Journal of Urban Health: Bulletin of the New York Academy of Medicine, Vol. 82, No. 2, Supplement 3
doi:10.1093/jurban/jti066

Cultural Adaptation in Translational Research: Field Experiences

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ABSTRACT *The increase in the incidence of HIV/AIDS among minorities in the United States and in certain developing nations has prompted new intervention priorities, stressing the adaptation of efficacious interventions for diverse and marginalized groups. The experiences of Florida International University's AIDS Prevention Program in translating HIV primary and secondary prevention interventions among these multicultural populations provide insight into the process of cultural adaptations and address the new scientific emphasis on ecological validity. An iterative process involving forward and backward translation, a cultural linguistic committee, focus group discussions, documentation of project procedures, and consultations with other researchers in the field was used to modify interventions. This article presents strategies used to ensure fidelity in implementing the efficacious core components of evidence-based interventions for reducing HIV transmission and drug use behaviors and the challenges posed by making cultural adaptation for participants with low literacy. This experience demonstrates the importance of integrating culturally relevant material in the translation process with intense focus on language and nuance. The process must ensure that the level of intervention is appropriate for the educational level of participants. Furthermore, the rights of participants must be protected during consenting procedures by instituting policies that recognize the socioeconomic, educational, and systemic pressures to participate in research.*

KEYWORDS *Cultural adaptation, HIV/AIDS, Literacy, Translational research.*

INTRODUCTION

The purpose of this article is to discuss field experiences of the *AIDS Prevention Program* at Florida International University in adapting evidence-based interventions for cultural subgroups within the United States and for populations in the Caribbean and South Africa. Based at the Stempel School of Public Health, the *AIDS Prevention Program* has adapted and is in the process of implementing intervention projects aimed at reducing the transmission of HIV.

The research was guided by the Centers for Disease Control and Prevention principles for effective programs.[1] In the adaptation process the researchers used strategies to ensure fidelity in replicating the components of an effective intervention

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while tailoring materials to different cultural subgroups. This occurred through accurate translation and cultural brokerage, processes to be discussed in this article. The low literacy among participants presented many challenges. The ethical implications of consent procedures are discussed along with aspects of the assessment, intervention, and analysis procedures. Conceptualization of the next generation of translational research utilized focus groups to identify problems, needs, and solutions during the formative stages of the cultural adaptation process. Focus groups were also used in the implementation and evaluation stages of new field intervention projects. These processes are particularly important among high-risk populations facing multiple interconnected conditions (e.g., unemployment, poverty, residential overcrowding or homelessness, environmental toxins, youth gang- and drug-related violence, health care inequality, poor diet).[2] An emerging macro-level structural approach calls for simultaneously addressing all variables of the "syndemic" (i.e., confluence of interrelated social and health conditions), to minimize spread of the disease within areas of concentrated poverty.

The adaptation procedures described are based primarily on the intervention projects with Haitian and Trinidadian adults in their respective countries and with monolingual Hispanic women in the United States. The projects utilized the core intervention model of cognitive-behavioral stress management (CBSM), which has been effectively used to improve immune function and increase adherence to antiretroviral therapy among HIV-positive persons.[3,4,5] Another project with Haitian American adolescents[6] is based on an adaptation of St. Lawrence's Becoming a Responsible Teen (BART) intervention that was used effectively among African American youth to reduce sexually risky behaviors.[7] In a project with South African adolescents and their parents, the research team plans to use several interventions deemed effective by the Centers for Disease Control and Prevention compendium[8], including an adaptation of *Focus on Kids/Informed Parents and Children Together*. This evidence-based intervention developed by Stanton and colleagues has been effective in reducing sexual risk behaviors and alcohol and drug use among African American youth.[9] A review of health disparities and their relationship to contextual factors associated with the progression of the HIV epidemic is warranted before discussing the adaptation process further.

Health Disparities and Contextual Factors

Health disparities arise from a combination of socioeconomic disadvantage and intercultural distinctions.[10] Poverty leading to health disparities is a major factor in the transmission of HIV in the United States and the regions of the world most heavily affected by the epidemic. The AIDS crisis provides a clear example of how the lack of access to care and medications and inadequate economic resources influence and are influenced by health disparities in these populations.[11,12] In an effort to help reduce disparities, the studies discussed here will assist in establishing: (1) which interventions are effective in these populations, (2) the specific components that may be effectively delivered, and (3) methodologies for adapting interventions to be more effective with specific populations.

