review, we recommend the following:

- The study's rationale should be well stated, clearly defining measurable goals and objectives, and corresponding interventions activities.
- The study design, methods of data collection and statistical analyses should be tailored to meet the study's objectives, including any prespecified hypotheses in order to avoid losing opportunities in the data collection phase and to ensure accurate reporting of findings.

Cycles of displacement and HIV/AIDS are importantly interlinked and factors affecting HIV transmission vary by phases of displacement [22]. To be effective, programs must therefore be tailored to respond to the specific contexts within which HIV risk behavior occurs. Interventions must include multidimensional, theory-based interventions that address individual and contextual variables as well as socio-cultural variables such as gender, class and ethnicity, and their influence on sexual behavior. Numerous cultural and socioeconomic factors unique to conflict-affected populations, particularly those migrating from less developed to more developed nations must be given consideration while developing HIV/AIDS interventions. To permit cross-national comparability, programs should be well defined along with eligibility criteria and methods of participants' selection.

Due to the highly sensitive and private nature of sexual behavior, innovative research strategies should be used to improve quality of data collected and facilitate comparisons of

results across studies [15]. Combined qualitative and quantitative approaches, standardization of HIV-related outcome indicators, and training interviewers to handle sensitive topics, such as those pertaining to sexual practices have been shown to be effective in assessing factors that affect HIV infection risk among conflict-affected and displaced populations. To help improve quality of data gathered in conflict and postconflict settings, the United States Agency for International Development (USAID) and the United Kingdom Department for International Development (UKDID) developed guidelines and recommendations for use with repeated behavioral surveys in populations at risk for HIV [1]. The guidelines and recommendations pertain to sampling approaches and techniques, data collection methods and statistical analyses. Standardized questionnaires for use with subpopulations at risk for HIV/AIDS are included. The guidelines have been successfully adopted by many Behavioral Surveillance Surveys including HIV behavioral surveillance survey conducted among refugees and surrounding host communities in Uganda [28] and HIV Behavioral Surveillance Survey in Juba Municipality in South Sudan [4]. To improve quality of data gathered from peer reviewed and nonpeer reviewed sources, researchers should exercise methodological precaution, promote confidentiality, careful pilot-test survey instruments, and train interviewers [15]. We further recommend improving data collection instruments in order to ensure quality of the data collected by: 1) conducting formal qualitative research before the survey to learn about the characteristics of the subpopulations ; 2) adapting and pretesting questionnaires to ensure they are suited to local context, and that the questions are unambiguous; and 3) translating and back-translating questionnaires, to ensure complex concepts are interpretable; 4) adequately training interviewers to handle sensitive topics, such as sexual behavior.

There were several limitations to this study. First, this review excluded articles that were not published in English. It is therefore possible that this review is a not complete representation of the available evidence. The review was limited to published articles and thus may have missed those that were not submitted or accepted for publication, presenting a possible publication bias. As only the first author performed the literature search and the subsequent selection of the studies to be considered in this review, a selection bias may be present. Additionally, the first

author performed the data abstraction, as well as a significant proportion of the rating and classification of the studies, which may present a data abstraction and evaluation bias.

In addition, we excluded abstracts for which full-length articles could not be retrieved from target databases or obtained from the authors despite requests. It is possible that important reports may have been missed. Some of the studies included in this review were undertaken prior to 2002, the year when standardized indicators for HIV were developed. This makes it difficult to evaluate individual studies objectively based on the use of the standardized indicators for HIV. Finally, some of the literature used to formulate this report was based on expert opinion found in narrative commentaries, editorials, and informal reports. To improve the rigor in the review of the literature, future efforts could investigate the validity of using expert opinion as a means for conducting literature reviews.

Conclusion

Existing research in conflict and postconflict settings only provides a rudimentary framework for examining factors that influence risk for HIV infection among conflict-affected populations. Overall, the studies reviewed were lacking the methodological rigor necessary to ensure reproducibility and external validity. Due to marked shortage of peer-reviewed research in both conflict and postconflict settings, models to direct the development of effective, culturally sensitive interventions for conflict-affected populations are lacking. To be effective, policies and programs must be guided by evidence. It is imperative that factors affecting HIV transmission during different phases of the cycle of displacement be addressed. Because the majority of refugees live within host communities, not in camps, integrating refugee programs with those of host populations is recommended.

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CHAPTER 3

DEVELOPMENT OF A QUESTIONNAIRE TO ASSESS KNOWLEDGE, ATTITUDES AND BEHAVIOR/PRACTICE IN A US-BASED REFUGEE POPULATION

Abstract

Although questionnaires are popular data collection tools, there is a shortage of culturally appropriate tools with demonstrated reliability or validity. The purpose of this study was to design a valid, culturally appropriate questionnaire to assess knowledge, attitudes, and behavior/practices related to HIV/AIDS in a US-based Burundi refugee population. This paper describes the process of developing and validating the questionnaire. The process described here serves as one model for the development of a culturally appropriate tool to assess knowledge, attitudes, and behavior/practices in refugee populations.

Introduction

Questionnaires are popular data collection tools in research. Despite the wealth of literature available globally documenting health-related knowledge, attitudes and behavior/practices (KABP) of many populations, there is still a paucity of valid, culturally sensitive tools for use with populations affected by conflict. Moreover, many questionnaires, developed in English are limited in their application to non-English speakers [1-2]. Cross-cultural adaptation and translation to address cultural, linguistic and literacy barriers are often lacking [3]. The aforementioned gaps form the basis of the present study.

The purpose of this study, therefore, was to develop a valid, culturally sensitive questionnaire to assess HIV/AIDS knowledge, attitudes, and practices/behavior in a US-based

Burundi refugee population. This paper describes the six sequential steps involved in developing and validating the questionnaire: literature review, key informant interviews, focus groups, individual in-depth interviews, cross-cultural adaptation/translation and pilot testing. We also report the results of the pilot test.

Methods

All protocols for this study were reviewed and approved by the Institutional Review Board of the University of Utah. The KABP questionnaire was developed in six sequential steps over a five-month period. Each step was dependent upon refinement of previous steps that had to be completed before the next step. Figure 1 illustrates the six steps.

1. We conducted a comprehensive review of literature pertaining to the HIV/AIDS KABP in conflict and postconflict settings. In order to get a better understanding of risk and protective factors for HIV infection, the review included theories and models of behavior. We created the first draft of the KABP questionnaire based on key findings from the literature review.
2. We conducted unstructured interviews with three community leaders who served as key informants in order to gain insight into the community's beliefs and perceptions regarding HIV/AIDS, build a relationship with the leaders, and begin the process of building trust, an essential step for reaching the community.
3. We conducted three [semistructured] focus group sessions with community members to better understand the community's attitude toward HIV/AIDS and people living with AIDS, identify additional topics to survey, and gather input from the group on how to refine the initial draft of the KABP questionnaire.
4. Next, we conducted individual, in-depth interviews with a subset of focus group participants in order to complement focus group discussions and gain insight into individual versus group perspectives.

5. The fifth step involved creating a draft questionnaire for cross-cultural adaption and translation. We developed the draft based upon literature review, semistructured interviews with key informants and focus group discussions.
6. Finally, we established validity using a pilot test and a panel of experts.

We assessed all aspects of the questionnaire including survey administration procedures, instructions, consent letters, item wording, response categories, question sequencing, overall flow, length of the survey, and acceptability of the survey.

Questionnaire Development

Step 1: Review of Literature, Theoretical Models and Questionnaire Conceptualization Review of Literature

Procedures

We searched both unpublished and published literature on etiological survey studies of HIV risk and protective factors and HIV/AIDS intervention studies that target these risk factors among displaced populations. The following keywords were used to search Medline, PsychInfo, Pub Med, and Embase databases: HIV, AIDS, HIV/AIDS knowledge, HIV/AIDS Attitudes, HIV/AIDS Behavior, and Theories of Behavior. The literature review included World Health Organization's guide to developing knowledge, attitude and practice surveys [4], Family Health International's Guidelines for Repeated Behavioral Surveys in Populations at Risk of HIV [5] and Theories and models of behavior [2, 6-7].

Findings

Research findings show that the effect of HIV and AIDS on all societies around the world is immense. With no cure in sight, efforts to reduce the spread and the impact of HIV/AIDS are often geared towards changing or modifying high-risk sexual behavior [6]. While individuals are responsible for instituting and maintaining behavior change necessary to reduce personal risk of HIV infection, behavior is not determined by individual factors alone [6]. The studies show that HIV risk is influenced by a complex interplay of individual level factors such as age, self-esteem, untreated sexually transmitted diseases, and alcohol and drug use; interpersonal factors such as

sex with a partner of unknown HIV status, sex with multiple partners, and negotiation of safe sex; social factors such as social norms and values, cultural and religious beliefs, gender roles, marginalization of ethnic minorities and people of color, sex workers, women, drug users and of homosexuals; and policy factors such as laws and regulations, racism, homophobia, and availability of basic public health preventive services [2, 6-7]. Socio-demographic risk factors associated with HIV infection include high unemployment rates and poverty, migration, poor education, and low socio-economic status [8-9].

There is ample research evidence of a relationship between HIV/AIDS knowledge/awareness and tolerant attitude towards persons with HIV/AIDS, with a correlation demonstrated between HIV/AIDS attitudes/beliefs and beliefs of susceptibility to the disease [2, 6-7, 10]. However, HIV/AIDS knowledge/awareness does not have a simple correlation with HIV protective behavior or behavior change [2, 6-7, 10]. Human behavior must therefore be addressed within the broader context of individual, social, cultural and environmental determinants [1, 6-7, 9-10].

Theoretical Models

Health behavior theories offer a generalizable framework for understanding human behavior and explain behavior in terms of factors amenable to change with an intervention [2]. The four most commonly cited theories in HIV/AIDS prevention literature are: The Health Belief Model (HBM), the AIDS Risk Reduction Model (ARM), Stages of Change (SC), Social Cognitive Theory (SCT) and the Theory of Planned Behavior (TPB) [11]. For this study, a conceptual map for examining relationships between variables and factors that that promote HIV risk behavior was developed using selected constructs from the Social Cognitive Theory (SCT) and the Theory of Planned Behavior (TPB). Both theories have been applied, tested, and verified in numerous published studies [2, 7, 11-12].