HIV has reached epidemic proportions in many countries of sub-Saharan Africa, and twelve countries in the Caribbean report generalized epidemics with prevalence levels second only to sub-Saharan Africa.[13] Estimated prevalence rates are high in the countries in which the intervention projects under discussion are planned or are underway. Seroprevalence rates are estimated at 20%, 5–6%, and 1% in South Africa,[14] Haiti,[15] and Trinidad[16], respectively. Among pregnant women in

Trinidad, seroprevalence rates are estimated at 2%.[17] Several factors have contributed to the high rates in these regions, including the low status of women,[13,14] high levels of forced sex at first intercourse,[18] and lowrates of condom use.[19] Age mixing, defined as older men having sex with younger women, has contributed to higher levels of HIV among young women compared to young men.[15]

Minority populations and individuals of low literacy and socioeconomic status are at increased risk of HIV infection because of social and structural factors that increase the likelihood of coming in contact with an HIV-infected person. In acknowledgement of this emerging social epidemiological picture of HIV transmission risk, some of the more innovative designs have expanded the scope of behavioral and psychosocial intervention to incorporate the "structural", that is, the physical, social, economic, and political contexts of the epidemic.[20]

To address the disparities found transnationally and within the United States among underserved populations, it is necessary to conduct translational research. Translational research is the process by which discoveries, generated by means of basic scientific research, are applied to the treatment or prevention of human disease. Cultural adaptation, the means by which an intervention is adapted to the language, values and mores, and literacy level of a population, is an essential component of this process. Successful implementation of evidence-based HIV risk-reduction projects may depend on effective cultural adaptation.

Cultural adaptation is derived from the accumulating experience in prevention–intervention studies in which contextual factors have emerged as important mediators and moderators of outcomes. The cognitive behavioral model incorporates key contextual factors and is the core model for all of the adapted intervention trials that form the basis for the cultural adaptation process to be discussed here. The description below shows how this model is framed and guided by a conceptual approach for understanding health disparities in the industrialized and developing world in the context of HIV.

Conceptual Approach to the Adaptation Process

The adaptation process should involve an intertwining of the components of the intervention with important principles, values, and realities of the new culture. Adaptation is a dialectical process in which the original intervention is confronted by the cultural realities of the new culture to arrive at a synthesis representing a meaningful adaptation. For example, CBSM has proven efficacy among selected HIV-positive populations. However, it is inappropriate to introduce this intervention in its original form to Haitian adults with low literacy because of the language differences and abstract concepts. The realities of the cultural and structural context for this population force a change or adaptation in the original intervention. The synthesis is reached by combining the original intervention with realities of the Haitian culture, improving the likelihood of desired intervention outcomes.

Operationalizing the Adaptation Process

The process of cultural adaptation is a painstaking one that involves ensuring fidelity to the original intent of the intervention and maintaining the nuances of language, both formal and informal. The methods used included documentation of project meetings and procedures with special focus placed on challenges faced and their solutions. A cultural linguistic committee was formed and structured feedback obtained through consultations with other researchers and focus group discussions with key individuals such as providers, community members, and potential participants.

Additional strategies to maintain fidelity in replicating core components include accurate translation and back-translation and cultural brokerage, that is, reviewing content for cultural appropriateness.

Bauman and colleagues provide a theoretical compass in which the goal is to maintain the basic integrity of an intervention's causal/conceptual model although modifications are undertaken to address the unique features of a different setting or the cultural preferences of a new population.[21] Integral to this approach are the institutionalization of a Community Advisory Board (CAB) and the use of focus groups. The establishment of a CAB is useful to monitor the progress of the project and provide guidance on cultural and community issues easily overlooked by research staff. Focus groups were used with adolescents in the current projects to incorporate culturally relevant content to enhance comprehension of program components.[22]

A systematic review of community-based, health promotion and disease prevention programs in the United States revealed that extensive formative research is an integral component of effective HIV programs.[23] Discussions with providers and community leaders are central to this process. They help to (1) establish the need for the project, (2) assess whether it could be realistically adapted to meet the needs of the population, and (3) review the mechanisms by which the adaptation process would occur. Through formative research, teams may assess how cultural norms and prohibitions, such as taboos on the discussion of sexual issues, may affect data collection.[24] For example, among Haitians, young girls are expected to remain naïve to the experience of and information about sex until marriage, whereas young men are encouraged to become skilled so they can teach their wives upon marriage.[25] In a research context, underreporting sexual activities by females and overreporting by males may be the outcome of these cultural beliefs and norms.