Social Cognitive Theory

Social Cognitive Theory (SCT) focuses on the psychosocial elements of health behaviors and provides a framework for understanding, predicting, and promoting individual behavior

change. The SCT describes human behavior as an interaction of personal factors, behavior, and the environment [11]. According to the SCT model, interaction between the person and behavior involves the influences of a person's thoughts and actions. An underlying assumption of the SCT is that behavior is dynamic and depends on environmental and personal constructs that influence each other simultaneously. The interaction between the person and the environment involves human beliefs and cognitive competencies that are developed and modified by social structures and parameters within the environment [11].

Theory of Planned Behavior

The Theory of Planned Behavior (TPB) posits that individual behavior is guided by beliefs about the likely consequences of the behavior (behavioral beliefs), beliefs about the normative expectations of others (normative beliefs), and beliefs about the presence of factors that may facilitate or impede performance of the behavior (control beliefs) [11]. Behavioral beliefs in turn produce either a favorable or unfavorable attitude (individual's positive or negative feelings about performing a behavior toward a specified behavior); normative beliefs give rise to perceived social pressure or subjective norm (one's perception of whether people important to the individual think the behavior should be performed); and control beliefs give rise to perceived behavioral control (individual's perception of the difficulty of performing a behavior). Attitude toward the behavior, subjective norm, and perception of behavioral control constitute behavioral intention [11].

Questionnaire Conceptualization

Based on key features of the literature review, we developed a conceptual framework to inform questionnaire construction. The framework, illustrated in Figure 2 was the first step in synopsizing and quantifying HIV risk and protective factors in the target population. Included in the framework are major variables that the study intends to measure, such as HIV/AIDS-related knowledge and attitudes, HIV risk behavior/practices, and self-efficacy.

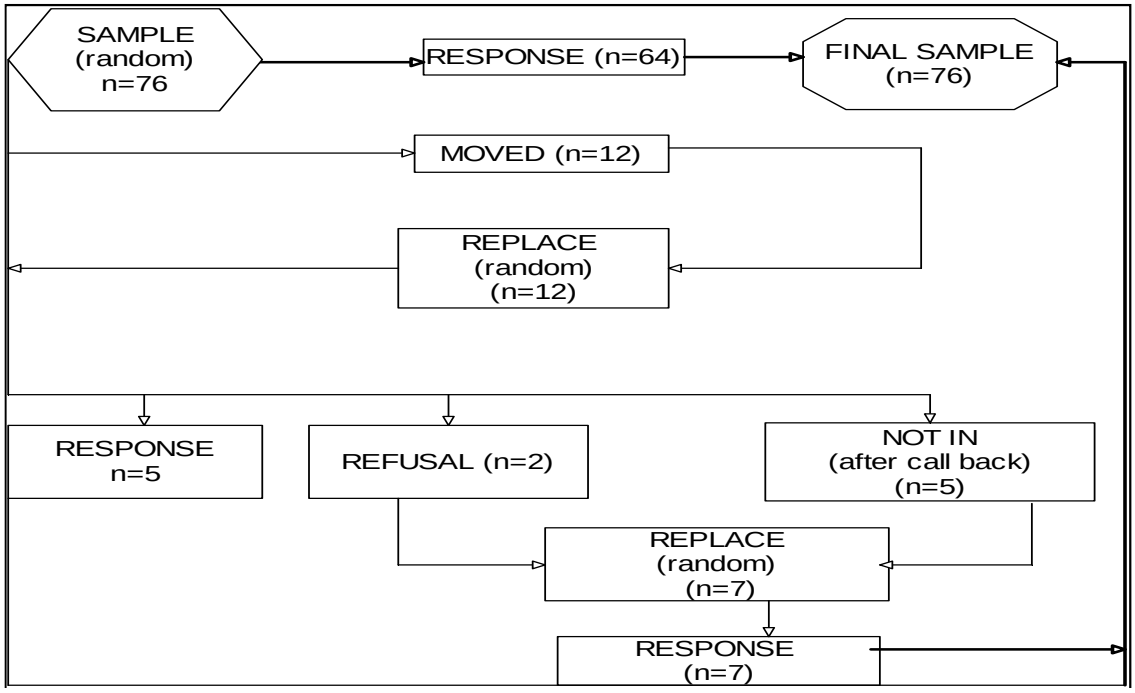

Figure 2. Selection of Participants Meeting Inclusion Criteria

Step 2: Key Informant Interviews

Procedures

We conducted two semistructured, in-depth interviews with three individuals from the community. In order to assure diverse perspectives, selection was based upon the longevity and/or the nature of the individuals' involvement with the community. Informant interviews were designed to assess HIV/AIDS issues in the community and explore prevailing HIV/AIDS-related attitudes, beliefs, perceptions, values, and behavior in the population. Our objective was to investigate the needs and services perceived as important by the community, identify issues that warrant further investigation, build a relationship with the leaders, and begin the process of building trust, an essential step for reaching the community.

Verbal consent to participate was obtained. Informants were clear about the purpose of the interview and were interested in participating. Interviews were conducted in participants' homes, in a distraction-free environment. We took notes during the interview. At the conclusion of each interview, we reviewed the notes and gave a 2- to 3-minute summary of what each respondent said in order to make it easier to transcribe and analyze data from the interviews.

Interviews lasted 60-90 minutes. A discussion guide consisting of 7 open-ended questions was used for every interview. The guide is shown in Appendix A.

Qualitative Data Analysis

Thematic analysis was used for qualitative data. Information gathered from the interviews was analyzed based on the topics discussed. We reread the notes taken during the interviews, identifying and writing down the main ideas that emerged. We then prepared a two-page interview summary sheet reducing information into manageable themes, issues, and recommendations. The summaries provided information about each informant's position in the society, reason for inclusion in the list of informants, main points made, and any insights or ideas gathered during the interviews.

Step 3: Focus Group Sessions

Procedures

Between October and December 2010, we conducted three focus groups with youth and adults in the from the target population. Our goal was to learn more about their attitudes, beliefs, opinions and perceptions regarding HIV/AIDS including how the views were formed. Participants were purposively selected with the help of refugee service providers and organizations. A total of 14 adults and 6 youth participated in the focus groups. Focus groups were representative of unmarried youth age 12-24, married and unmarried women age ≥ 25, and married and unmarried men age ≥ 25. The groups were sized so as to represent a sufficiently broad spectrum of perceptions, opinions, and beliefs from the community while ensuring active participation of all members in each group. Inclusion criteria were age (≥ 12 years) and ability to speak Kirundi. Key characteristics of focus groups were as follows:

- Unmarried youth (age 12-24)
    - Six youth participated in the focus group.
    - Two participants were age 12-18 years and four were age 19-24 years.
    - Focus groups were conducted at the home of one participant.
- Married and unmarried women (age ≥ 25)

  - Eight adults participated in the focus group.
  - Two participants were age 25-32 years and six were age 42-55 years.
  - Focus groups were conducted at the Asian Association of Utah.
- Married and unmarried men (age ≥ 25)
  - Six adults participated in the focus groups
  - One participant was 28 years old and five were age 32-44 years.
  - Focus groups were conducted at a community center.

Locations were neutral, mutually-agreed upon, and accessible to all attendees. Adult sessions for men and women were held separately because the theoretical framework of gender and power (18) makes it possible to assume that perceptions, opinions, and beliefs related to HIV/AIDS could differ substantially between the two groups, and discussing them openly might inhibit persons of the opposite sex.

Male and female moderators were selected to facilitate discussions in men and women's groups, respectively. The youth group unanimously chose a male moderator to facilitate their session. Moderators were selected based on prior experience in leading group discussions or meetings and familiarity with the topic of HIV/AIDS. Discussions were conducted in a quiet, distraction-free environment, with seating arranged in a 'U' shape so participants could see and hear each other clearly. All sessions were audio taped with the help of an assistant moderator.

Discussions started with general questions in order to allow participants to become more familiar with the topic. Key questions relating to major themes around which the KABP questionnaire was developed (HIV/AIDS-knowledge, Attitudes and HIV risk behaviors/practices) were then introduced. To assure anonymity and confidentiality, participants were asked not to use names during discussions. Three identical focus group guides were prepared in advance to help facilitators keep discussions on track, while allowing participants to freely express themselves. A copy of the focus group questions is provided in Appendix B.

The assistant moderator devoted primary attention to taking notes and capturing important aspects of the discussion including obvious body language, silent agreement and contradictory statements. Sessions lasted 60 to 90 minutes. Participants were offered

opportunity for questions and comments at the end of each session. As soon as each focus group was concluded, the assistant moderator spot-checked the audio tape in order to gain a sense of the quality of recordings. The three moderators and the assistant moderator debriefed one another immediately after each focus group in a private location. All tapes and field notes were summarized before leaving the site. The focus group approach used in this study is described in detail in Krueger R, Casey MA. Focus Groups: A Practical Guide for Applied Research [13].

Tape-Based Analysis

The digital audio recordings were transcribed into readable text within hours of focus groups to help avoid memory lapse. Before the analysis, back-up copies of recordings were made and original copies retained on the investigator's file. First, we listened to the entire tape without writing anything down, in order to get a general understanding of thoughts expressed and terminology used. We then listened to the audio tape a second time, noting comments that relate directly to the KABP questionnaire's key themes (HIV/AIDS-knowledge, Attitudes and HIV risk behaviors/practices). Next, we reviewed field notes and moderator debriefing, diagramming relationships that emerged. An abridged transcript was prepared after listening to tapes and reviewing field notes and moderator debriefing. Lastly, we prepared a written report of key findings based on the abridged transcript. Selected quotes were used in the report to illustrate major themes.