The process of adaptation involves translation and back-translation of assessment and intervention materials, review of materials for cultural appropriateness and relevance,[26] and recruitment and training of culturally competent clinicians and assessors.[27] As a first step in this process, a cultural/linguistic planning committee was formed to review materials for the intervention study with HIV-positive drug abusing monolingual Spanish-speaking women. The committee's main task was to adapt the intervention and measures to maximize cultural and linguistic relevance for the sample. A similar committee was formed to conduct the translations of the CBSM intervention for Haitian adults. The committee consisted of two groups: members of the Haitian Study Group on Kaposi's Sarcoma and Opportunistic Infections in Haiti (GHESKIO) who performed the original translation and back-translation and members in Miami who were most familiar with the instruments and ensured that the translation maintained the original meaning.

Bauman's recommendation to maintain the integrity of the intervention while modifying for the unique features of the culture[21] may be adapted to include literacy as one of those unique features. It is challenging to strike a balance between adapting for a lower literacy population without simplifying so much that the main tenets of the intervention are lost or obscured. In the adaptation process, the research team minimizes drift and loss of content by regularly checking fidelity to the instruments and intervention. Vigilance to the process and awareness of the original intent are necessary to ensure that the adaptation does not create a new intervention.

In the final phase of the adaptation process, cultural brokerage is used to ensure cultural appropriateness. Jezewski and Sotnik describe this process as one in which arbitration occurs between people of differing cultural backgrounds to reduce

conflict or produce change.[28] The AIDS Prevention Program has drawn upon the expertise of the CAB and the values, traditions, and customs of the culture, to ensure that the beliefs and realities of the culture are accurately reflected in the intervention.

Literacy Concerns

Low literacy among potential participants poses a challenge in the adaptation process. Studies have shown that individuals with lower literacy have significantly poorer health status (e.g., lower adherence to antiretroviral therapy and lower CD4 counts) than those with higher literacy.[29] Differences in cultural medical traditions may exacerbate literacy factors, leading individuals to misunderstand the intent of instructions, even when they understand the words of instruction.[30] To reduce reliance on reading skills, assessments were administered by an interviewer. Experiences in the field have provided the research team with various informal ways of assessing the literacy level of potential participants, such as observation of their comfort with consent procedures, their ability to write, and their ease in responding to more complex items. Knowledge of these potential difficulties should alert researchers to challenges if they attempt to impart information that is too dense, abstract, or discordant with the life experiences of participants.

Literacy is inextricably tied to issues of informed consent among the populations most often burdened by HIV/AIDS. A study in a public health hospital, for example, showed that 59% of the participants did not understand a standard medical informed consent form.[31] In addition, there may be an element of coercion or perceived coercion among low-income individuals for whom the financial benefits of participating in the research far outweigh any reluctance to participate. Moreover, in some cultures individuals do not easily refuse the requests of those in higher authority. In such cases, the element of coercion may be further exacerbated. For example, individuals who are approached to participate in the study may fear that medical treatment may be withheld if they do not participate, even when they are told otherwise.[6]

Assessment, Intervention, and Analysis Processes

In many nonliterate and low literate cultures, response styles are generally discursive or narratively based. Discrete response sets, such as those required by Likert responses, may be difficult for individuals from other cultures to initially comprehend. The typical Likert scale responses may not correspond to the categories of assent (or lack of assent) used by persons in other cultures or languages. Interpretation and analysis of such responses may misrepresent the range of meanings intended by respondents, especially when there is strong, cultural disapproval for disagreeing with persons in authority. The importance of attending to these issues is illustrated by a study comparing response styles among different ethnic groups in the United States. Construct validity was better for certain groups when there were four response choices, but better for others when there were seven choices.[32] In another study, researchers found a lack of association between a quantitative

Likert-type scale and qualitative vignettes, suggesting that the Likert format may confuse and not adequately reflect the views of recently arrived Mexican immigrants.[33] When measures are adapted from existing questionnaires and renormed, it is prudent to conduct exploratory analyses of response patterns, ceiling/floor effects, and subscales, as well as to examine the relationship between responses and

criterion behaviors.[34] These realities should be taken into account when reviewing the appropriateness of adapted measures for new cultural groups.

Given the inherent bias in the assessment process, it is essential for assessors to be trained on rewording unclear concepts in a nonleading manner to ensure the validity of participant responses. Other forms of problematic response patterns, such as nondisclosure/refusals and minimization should be examined to determine whether these can be explained by problems with rapport, gender mismatch, or concerns about privacy. For example, research suggests that ethnic minorities in the United States may underreport certain behaviors because of lack of trust in institutions.[24]

Researchers have recommended that when targeting low-income, low-health literate minority populations, appropriate intervention practices should attend to the social, racial, and cultural context, including the cultural beliefs and practices of the individual.[35,36] In the spirit of these recommendations, the *Let's Educate Adolescents and Parents* project sought original testimonials that are representative of the culture and normative concerns of local HIV-positive youth. An intervention video was modified to be more representative of the mix of Black and Hispanic youth and parents targeted in the intervention. The modified video expanded dialogues to ensure that important points were clear. Similarly, in an intervention with recovering drug abusers, specific cultural values and beliefs, including assertiveness, prayer, and social support were integrated into the intervention with positive effects.[37]