Step 4: Individual Interviews

Procedures

In order to gain insight into individual versus group perspectives, a self-selected sample of one participant from each focus group participated in a 30-minute, conversational format, in-depth interview. Informed consent to participate was obtained from the participants. Interviews were audio taped. An interview guide consisting of general, nondirective questions was prepared using topics abstracted from the focus group guide. Questions asked are included in Appendix C. Interviews began with general topics and moved to specific, sensitive issues when informants were sufficiently relaxed. We, however, did not inquire about respondents' private sexual

behavior. Participants were encouraged to share their personal opinions, beliefs, and attitudes about HIV/AIDS. Probes and follow-up questions were used to elaborate on statements, clarify issues and focus on new dimensions of specific issues. Interviews concluded by thanking respondents and allowing a few minutes for questions and comments. Once the interviews were formally completed, we quickly reviewed interview notes for any errors or omissions before leaving the site. A detailed summary report was written within a few days of the interviews.

Tape-Based Analysis

The same analytic approach as above was used.

Step 5: Creating and Adapting the Questionnaire

Questionnaire: Draft 2

Findings from key informant interviews, focus group discussions, and individual in-depth interviews were taken into consideration when developing a second draft of the KABP questionnaire. Revisions to the first draft involved reformatting and rewording 3 questions, deleting 1 question that ambiguous, and adding 3 new questions. The second draft consisted of 67 items, distributed among 5 domains:

1. Socio-demographic characteristics (age, gender, marital status, income level, educational level and employment status (10 items);
2. HIV/AIDS related knowledge covering general HIV/AIDS information, modes of HIV transmission and HIV prevention (12 items);
3. Attitudes towards HIV/AIDS (10 items);
4. Behaviors/Practices that influence HIV risk (15 items);
5. Self-efficacy (10 items);
6. HIV/AIDS informational needs (10 items).

Cross-cultural Adaption and Translation

Cross-cultural adaptation and translation processes addressed all components of the questionnaire including consent forms, assent forms, cover letters, and the instructions. The

source version of the questionnaire was written in American English. Based on recommendations and guidelines for cross-cultural adaptation of self-report measures, the second draft of the KABP measure was cross-culturally adapted and translated in 4 phases [3, 14-16].

Phase I. Initial translation from English to Kirundi (forward translation) was performed by two independent translators whose native language is Kirundi. Both translators were fluent in English and had knowledge of the concepts being examined in the questionnaire. Initial contact with translators was made during community meetings. The purpose of the project was explained to both of them in English and their collaboration was requested. Upon consenting, the draft KABP questionnaire was distributed to each expert for comments regarding the cultural relevance and appropriateness of each item. Both translators made written reports regarding linguistic difficulties and inconsistencies. All feedback was collected a month later at the next community meeting.

Phase II. Comments and suggestions were subsequently discussed with both experts and a consensus was reached regarding suggested revisions during the meeting. The procedure was documented in a written report.

Phase III. In the next step, all components of the KABP questionnaire were back-translated from Kirundi to English by two additional bilingual translators fluent in both English and Kirundi. This step was supposed to be completed by native English American speakers, fluent in Kirundi. None exist. The translators, however, did not have significant HIV/AIDS background and were unaware of the concepts being examined in the questionnaire. Their interpretation of words related to HIV/AIDS was therefore assumed to be similar to the interpretations of most people in the target population, who do not have such experience.

Step 6: Establishing Validity

Content validity was established using a pilot test and the panel of experts who took part in phase IV of cultural adaptation and translation process (principal investigator, American-English native speaker, forward translators and back-translators). We measured content validity by asking the panel to evaluate the content and layout of the questionnaire. A pilot test was then

conducted in order to identify flaws in the questionnaire that may have been previously overlooked.

Expert Panel

The translated source (American English) version and the target (Kirundi) versions were then reviewed by an expert panel in order to assess completeness and consistency of the questionnaire and minimize cultural and linguistic biases. The expert panel consisted of the principal investigator, American-English native speaker, forward translators and back-translators. To determine equivalence in translation, the panel compared the back-translated version with the English version, giving attention to the meaning of words in the two languages. In keeping with the literature on generating valid, cross-cultural translations [3, 14-16], the panel reviewed all original and back translated components of the questionnaire for semantic, idiomatic, experiential, and conceptual equivalence.

The validation process addressed the following questions: Is the questionnaire measuring what it intended to measure, that is, is the questionnaire valid? 2. Does the questionnaire represent the content? 3. Is the instrument appropriate for the study population? 4. Is the instrument comprehensive enough to collect all the information pertaining to the goals and objectives of the study? 5. Does the instrument look like a questionnaire?

The process uncovered five phrases in the source version that did not translate well into English because of cultural or language differences. To achieve cultural and linguistic relevance, the source version was revised to convey meanings of phrases as opposed to literal meanings of words. Changes were made as appropriate and a third draft of KABP questionnaire was produced. Draft 3 was ready for pilot testing.

Pilot Test

Following IRB approval, we conducted a pilot test to help evaluate all aspects of the questionnaire including questionnaire items, response choices, directions and the cover letter. Participants were selected purposively from a group that is similar in makeup to the one that ultimately will be sampled. Those selected were invited to a community center by phone calls,

word of mouth, and home visits. If a person had moved out of the area, could not be traced, of if the phone number or person was unknown, a replacement was be made from a list of substitutes/reserves that was made beforehand. To be included, participants were required to understand Kirundi and be literate at the third grade level. Those with hearing or visual impairments were excluded from the study. The size of the pretest sample was considered sufficient to determine how well each question was understood and to assess the feasibility of a full-scale KABP survey.

Procedures. The draft questionnaire was pilot tested using the same administrative procedures that will be used in the formal study. Participants were invited to a neutral place that was accessible to attendees. Two men (age 17 and 45) and three women (age 24, 38 and 55) agreed to participate. The questionnaire was administered in Kirundi (a local language). The informed consent process was explained verbally, allowing sufficient time for clarification so as to ensure participant understood the research process including anticipated risks, risk mitigation plans, and benefits of participating in the study. All subjects were informed that participation in the study was strictly voluntary and were told that the data collected would not be used for anything except the research aim. Parental consent for the 17-year-old participant was obtained.

Several measures were taken to ensure confidentiality. The questionnaire was self-administered and respondents were asked not to identify themselves. They were assured that only the investigators would have access to their responses. In order to reduce time for administration, we administered the questionnaire in a group setting. Questions were in "Yes/No"/“Don’t know/Not applicable” format. A demonstration on how to mark appropriate responses was given and participants were allowed sufficient time to practice how to circle the answers on a piece of paper provided for that purpose. Assistance was offered as needed.

To ensure privacy, a tent-shaped cardboard barrier was used so the investigator or others in the group would not see what respondents were marking. Confidentiality was further assured by separating respondents within the room with at least four feet (1.2 meters) of empty space on all sides.

Each respondent was supplied with a pen, a Ziploc bag, and an envelope. At the beginning of each section, a 3- by 5-inch booklet containing question numbers and possible answer choices for each section of the KABP questionnaire was handed out. Questions in their entirety were not printed on the booklets. Introductory statements for each section were read audibly at the beginning of each section followed by instructions on how to answer questions for the sections. As questions were read, the investigator observed participants' reaction, watching for any hesitation and recording other nonverbal cues. At the end of each section, respondents were asked to store their booklets safely in the Ziploc bag. A new booklet was handed out for every section. At the end of the survey, respondents placed their completed questionnaires inside a cardboard box provided for that purpose. The entire questionnaire took approximately 20-30 minutes to complete.

The time taken to complete each questionnaire was recorded so as to approximate time needed for the formal survey. To ensure validity of the data collected, respondents were invited to give feedback on survey administration process and questionnaire content, and share ideas on how the questionnaire could be refined. Respondents' feedback was considered in making final revisions to the questionnaire.

Pilot data analysis. First, each questionnaire was manually checked for errors and omissions. A data dictionary containing numerical codes for each quantitative variable was then created using Excel. Responses were found to be consistent, clear and legible, with no missing values or outliers. Statistical analysis was then performed using STATA (College Station, Texas version 10.1). Analysis was limited to frequency counts and distributions of all relevant individual variables. Quantitative variables were expressed as means of ± SD.

Results

Findings from Key Informant Interviews

Findings from key informant interviews focused on content, rather than what was said by particular individuals. Participants recognized that HIV/AIDS is a worldwide pandemic. According to informants, the HIV/AIDS situation is bad among conflict-affected populations due to low

literacy levels combined with poor access to health care and low socio-economic status even after resettlement. Although resettlement affords women new economic opportunities and responsibilities in the work force, it was noted that patriarchal gender roles and relations re-emerge. Culturally bound gender roles create imbalances in heterosexual relationships; whereas "men's work" is highly recognized either directly through paid remuneration or indirectly through high social status, "women's work" is often unrecognized and has less value. These economic imbalances subsequently create conditions that increase women's risk for HIV infection.

Although key informants could name several places where HIV testing was available, accessibility was hindered by language and transportation barriers. Recommendations for effective interpreter services and culturally competent health promotion initiatives were made. The results of the interviews helped to identify and select issues to be covered in focus groups and surveys, and to frame the questions appropriately.

Findings from Focus Group Discussions

Findings from focus groups were organized according to 3 key areas around which the KABP questionnaire was developed: HIV/AIDS Knowledge; Attitude towards AIDS; HIV risk behavior/practices, self-efficacy and information needs.

HIV/AIDS Knowledge

We found that men and women across the focus groups responded in a similar manner to the question, "What comes to mind when you hear about HIV/AIDS?" A majority of men and women in all groups knew that AIDS cannot be cured. A few however remained skeptical. A married man stated, "There's cure for AIDS. It's just not easy to find." When probed further, he remarked, "Some people with AIDS are healthy and live long. Others die right away." A diversity of opinions surfaced in the groups about the appearance of AIDS patients. Two young women thought a person infected with HIV can be asymptomatic but three older women weren't so sure. When asked if AIDS is a punishment from God, older men and women were in agreement. Most participants in the group thought AIDS is some form of punishment for immorality and held a fatalistic view toward life. Selected comments include:

- “If you do bad deeds, you deserve what you get.”
- “I pray to God not to punish us.”
- “People should stop this homosexual thing. They should obey God.”

Although HIV/AIDS prevention knowledge was similar in all groups, knowledge of HIV/AIDS transmission differed. Nearly all youth had correct knowledge about HIV transmission. Older women were generally uninformed and many older participants thought the chance of heterosexual transmission was negligible.

Attitude

The general reaction was that of fear. HIV/AIDS was described with the words: “danger,” “killer,” and “evil.” A married female participant remarked, “I’m scared to think of AIDS. You don’t know that someone has AIDS until they die. Then you hear they died of AIDS and you know more people will die after that.” A male participant from the youth focus group noted that HIV and AIDS were not a priority in the community. He stated: “Many people have a very hard life, and therefore they don’t give much thought to the risk of HIV/AIDS.”

Nearly all participants in the three focus groups were ambivalent about caring for a relative infected with HIV. While the majority of the young men and women thought HIV/AIDS subject is important and deserves attention, AIDS is still a taboo topic in the community. Almost all participants believe HIV positive people should keep their status a secret. For many married men and women, it was often difficult to discuss topics related to sexual behavior and practices openly.

Behavior/Practice

Little attention was given to HIV risk behavior. A thought that was commonly expressed in the men’s focus group was that people should not be overly concerned about HIV/AIDS. As a young man remarked, “If it’s your time to die, there’s nothing you can do about it.” “It’s like dying from a car accident.” Another man in the group added: “If you die, does it matter how?” The majority of men and women were however, willing to be tested for HIV.

Self-efficacy

When asked if women should insist on safe sex, one married man said: “It’s not for the woman to decide.” Then, explaining what rights he gained by paying dowry for a woman, he said half-jokingly, “If I marry a woman, I expect her to do what I say. Sex with a condom is not really sex.” Other men in the group echoed the sentiments. The same question was asked to the group of married and unmarried women. They confirmed that men have more rights than women when it comes to sexual matters. Opinions in the youth group however, differed. Most youth however were in favor of “equality in relationships and marriage.” “Are men and women not equal in God’s eyes?” asked a young man.

Informational Needs

Responses to questions on preferred means of receiving HIV/AIDS information varied between and within groups, with many older participants showing preference for private settings. A married woman stated: “The television is not good. You have the whole family watching and children will ask questions.” The youth showed preference for media and health promotion workshops. All participants expressed the desire and willingness to learn more about HIV/AIDS.

Findings from In-depth Interviews

Participants were generally knowledgeable on HIV/AIDS facts and HIV prevention. However, myths and misperceptions regarding HIV transmission persist. Despite assurance of confidentiality, participants were unwilling to discuss topics related to sexual behavior and practices. Qualitative themes that emerged from the interviews included lack of accurate information about HIV transmission and barriers to preventive services. Two participants expressed willingness to be tested for HIV.

Validity Test Findings

Feasibility and Acceptability

Respondents reported that the questionnaire was easy to complete. No problems with irregularities of questionnaire items, wording, appearance or measurement scales were encountered. Instructions provided at the beginning of each section were clear and easy to understand. Participants confirmed that the study methodology was culturally competent, and methods for contacting, recruiting, and engaging participants were acceptable.

There were no problems pertaining to sensitivity of information solicited or the research protocol was realistic and feasible. A double barred question in the general knowledge section was, however, identified. The question was deleted and replaced with two questions covering the general knowledge concept. Ten items identified as culturally inappropriate were deleted. The questionnaire was then proofread one final time to ensure that all errors were corrected. When no more errors were found, the process of developing and validating a questionnaire to assess HIV/AIDS-Knowledge, Attitudes, and Behavior/Practices in the Burundi refugee population was considered complete. The final KABP questionnaire consisted of 57 items, distributed among 5 domains:

1. Socio-demographic characteristics (age, gender, marital status, income level, educational level and employment status (8 items);
2. HIV/AIDS related knowledge covering general HIV/AIDS information, modes of HIV transmission and HIV prevention (12 items);
3. Attitudes towards HIV/AIDS (6 items);
4. Behaviors/Practices that influence HIV risk (15 items);
5. Self-efficacy (6 items);
6. HIV/AIDS informational needs (10 items).

Discussion

Development of the valid, culturally sensitive questionnaire involved several steps taking considerable resources, time, and effort. Each step helped to enhance the quality of research. To

our knowledge, this is the first study to develop and validate a culturally-relevant questionnaire for use in assessing HIV/AIDS knowledge, attitudes, and practices/behavior in a US-based Burundi refugee population.

Focus group findings point to the need for appropriate educational messages to counter stigma and stereotypes associated with HIV and AIDS and clarify common myths and misconceptions surrounding HIV/AIDS. Education on transmission and prevention methods is needed, including information on locations where HIV/AIDS education material can be obtained. It's equally important to consider age and gender differences in HIV/AIDS knowledge when developing HIV/AIDS prevention programs for the community. Education messages can be conveyed via community forums, written fact sheets, and health promotion material. Although significant time and resources were required to conduct individual and focus group sessions and analyze resulting data, the sessions provided first-hand information pertaining to themes of this study and explored ideas and perspectives not considered previously.

We found that in-depth interviewing was an effective means of gaining insight into individual perspectives and exploring general topics. The method was, however, less effective than focus groups in getting people to discuss topics related to sexual behavior and practices. Nevertheless, we identified three characteristics of potentially effective interventions for HIV prevention based on the interviews: linguistic and literacy appropriateness, cultural sensitivity and involvement of refugees in program design and implementation.

An important limitation of this study is that focus group data were likely subject to bias resulting from group dynamics such as polarization, censoring, or conformity. Individual qualitative interviews may also have been susceptible to error, interviewer bias, and misinterpretation. To minimize bias from key informants, we used more than one person who represents the community. Another limitation of this study is that reliability was not addressed in the pilot test due to the small pilot sample. Although content validity was well established, further research with larger samples will be necessary to establish predictive validity. In addition, appropriate reliability analyses would clearly require a larger sample than was used in the pilot study.

Despite the limitations, triangulated methodology incorporating qualitative in-depth interviews and focus groups and a structured quantitative pilot-test constitutes a major strength of this study. The mixed-method approach helped to enhance the study's validity. To further enhance the study's validity, we enlisted support, endorsements, and direct involvement of highly respected community leaders, the office of refugee services, refugee service agencies, Community Based Organizations, local religious leaders and the Department of Health.

Conclusion

The 57-item KABP questionnaire we created is a valid, culturally sensitive user-friendly instrument for obtaining self-reported measures of HIV/AIDS knowledge, attitudes and behavior/practices. The instrument can be used in a formal, full-scale survey to assess HIV/AIDS-Knowledge, Attitudes, and Behavior/Practices in Kirundi-speaking populations.

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CHAPTER 4

ASSESSING HIV/AIDS KNOWLEDGE, ATTITUDES, AND BEHAVIOR/ PRACTICES IN A US-BASED REFUGEE POPULATION

Abstract

Human Immunodeficiency Virus (HIV) infection and Acquired Immunodeficiency Syndrome (AIDS) continue to be major global health priorities. Given the high societal costs of HIV infection, it is no surprise that research on HIV prevention has become increasingly important. Although forced displacement is believed to fuel HIV/AIDS epidemic in countries affected by conflict, factors associated with forced displacement and HIV risk in conflict-affected populations are not well understood.

The objective of this study was to assess HIV/AIDS- knowledge, attitudes and behavior/practices (KAB/P) in a US-based refugee population in order to gain an understanding of factors of relevance to the transmission of HIV/AIDS in the population and develop a preliminary evidence base to inform and guide targeted HIV/AIDS strategies. A predesigned, validated questionnaire was administered in a cross-sectional study to a random sample of US-based Burundi refugees *(n = 76)*.

We performed univariate, bivariate, and multivariate analysis to assess associations between HIV/AIDS behavior/practices, knowledge of HIV/AIDS, attitude towards HIV/AIDS, self-efficacy for engaging in protective behaviors/practices, and socio-demographic variables. Cronbach's Alpha analysis was used to determine the questionnaire's reliability. Significant predictors of protective HIV/AIDS Behavior/Practices were self-efficacy (*b= 0.248, p=0.027*) and Knowledge (*b= 0.454, p<0.001*). Attitude towards HIV/AIDS (*b= 0.5071, p<0.001*) was a significant predictor of HIV/AIDS Knowledge. In general, men were more knowledgeable than women and demonstrated higher self-efficacy for engaging in HIV protective behavior. Women scored higher in measures of HIV/AIDS behavior and practices and had more positive attitude towards HIV/AIDS compared with men. The majority of respondents (91.9%) were interested in learning more about HIV/AIDS. Findings create foundational knowledge about HIV/AIDS

knowledge, attitude and behavior as a basis for designing targeted, culturally-tailored HIV/AIDS interventions strategies for the population.

Results suggest that interventions aimed at increasing HIV/AIDS knowledge and enhancing self-efficacy would be most beneficial in promoting protective HIV/AIDS behavior/ practices. Recognizing that individual behavior is determined to a large extent by the social environment [1] preventive strategies will involve combination of effort at individual, interpersonal, organizational, community, and public policy levels.

Introduction

HIV and AIDS have become one of the most serious health and social problems [2-5]. In the United States, it is estimated that more than one million people are living with HIV and that the death toll is over half a million [4-5]. The projected discounted cost of medical care for HIV-infected adults using current antiretroviral therapy (ART) standards from the time of infection until death is approximately $385,200 [6]. Given the high societal costs of HIV infection, it is no surprise that research on HIV prevention has become increasingly important. HIV infection is spread mainly through sexual behavior. For this reason, sexual behavior change is a major focus of HIV prevention efforts. It is however important to first understand the demographic, social, and behavioral aspects of HIV transmission through sexual contact before attempting to direct behavior change or develop policy.