Cultural issues may be more salient among more traditional and less educated clients, therefore attention should be paid during the analysis process to subgroup differences. Stratification to test the effects of cultural variables may accurately assess these differences.[27] Pantin and colleagues, for example, have shown that the efficacy of a preventive intervention in a Hispanic sample varied by level of acculturation. Those parents who reported being most acculturated were more likely to show the desired change because of being in the experimental condition.[38] In addition to acculturation, Gonzalez Castro and Garfinkle further recommend a focus on traditionalism vs. modernism and socioeconomic status during the analysis process.[27]

DISCUSSION

The concerns and guidelines presented here are relevant to populations in developing countries as well as to minority populations in developed countries whose cultural norms differ from those of the dominant culture. Reducing health disparities in these populations is a long-term effort, related to politics, economics, and policy commitment by government officials. There are intermediate steps that can be beneficial to those who are most burdened by the HIV epidemic. For example, the scientific community and public health funding agencies can offer a strategic response within their own mandates by providing increased access to services proven to work in other populations. It is also necessary to train a cadre of professionals who are willing to work with the underserved and to improve researchers' capacity to develop and evaluate the effectiveness of interventions. Communities can bridge gaps in knowledge and services to vulnerable populations by recognizing the importance of cultural relevance and acknowledging the barriers to change that impede intervention effectiveness.[39]

Many researchers in the past have approached various cultural groups with an already existing protocol and have proceeded to adapt the intervention for the cultural realities of the new population group. To enhance the intervention development

process, investigators have successfully used CABs, focus groups, and even scientific peers to provide input at the formative phases and contribute to the intervention refinement process. An additional illustration of such an approach is one study in the Philippines where partnership with researchers in the formative phase led to significant reductions in risky sexual behaviors.[40] A future challenge to the HIV/AIDS prevention community is to find testable, valid ways to embed such social brokers in all phases of adapting and transporting core intervention designs into new populations.

Our experience in the field has demonstrated the importance of integrating culturally relevant material in the translation process with a particular focus on language and nuance, acknowledging the barriers to change, and ensuring that the content of the intervention is appropriate. Minor, but important modifications to language, the inclusion of cultural brokers, key players, and community members who facilitate access, may improve the chances that the program will be accepted and sustained. However, extreme care needs to be taken in ensuring that the intervention and assessment materials are at a level that can be understood by the average participant and that the rights of participants are protected during the consenting procedures.

On the basis of this work, it is concluded that reductions in health disparities may be achieved by micro adjustments to existing protocols as well as by macro level policy changes. The macro level implications of these findings relate to health policies that may facilitate implementation of protocols with new populations and encourage multi-sectoral involvement to address the particular needs of the local population. These policies may include reducing barriers to access, both economic and structural, and encouraging high-level, open communication of the impact of the disease on populations. Openness and multi-sectoral involvement in addressing the HIV epidemic has been successful in Uganda, where government, church, and grassroots community groups have combined forces to achieve reductions in incidence rates.[41]

The multicomponent approach to the adaptation process (e.g., utilizing focus groups and a cultural linguistic committee) is one of the major strengths of these studies. In addition the research team includes a multicultural, multilingual staff that adds further depth in our abilities to design effective interventions. The iterative approach, with each project informing, and improving upon the later projects, produces a final product that has been tested repeatedly at different levels for adherence to the original intervention and for cultural relevance.

Future research should examine which components of these interventions are most effective in producing desired outcomes. Certain types of interventions may be more effective with specific populations. For example, even though cognitive-behavioral therapy may be the common underlying theory in these interventions, there may be particular delivery methods, or thematic approaches that may resonate more effectively with different populations. It is recommended that future research utilize the participatory methods discussed here for the purpose of adapting instruments. The intervention should include focus groups, for example, to provide feedback on other phases of the research. Finally, the research may further be improved by a deeper evaluation and documentation of process research and implementation experiences, so that there can be an implementation and management documentary to share with the research community.

In conclusion, these words encapsulate the importance of the translation and adaptation processes to program success: “If people do not identify with the materials, they will reject it. If people do not see themselves in the message, they will not listen. If people do not understand the message, they will not respond.”[42]

ACKNOWLEDGEMENT

This work was funded in part by R01 DA13802 and R01 DA14715 from the National Institute on Drug Abuse and R01 HD38458 from the National Institute of Child Health and Human Development.

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