In regions affected by conflict, forced displacement is believed to fuel HIV/AIDS epidemic [7-8]. The extent to which conflict and forced displacement influence risk for HIV transmission during the emergency stage, when affected populations are seeking refuge, depends upon numerous, interacting factors such as, sexual violence particularly toward women and youth, breakdown of health services and social infrastructure, loss of livelihoods, availability of education and social services, type and length of conflict, lack of access to health services, including HIV and sexual and reproductive health programs, and behavioral changes resulting from breakdown of traditional community support structures [7-10].

Factors affecting HIV risk in postemergency and resettlement phases, when refugees are lawfully admitted to safety in another country and durable solution are secured, are less well understood [7]. Although the resettlement phase allows for innovative strategies for addressing the needs of conflict-affected populations, [11] these populations are often excluded from HIV/AIDS National Strategic Plans (NSP) and funding proposals for host countries [11-12]. In many cases, cultural and linguistic barriers prevent refugees from accessing HIV prevention and education programs in countries of resettlement [8] . Exclusion and lack of access to preventive services undermines effective HIV prevention and AIDS mitigation efforts not only for conflict-affected populations but also for host populations [7-8, 13]. It is imperative that effective and efficient programs be designed to address the unique factors affecting HIV risk in populations affected by conflict [8, 11, 13-14].

The objective of this study was to assess HIV/AIDS Knowledge, Attitudes, and Behavior/Practices (KAB/P) in a US-based Burundi refugee population as a basis for designing targeted HIV/AIDS prevention strategies for the population.

Methods

A predesigned, validated questionnaire was administered in a cross-sectional study. The survey targeted all US-based Burundi refugees over 12 years of age living in Utah, excluding those in hospitals and/or the military, and individuals with hearing or visual impairments. Participants were required to understand and speak Kirundi, the dominant language of Burundi refugees. We used STATA (College Station, Texas, USA, Version 10.1) to draw a random sample (n = 76) with replacement from a comprehensive database of 215 US-based Burundi refugees in Utah. When determining the sample size, we took into account that some of those selected may be difficult or impossible to contact, or unwilling to participate in the study. Sampling was therefore done with replacement. Individuals selected were invited to a neutral and acceptable community center by letters and telephone calls. Recruitment included home visits as well. Figure 2 represents our recruitment strategy.

A 49-item, predesigned, validated questionnaire was then administered in a cross-sectional study to assess knowledge of HIV/AIDS, attitude towards HIV/AIDS, HIV/AIDS behavior/practices and self-efficacy, and collect information on socio-demographic variables. Questionnaire development process involved extensive literature reviews, key informant interviews, focus group discussions, and in-depth interviews. The questionnaire was divided into six sections covering the following domains: Socio demographics (8 items), HIV/AIDS knowledge (11 items), attitudes (6 items), behavior/practices (13 items), self-efficacy (5 items), and HIV/AIDS information (6 items). Questionnaire validity was confirmed using a panel of experts and a pilot test. We reported details of the questionnaire development process previously [15]. (A copy of the questionnaire is available upon request.)

Ethical approval for conducting the study was obtained from the Institution Review Board of the University of Utah. For eligible participants, we sought informed consent in a noncoercive manner, and in accordance to ethical principles and guidelines for protection of human subjects of research [16]. Assent to participate in the study was sought for participants between the ages of 12 and 17. We sought parental permission as well. The informed consent process was explained verbally with the help of an interpreter. Anonymity and confidentiality were reassured by reiterating that questionnaires would not contain any personal identifiers, and that data would be secured in a password-protected computer. Participants were allowed sufficient time to consider whether or not to participate and were free from any pressure or duress to do so. After giving consent to participate, each participant was given a copy of the questionnaire.

Survey administration took place in a distraction-free environment with comfortable seating and adequate work surfaces with no obstructions overhead or underneath. Participants were divided into 3 groups according to age and gender: married and unmarried women age 25 and above, married and unmarried men age 25 and above, and unmarried men and women age 12 -24. Clear and concise instructions on how to complete the questionnaire were read aloud and comprehension assessed through open dialogue. We gave a demonstration on how to circle the appropriate answers, allowing participants enough time to practice. Only when all participants demonstrated the ability to circle answers correctly did the survey begin. Each participant was

supplied with a pen, a Ziploc bag, and an envelope. Unique-color booklets for each section of the survey were also handed out. In order to maintain confidentiality, participants were separated by at least four feet (1.2 meters) of empty space on all sides. To further ensure privacy, a tent-shaped manila folder was used so the interviewer and others in the group could not see what respondents were marking.

Research assistants were available to answer questions and monitor the data collection environment. Participants returned their completed surveys to the principal investigator. In addition to verbal consent, return of the questionnaire was taken as evidence of consent. Each participant was given a $5.00 honorarium.

Data Analysis

Data were double entered into Microsoft Excel for manual inspection and coding. All entries were manually checked for logical inconsistencies, and impossibilities. Incorrect and missing entries were examined and verified against the original survey questions. Missing entries that could not be verified were excluded from subsequent analysis. Data were cleaned for errors and transferred into STATA software for rechecking and coding. Frequency distributions were run to check for illegal codes, omissions, inconsistencies, and improbabilities.

HIV/AIDS knowledge, Attitude, Behavior/Practice and Self-efficacy scales were each scored for the number of correct responses. Response options for the sections were either yes, no, does not know or not applicable. Not applicable' and 'Don't know' responses for all scales were scored as 'valid skips' and 'incorrect,' respectively. Correct responses were scored with '1' and incorrect responses were scored with a '0'. Valid skips were not scored.

Demographic characteristics including gender, age, marital status, religious observance, employment, household size, level of education, and length of stay in the United States were identified as predictor (independent) variables for this study. Other predictor variables included knowledge of HIV/AIDS, attitude towards HIV/AIDS and people living with HIV/AIDS, self-efficacy for engaging in protective behavior. Predictor variables were identified from the literature as factors that help to explain how health behavior is acquired and maintained [2, 17-20].

The main outcome (dependent) variable for this study was HIV/AIDS Behavior/practices. Three other predictor variables were designated as outcome variables to further analyze associations between outcome variables and socio-demographic characteristics. They were: (1) knowledge of HIV/AIDS; (2) attitude towards HIV/AIDS and people living with HIV/AIDS; (3) Self-efficacy for engaging in protective behavior. Outcome variables were chosen because of their relevance to HIV/AIDS intervention programming.

Statistical Analysis

Statistical analysis was performed using STATA software. First, we conducted preliminary univariate analyses in order to examine distribution of all variables in the study. Frequencies, percentages, means, and standard deviations were used to describe the socio-demographic characteristics of the sample and HIV/AIDS Knowledge, Attitude, Behavior/Practices, and Self-efficacy scales.

We then performed independent t-tests to evaluate differences in mean scores for the four scales by age, gender, level of education, and marital status. Chi-square analysis was performed to assess how respondents' HIV/AIDS Behavior/practices, knowledge of HIV/AIDS, attitude towards HIV/AIDS, and self-efficacy varied by gender, age, level of education, and marital status. When the chi-square was 0 .05 or lower, we rejected the possibility that no association exists between variables. More comparative analysis of scores in the four scales (Knowledge, Attitude, Behavior/Practices, and Self-efficacy) was performed using ANOVA with contrasts and posthoc analyses.

Subsequently, we performed multiple regression analysis using backward elimination to determine what variables were significant in predicting HIV/AIDS Behavior/practices, knowledge of HIV/AIDS, attitude towards HIV/AIDS, and self-efficacy. Multicollinearity was assessed by examining both correlation coefficients between variables and variance inflation factors. We used a backward elimination technique by calculating F-statistics for each model, including all independent variables. At each step of backward elimination, the variable showing the smallest

contribution to the model was deleted. We eliminated variables from the model one by one until all the remaining variables in the model produced F-statistics significant at $P<0.05$.
A 5% significance level ($\alpha = 0.05$) was used in all the analyses. We report Regression estimates (beta coefficients, t value, standard error, and p-values) for statistically significant predictor variables. By construction, these results were adjusted for all other covariates in the model.

Results

A total of 76 anonymous surveys were completed individually and on-site. Each participant took approximately 40 minutes to complete the survey. Seventy-four respondents had complete data on all the study variables, except 3, who had missing information on two questions in the socio-demographic section. Two surveys that had missing data on all questions in the behavior/practice and attitude sections were excluded in subsequent analysis.

Socio-demographic Profile

Participants' socio-demographic characteristics are shown in Table 3. Most, 56.76%, of the participants were female, and most, 58.11%, were married. Participants' age ranged from 12 to ≥49 years. The majority, 78.37% were between the ages of 15-49, and 54.05% had an income-generating activity.

Results on educational attainment showed that a small percentage of respondents (9.46%) had received no formal education. In response to the question on religious affiliation, 90.54% of the respondents indicated that they attended religious services, and 83.78% had lived in the US for more than 12 months.

Respondents' Knowledge of HIV/AIDS

Responses to questions concerning HIV/AIDS knowledge are shown in Table 4. Although factual knowledge about HIV/AIDS was high, the study uncovered misperceptions regarding the likelihood of HIV transmission through casual contact such as shaking hands. The majority of respondents (97.29%) indicated that they had heard of HIV/AIDS. Overall, respondents were knowledgeable on general HIV AIDS facts. Although most respondents (70%) correctly answered

Table 3

Demographic Characteristics of Participants

	%
Male	43
Age(years)	
12-14	4
15-24	4
25-49	5
> 49	18
Marital status	
Single	31
Married	58
Widowed	4
Divorced or separated	0
Living together	7
Employment	
Yes	54
No	55
Household size	
1-3	34
4-5	34
> 6	32
Education	
No education	9
Primary school	41
High school	27
College	23
Religious observance	
Yes	91
No	9
Duration of stay in the United States	
1-6 months	9
6–12 months	7
12 months or more	84

Table 4

Participants' Knowledge of HIV/AIDS

	Yes (%)	No (%)	Don't Know (%)
Heard of HIV/AIDS	94	3	3
Can HIV/AIDS be cured?	10	88	2
Is it possible for a healthy-looking person to be infected with HIV/ AIDS?	80	16	4
Can a person who is living in the United States be infected with HIV/AIDS?	8	82	10
Can traditional healers cure HIV/AIDS?	12	80	8
Can a person get HIV/AIDS through the air when a person with HIV/AIDS coughs or sneezes?	2	81	17
Can a person get HIV/AIDS by shaking hands with a person who is infected with HIV/AIDS?	14	76	11
Can people get infected with HIV/AIDS by using the same cup or plate with a person who is infected with HIV/AIDS?	39	51	9
Can a person get HIV/AIDS from witchcraft?	45	50	5
Can people protect themselves from getting HIV/AIDS by having sex with only one faithful, uninfected partner?	66	15	19
Can people protect themselves from HIV/AIDS by using a condom correctly every time they have sex?	73	15	19
Do you think male circumcision is good protection against HIV/AIDS during sexual intercourse?	31	47	22

two items concerning the possibility of HIV/AIDS transmission through nonsexual contact (sneezing, shaking hands), 40% had incorrect knowledge.

Interestingly, 44.59% of the respondents believed that HIV/AIDS could be transmitted through witchcraft and 47.30% did not think male circumcision was good prevention against HIV infection. Though 72.97% believed condoms to be good protection against HIV when used correctly, 14.86% did not think condoms were effective, and 18.92% were not sure. There was no significant difference in knowledge scores for men and women.

HIV/AIDS Attitude

Responses to questions concerning attitude toward HIV/AIDS are shown in Table 5. Among the respondents, 29.7% indicated they would not buy food from a vendor who has HIV/AIDS, 39.2% thought that students with HIV/AIDS should not attend the same schools as those without AIDS, and 14.9% indicated that a person who is infected with HIV/AIDS should not be allowed to work. More than half (60.8%) would like a family member's HIV status to remain a secret. Responses to the question 'would be willing to care for a family member who was infected with HIV/AIDS' did not differ significantly based on age, gender, or level of education, but differed based on marital status. In general,

Table 5

HIV/AIDS Attitude

	Yes (%)	No (%)
If you believed a food seller had HIV/AIDS, would you buy food from him or her?	97	3
Would you sit next to someone who is infected with HIV/AIDS?	12	88
Should students with HIV/AIDS go to special schools for those with HIV/AIDS?	84	16
If a person got infected with HIV/AIDS, should he or she be allowed to stay in his/her work place?	8	82
If a member of your family got infected with HIV/AIDS, would you want it to remain a secret?	12	88
If a member of your family became sick with the virus that causes HIV/AIDS, would you be willing to care for him or her in your own household?	1	99

women had more positive attitudes towards HIV/AIDS than men. The difference was, however, not statistically significant.

HIV/AIDS Behavior/Practices

The study found moderate to high levels of HIV risk behaviors and practices (see Table 6). HIV risk behavior/practices was determined by multiplicity of sexual partners, condom use with unfamiliar partners, and the extent to which participants reported they were faithful to their marital or live-in partners. Slightly more than a third (36.49%) of the respondents reported having unprotected sex with more than one partner in the previous 12 months. The greatest risk behavior was in the area of marital/partner fidelity: 44.59% did not think a man should be faithful to his partner and 45.95% did not think a woman should be faithful to her partner. Responses did not differ significantly based on age, level of education, or marital status, but differed based on gender: 88.2% of the men believe that women should be faithful to their partners, but only 26.7% of the men thought men should be faithful to their partners.

Self-efficacy

Responses to self-efficacy questions are shown in Table 7. Overall, perceived self-efficacy for engaging in protective behavior was moderate. Most participants (81.06%) said they would communicate freely with their partners on matters concerning sex, 63.5% said they would insist on using a condom with a partner if necessary, and 76.7% were confident they can protect themselves from HIV/AIDS. Responses did not differ by education level, age or marital status. Mean scores for men were statistically significantly higher than women's scores ($p < 0.02$).

Voluntary Testing and Counseling

Most respondents (55.41%) were willing to be tested for HIV though, only 29.73% had been tested in the last 12 months. Among all participants, 75.68% were willing to be tested at a health care center or hospital. However, 75.68% were not willing to be tested for HIV during a public event such as the World Refugee Day. Two people reported being seropositive. Responses to voluntary testing and counseling are shown in Table 8.

Table 6

Participants' HIV Risk Behavior/Practices

	Yes (%)	No (%)
Have you ever had sexual intercourse?	81	19
During the last 12 months, did you have sex with more than one partner?	36	64
In the last 12 months, did you have sex with a person that is not your marriage or live-in partner?	22	78
If you answered YES did you use a condom?	69	31
Have you had sex in exchange for money or gifts in the last 12 months?	19	81
If you answered YES did you use a condom?	71	29
In the last 12 months, did you have sex while under the influence of alcohol?	14	76
Should a woman be faithful to one partner?	55	45
Should a man be faithful to one partner?	46	54
Have you ever been told by a doctor or health professional that you have a sexually transmitted disease?	27	73
Have you been tested for HIV in the last 12 months?	30	70
Do you know a place in the (United States) where a person can be tested for HIV?	57	43
Have you ever been told by a doctor or health professional that you have HIV/AIDS?	3	97

Table 7

Participants' Self-Efficacy in Protecting Themselves from HIV/AIDS

	Yes (%)	No (%)	Don't know (%)
Can you communicate freely with your partner on matters concerning sex?	81	12	7
Are you confident that you can protect yourself from HIV/AIDS?	77	19	4
If you think it's necessary, would you insist on using a condom with your partner?	64	31	5
Should a woman refuse to have sex with her husband?	43	57	0
Would you voluntarily go for HIV testing	55	45	0

Table 8

Acceptance of Voluntary Testing and Counseling

	Yes (%)	No (%)	Not applicable (%)
Would you be willing to be tested for HIV at your own home?	34	50	16
Would you be willing to be tested for HIV at a health center or hospital?	76	8	16
Would you be willing to be tested for HIV during a public event such as the World Refugee Day?	10	76	14

HIV/AIDS Informational Needs

Findings from the study indicate a very high interest level on the part of participants in acquiring HIV/AIDS knowledge. More than 90% indicated willingness to learn more about HIV/AIDS. When asked which setting they felt would be appropriate for receiving HIV/AIDS education and from whom they would feel most comfortable receiving the information, several methods were identified. The most popular method identified as appropriate for information dissemination was the healthcare system (93%). Television was the least popular method (33%). Means of information dissemination in order of preference are shown in Table 9.

Bivariate Analysis

Table 10 presents the results of the bivariate analysis (Pearson Correlation) with of HIV/AIDS behaviors/practices, HIV/AIDS Knowledge, Attitude towards HIV/AIDS, and Self-efficacy. A number of statistically significant relationships emerged. The strongest overall correlation was between knowledge and attitude scores ($r = 0.6302$, $p < 0.001$), followed by knowledge and behavior/practice scores ($r = 0.4529$, $p < 0.001$). The weakest correlation was between attitudes and self-efficacy scores ($r = 0.2908$, $p = 0.01$).

Table 9

Preferred Methods of Information Delivery

	(%)
Doctor or health care provider	93
Internet	87
Books	76
Public gathering	71
School	70
Trusted friend	67
Case worker	66
Family member	63
Television	33

Table 10

Bivariate Analysis of HIV/AIDS Knowledge, Attitude, and Practices

	HIV/AIDS Knowledge		Attitude Towards HIV/AIDS		Behavior/Practices	
	Coefficient	P- value	Coefficient	P- value	Coefficient	P- value
Attitude Towards HIV/AIDS	0.6302	0.0000				
Behavior/Practices	0.4529	0.0001	0.3472	0.0024		
Self-efficacy	0.3549	0.0019	0.2908	0.0120	0.3221	0.0051

We found that:

- High self-efficacy for engaging in protective behavior/practices was associated with HIV protective behavior or sexual practices.
- Positive attitudes towards HIV/AIDS or people living with HIV/AIDS were associated with HIV protective behavior or sexual practices.
- High knowledge of HIV/AIDS was associated with HIV protective behavior or sexual practices.
- High knowledge of HIV/AIDS was associated with positive attitudes towards HIV/AIDS or people living with HIV/AIDS.
- Positive attitudes towards HIV/AIDS or people living with HIV/AIDS were associated with high self-efficacy for engaging in protective behavior/practices.
- High self-efficacy for engaging in protective behavior/practices was associated with both high knowledge of HIV/AIDS and protective behavior/practices.

Table 11

Effects of Knowledge, Attitude, and Self-efficacy on the Odds of Engaging in HIV Risk Behavior/Practices

	Model 1 Behavior/ Practice	Model 2 Knowledge	Model 3 Attitude	Model 4 Self-efficacy
	B(SE),P	B(SE),P	B(SE),P	B(SE),P
Knowledge	0.456(0.115), 0.000		0.618(0.0844), 0.000	0.0425(.1684) 0.801
Attitude	0.027(0.161), 0.866	0.0507(0.087),0.000		0.304(0.130), 0.022
Behavior/ Practice		0.347(0.073), 0.000	0.0156(.092), 0.866	0.278(0.103),0.009

Multivariate Analysis

Table 11 presents the results of linear regression analyses and consists of 4 models.

Model 1

The main outcome (dependent) variable was HIV/AIDS Behavior/practices. Predictor variables were knowledge of HIV/AIDS, attitude towards HIV/AIDS and people living with HIV/AIDS, self-efficacy for engaging in protective behavior and all socio-demographic variables (gender, age, marital status, religious observance, employment, household size, level of education, and length of stay in the United States). This model revealed that 4 of the independent variables emerged as significant: HIV/AIDS knowledge, self-efficacy, gender, and household size. In general, persons with high self-efficacy were more likely to engage in HIV protective behavior (B= 0.248, P=0.027) compared to those with low-efficacy and persons with more knowledge about HIV/AIDS were more likely to engage in protective HIV/AIDS Behavior/practices (B= 0.454, P<0.001) than were persons who were less knowledgeable about HIV/AIDS. Persons living in households with 6 or more people were more likely to engage in protective HIV behavior (B= 1.411, P<0.001), compared with those living in households with 1-3 people. Being male was

associated with more risky HIV/AIDS behavior; in comparison to women, men were more likely to engage in high risk behavior/practices (B= -.87539, P=0.005).

The multivariate analysis found no association between HIV/AIDS behavior/practices and respondents' age, level of education, marital status, employment, religious affiliation, and length of stay in the United States. The model explained 46% of the variance in HIV/AIDS Behavior/practices.

Model 2

The main outcome variable was knowledge of HIV/AIDS. Predictor variables were HIV/AIDS Behavior/practices, attitude towards HIV/AIDS and people living with HIV/AIDS, self-efficacy for engaging in protective behavior and all socio-demographic variables (gender, age, marital status, religious observance, employment, household size, level of education, and length of stay in the United States). This model revealed 3 significant independent variables. Attitude towards HIV/AIDS was a strong predictor of HIV/AIDS knowledge; people with more knowledge about HIV/AIDS were more likely to have a positive attitude towards HIV/AIDS (B= 0.5071, P<0.001) compared to those with less HIV/AIDS knowledge. Also, persons with more knowledge of HIV/AIDS were more likely to report protective HIV/AIDS behavior (B= 0.348, P<0.001) compared with persons with less HIV/AIDS knowledge. Compared with women, men had higher HIV/AIDS knowledge (B= .6992, P<0.004). Association between HIV/AIDS knowledge and respondents' age, level of education, marital status, employment, religious affiliation, and length of stay in the United States were not statistically significant. The model explained 49% of the variance in HIV/AIDS knowledge.

Model 3

The main outcome variable was Attitude towards HIV/AIDS. Predictor variables were HIV/AIDS Behavior/practices, knowledge of HIV/AIDS, self-efficacy for engaging in protective behavior and all socio-demographic variables (gender, age, marital status, religious observance, employment, household size, level of education, and length of stay in the United States). With this model, HIV/AIDS knowledge and gender were strongly associated with attitude towards

HIV/AIDS. In general, men had less positive attitude towards HIV/AIDS (B= -0.5418231, P= 0.018) compared with women. High knowledge of HIV/AIDS was associated with positive attitude towards HIV/AIDS (B= 0.5071, P<0.001). The multivariate analysis did not find association between Attitude towards HIV/AIDS and respondents' age, level of education, marital status, employment, religious affiliation, and length of stay in the United States. The model explained 44% of the variance in Attitude towards HIV/AIDS.

Model 4

The main outcome variable was self-efficacy. Predictor variables were HIV/AIDS Behavior/practices, knowledge of HIV/AIDS, attitude toward HIV/AIDS, and all socio-demographic variables (gender, age, marital status, religious observance, employment, household size, level of education, and length of stay in the United States). Persons with high self-efficacy were more likely to report protective behavior/practice (*b = 0.294069, p= 0.005*), when compared with persons with low self-efficacy. High self-efficacy was also associated with positive attitude towards HIV/AIDS (*b = 0.2853, p= 0.03*). Compared to women, men in the sample had a higher self-efficacy (*b = 1.1482, p< 0.001*) for engaging in protective behavior. The multivariate analysis did not find association between self-efficacy and respondents' age, level of education, marital status, employment, religious affiliation, length of stay in the United States, and level of HIV/AIDS Knowledge. The model explained 28% of the variance in self-efficacy.

Reliability

The reliability of the questionnaire was satisfactory. The range for HIV/AIDS knowledge scale was 0-12 (Cronbach's alpha, 0.70). Scores for the attitude scale were in the range of 0-6 (Cronbach’s alpha, 0.71), Behavior/Practice scores were in the range of 1-13 (Cronbach's alpha, 0.80), and self-efficacy scores were in the range 0-6 (Cronbach's alpha, 0.71).

Discussion

HIV prevention strategies which are culturally sensitive and specific to US-based Burundi refugees is needed. To be effective strategies must be anchored on empirical evidence on level

of HIV/AIDS knowledge, attitudes towards HIV/AIDS, and risk behavior/practices in the target population. We believe that our findings create foundational knowledge about HIV/AIDS knowledge, attitude and behavior as a basis for designing targeted interventions for the population. Findings suggest that interventions aimed at increasing HIV/AIDS knowledge would be most beneficial in promoting protective HIV/AIDS behavior and practices. We therefore make recommendations for educational program aimed at improving knowledge of HIV/AIDS, in particular, knowledge of modes of in the population. Recognizing that individual behavior is determined to a large extent by social environment, the most effective approach leading to protective behavior/practices is a combination of effort at individual, interpersonal, organizational, community, and public policy levels.

Information gathered from this study will be used to engage community members, stakeholders, and health professionals in a dialogue to prioritize structures to target for interventions, determine the intervention channels, devise a plan for promotion, dissemination, implementation, and maintenance of the program, and develop an evaluation plan to assess changes in HIV/AIDS risk behavior and practices.

HIV/AIDS Behavior/Practice

The study found moderate levels of HIV risk behaviors and practices. However, as with all studies of sensitive issues, data pertaining to sexual behavior and practices are likely to be biased. The Burundian family is generally acknowledged as moralistic and traditional, suggesting that HIV risk behavior/practices may have been under reported or intentionally misreported. Negative attribution of socially undesirable practices such as cohabitation, commercial sex and sex with multiple partners leads to social denial and may interfere with willingness to disclose the risk behavior/practices, potentially hindering HIV prevention efforts. Information on the true extent of HIV infection in the community is also limited due to stigmatization surrounding HIV/AIDS, fear of alienation, and ethical considerations in HIV screening. These findings suggest strategies for developing messages that could help reduce the social stigma that hinders disclosure of HIV risk behavior, so that needed support can be forthcoming.

However, HIV/AIDS prevention requires understanding of the social and cultural contexts in which HIV-risk behaviors occur. Knowledge of gender relations and the socio-cultural environment in which relationships, including sexual relationships, are played out is important in developing HIV/AIDS prevention strategies. Men's greater power and status in Burundi, as in most African societies, underlie the differences in gender roles. The powerful roles held by men lead to development of related traits, such as aggressiveness and assertiveness. On the contrary, women develop traits consistent with their subordinate roles, such as submissiveness. Societal norms about masculinity encourage men to engage in risk-taking behavior and practices, making them vulnerable to HIV infection. In a context where men grow up believing masculinity means having a multiplicity of sexual partners, being faithful to one's husband does not confer protection from HIV infection.

HIV prevention programs for Burundi refugees will therefore need to be culturally tailored, with focus on means of eliminating abuses of sexual power towards women in heterosexual relationships, in order to provide a safe environment for women to practice HIV preventive behavior.

HIV/AIDS Knowledge

Although factual knowledge of HIV/AIDS was high, many respondents were misinformed about modes of HIV transmission and methods of prevention. Ignorance of some basic facts on transmissibility points to the need for considerable education to correct misperceptions and educate people on modes of HIV transmission and how to recognize the signs and symptoms of the disease. Although knowledge is a common prerequisite for behavior change, research shows that knowledge alone is not sufficient to promote or sustain behavior change. In addition to adequate knowledge, a person must have self-efficacy, a sense of control to facilitate a change of health behavior. Self-efficacy influences the effort one puts forth to modify risk behavior and the persistence to continue striving despite barriers or setbacks that may undermine personal motivation [17].

Self-efficacy

According to research, the degree to which men and women are able to control various aspects of their sexual lives such as ability to negotiate the timing of sex and conditions under which sexual relations takes place, plays a critical role in determining vulnerability to HIV infection [20]. This study found that men had higher self-efficacy for engaging in protective behavior than women, including negotiating use of condoms. High self-efficacy was associated with protective behavior and practices. Consistent with these findings are other studies that show women who are afraid of partner reaction to condom use are less likely to assertively negotiate condom use [21-23]. A woman's ability to practice safe sex may be influenced by her ability to communicate openly about sex with her partner, the power dynamic in their relationship, or how much the partner believes in traditional gender roles [2, 22]. The power imbalance curtails women's sexual autonomy and expands men's sexual freedom and control over sexuality. The findings indicate that improving self-efficacy for engaging in protective behavior can help reduce HIV transmission and risk behavior/practices in the Burundi population. Thus, HIV/AIDS prevention programs should include a focus on enhancing self-efficacy for reducing risk behaviors. To be effective, prevention initiatives must also take into account social and cultural norms that perpetuate gender-based imbalance in heterosexual relationships.

Voluntary Testing and Counseling

Testing for HIV antibody status has been used as a mechanism to inform and counsel people who are likely to be practicing high-risk behaviors [24]. It is important for people to know their HIV status to enable them to seek appropriate treatment as well as enable them to choose prevention strategies. In this study, most respondents expressed willingness to be tested for HIV, with the majority showing preference for testing in hospitals or healthcare settings. These findings suggest the need for access to testing and counseling to help the population evaluate their risk of HIV exposure and to educate them about how to reduce risk for HIV infection. Interventions should include provision of confidential testing for individuals at high risk and counseling for those

who test seropositive for HIV exposure, and should use procedures that are acceptable to the community.

Informational Needs

Efforts must be made to ensure that Burundi refugees have access to educational opportunities that provide essential skills and knowledge for prevention of HIV. To the extent possible, HIV-prevention intervention should be adapted to the socio-cultural context of Burundi. Culturally tailored educational programs may help to overcome the barriers that hinder HIV prevention and can create conditions of understanding and tolerance that contribute to reduced stigma and discrimination against people living with HIV [2].

A person's sense of trust in the educator is critical to his or her decision to engage in the education process. The sensitivity of HIV/AIDS and issues associated with stigma in the community places high premium on educators who can be trusted and are sensitive to the community's values, norms, and beliefs. Policies and programs must therefore be culturally sensitive and to the maximum extent possible, be designed, implemented, monitored and evaluated the participation of refugee peer educators, community leaders, and persons who have vested interest in the community. Health and social services including those for treating sexually transmitted diseases, counseling, and HIV antibody testing need to be particularly accessible, with staff trained to give culturally competent care. Information leading to behavior change can be enhanced by the influence of opinion leaders. It will be imperative to identify these leaders and change agents in order to create an environment supportive of new ideas for HIV prevention.

Identification of suitable means of information dissemination is equally important. Although mass media, independent agents and health care providers are able to influence individuals directly by setting agenda for changes, messages must be culturally appropriate and acceptable to the target population. Information that fails to take cultural and linguistic diversity into account will at the very least be ignored.

This study exhibits two main limitations. As a cross-sectional study, causality between variables contributing to HIV/AIDS risk or protective behavior cannot be inferred. A further

limitation was use of self-reported data on sex-related items. As with all studies of sensitive issues, data are likely to be biased. Intentional misreporting or underreporting of sex-related issues may have contributed to threats of internal validity. Despite the limitations, the study has important value. It presents information on a population which has previously been neglected in the public health literature. The principal strength of this study lies in its random sampling methodology, with a sample size that is large enough to represent Burundian refugees in the study's geographic area, and rigorous methods to guard against internal and external validity.

Conclusion

We recommend developing and implementing an educational program aimed at increasing knowledge of HIV/AIDS in the population. Cognitive-behavioral and risk-reduction skills training will be provided as a necessary first step in making informed choices about actions to deal with the HIV/AIDS.

The program will focus on increasing HIV/AIDS knowledge, correcting myths and misperceptions regarding HIV/AIDS, and influencing attitudes towards HIV/AIDS. Strategies will mainly be aimed at encouraging abstinence, marital faithfulness and condom use. The program will also address socio-cultural norms and beliefs that facilitate the spread of HIV/AIDS. Individuals' self-efficacy to perform the skills taught will be enhanced by providing opportunities to model the skills learned.

Proposed interventions will draw primarily from the Social Cognitive Theory [17] and the Theory of Gender and Power [25], and also integrate selected concepts from the Social-ecological model [26] and Theory of Reasoned Action and Planned Behavior [27]. Strategies will be developed through consultation and consensus with the target population and stakeholders, will utilize educational modalities (formal, nonformal and informal), and will ensure multisectoral collaboration in an effective and efficient way. Whenever feasible, HIV and AIDS educational activities will be coordinated with other educational initiatives at the State level in order to maximize use of available financial, material, and human resources and avoid duplication of efforts. Collaborations may also help to strengthen relationships between the host community and

US-based Burundi refugees and reduce the stigma and discrimination which the refugees often face. Lastly, an evaluation and monitoring plan for the program will be instituted to guide future actions and take corrective measures when needed.

Essential components of the proposed intervention will include: (1) Gender-based education; (2) educator training and support; (3) Voluntary Testing and Counseling (VCT); (4) cost-effective Outreach and Dissemination.

Gender-based Education

Social-cultural norms associated with masculinity as well as prescribed gender roles in the Burundi community will be addressed. Educational programs will also focus on means of eliminating abuses of sexual power towards Burundian refugee women in heterosexual relationships in order to provide a safe environment for women to practice HIV preventive behavior. Both men and women should be educated about sexual means of HIV/AIDS transmission and methods of prevention using different approaches.

Women's programs will be aimed at enhancing self-efficacy for engaging in self-protective behaviors and promoting the acquisition of skills necessary to reduce risk for HIV infection. Sexual assertiveness, negotiation and communication will be taught along with planned activities for modeling the skills.

Educator Training and Support

Community-based leaders and peer educators could play a vitally important role in developing and implementing programs to contain the spread of HIV/AIDS. Community leaders and peer educators are accessible to the local community and have credibility, respect as well as prestige in the community, and can use their position to influence behavior. Both the leaders and peer-educators will be trained in HIV prevention because are in a unique position to motivate the community to adopt HIV/AIDS preventive measures and deliver services in ways that are culturally appropriate and persuasive.

Voluntary Testing and Counseling (VTC)

Interventions should include provision of confidential testing for individuals at high risk followed by counseling for those with seropositive test results for HIV exposure, using procedures that are acceptable to the community for identifying persons to be tested.

Cost-effective Outreach and Dissemination

Since HIV/AIDS is sexually transmitted, organizations dealing with sexually transmitted infections such as state health departments are obvious candidates for partnership in providing prevention education, counseling, condom distribution, and disseminating information in efforts to contain the spread of HIV/AIDS. Informal gender-based groups and networks within the community, such as 'Burundi Drummers' and 'Best of Africa' can be employed in outreach efforts to educate and motivate behavior change among men and women respectively. The networks can also be useful in condom distribution. Further, existing formal programs could be strengthened with new focus on prevention interventions for vulnerable populations. It should be recognized, however, that exclusive focus on refugees is insufficient and may only serves to stigmatize them further.

This study provided foundational knowledge about HIV/AIDS knowledge, attitude and behavior/practices in the population as a basis for designing interventions that are culturally sensitive and tailored to specific needs of the US-based Burundi community. We recommend incorporating refugees into national HIV/AIDS educational activities, policies and strategic plans for host countries educational whenever feasible, in order to maximize use of available financial, material, and human resources.

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CHAPTER 5

CONCLUSION

The purpose of this study was to investigate the knowledge levels, attitudes, and behavior/practices of HIV/AIDS among the US Burundi refugees. The research also investigated the socio-demographic variables that are relevant to the transmission of HIV/AIDS in the population. Findings provided foundational knowledge about HIV/AIDS knowledge, attitude and behavior/practices in the population as a basis for designing interventions that are culturally sensitive and tailored to specific needs of the US-based Burundi community.

Summary

The study found moderate to high levels of HIV risk behaviors and practices, with the greatest risk behavior being in the area of marital/partner fidelity. In comparison to women, men scored lower in behavior/practices but scored higher in measures of self-efficacy for engaging in protective behavior. Overall, participants demonstrated a high level of factual knowledge about HIV/AIDS. The high level of knowledge demonstrates that the participants are very aware of the seriousness of HIV/AIDS, a finding that is consistent with previous research [1-5]. Knowledge of HIV/AIDS was also significant in predicting attitudes towards HIV/AIDS. The implication of these finding is that individuals who are more knowledgeable about the different aspects of HIV/AIDS, including symptoms, causes, and transmission may be less likely to hold negative attitudes towards HIV/AIDS or harbor misconceptions about the disease, and consequently adopt HIV protective behavior.

Knowledge of HIV/AIDS, attitudes, and self-efficacy were significant in predicting HIV/AIDS behavior/practice. Overall, the study findings are important as they highlight the supportive role that knowledge, attitudes, and self-efficacy could play in promoting protective

HIV/AIDS behaviors and practices. The following programmatic and practice recommendations were made based on the findings:

- Implement culturally competent educational programs
- Programs should be gender-specific, group-based or individual-based.
- Programs should be structured by age and level of education.
- Focus on HIV/AIDS prevention and transmission, abstinence, marital faithfulness, and condom use.
- Use peer educators and, or culturally competent health educators.
- Address social-cultural norms, myths and misconceptions, taboos, stigma and secrecy.
- Address culturally defined standards of male behavior.
- Include voluntary counseling and testing (VCT).
- Collaborate with community and stakeholders.
- Leverage available resources.
- Incorporate refugees into policies, national strategic plans and programs.
- Design evaluation and monitoring plans.

One limitation of this study is that causality between variables cannot be inferred as it is a cross-sectional study. A further limitation was use of self-reported data on sex-related items. As with all studies of sensitive issues, data are likely to be biased. Intentional misreporting or underreporting of sex-related issues may have contributed to threats of internal validity. Despite the limitations, the study has important value. It presents information on a population which has previously been neglected in the public health literature. The principal strength of this study lies in its random sampling methodology, with a sample size that is large enough to represent Burundian refugees in the study's geographic area, and rigorous methods to preserve the study's internal and external validity. Research findings will be generalized from the study sample to the entire Burundian refugee population. With appropriate adaptations, partial generalizations to similar populations may be possible.

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APPENDIX A

KEY INFORMANT DISCUSSION GUIDE

Tell me about your involvement with the Burundi community.

How long have you been involved in the community?

What needs and services are perceived as important by your community?

How serious is HIV infection compared to other problems in the community?

What populations within your community do you think are most at risk for HIV?

Where do people get information about HIV/AIDS?

Is there anything else that you would like to add?

APPENDIX B

FOCUS GROUP DISCUSSION GUIDE

HIV/AIDS Knowledge

Have you ever heard of HIV or a disease called AIDS?

AIDS is a contagious disease

There is no cure for AIDS

AIDS is mostly seen in the developing or underdeveloped countries.

There is a vaccine for AIDS

We can distinguish AIDS patients from others by their appearance

HIV/AIDS Can Be Contracted Through:

Using the same glass or cup with a HIV positive person

The bite of a mosquito

The breast milk of an infected person

Misconceptions Towards HIV/AIDS

A person can be infected with AIDS through witchcraft

AIDS is a punishment from God

Attitudes

Students with AIDS should go to special schools for those with AIDS

I would not sit in the same armchair or desk with a person with AIDS

I would not kiss someone with AIDS

Practice

If you tested positive for HIV, would you want it to remain a secret?

Information Needs

Would you like to learn more about HIV/AIDS?

APPENDIX C

INDIVIDUAL INTERVIEWS DISCUSSION GUIDE

HIV/AIDS Knowledge

Have you ever heard of HIV or a disease called AIDS?

We can distinguish AIDS patients from others by their appearance

Can HIV/AIDS be contacted through using the same glass or cup with a HIV positive person?

Can a person be infected with AIDS through witchcraft?

Attitudes

Students with AIDS should go to special schools for those with AIDS

I would not kiss someone with AIDS

Practice

If you tested positive for HIV, would you want it to remain a secret?

Information Needs

Would you like to learn more about HIV/AIDS?