

**NATIONAL INSTITUTES OF HEALTH
NATIONAL INSTITUTE OF NURSING RESEARCH
REPORT**

**Workshop
Cultural Dynamics in HIV/AIDS Biobehavioral Research Among Young People
September 15-16, 2005
Bethesda Marriott
Bethesda, Maryland**

BACKGROUND

The National Institute of Nursing Research (NINR), the Office of Rare Diseases (ORD), the Office of AIDS Research (OAR) and the Office of Behavioral and Social Science Research (OBSSR) at the National Institutes of Health (NIH) convened the workshop, “Cultural Dynamics in HIV/AIDS Biobehavioral Research Among Young People” on September 15-16, 2005 in Bethesda, Maryland.

PURPOSE

It is estimated that as of the end of 2003, 38 million adults and children were living with HIV worldwide. More than half of new infections occur in those aged 24 or younger. Twenty-five years of behavioral and biomedical research have led to breakthroughs in treatment of HIV disease, increases in life span, and prevention strategies to reduce transmission of the disease. However, there are many populations both domestically and internationally, who have not benefited from these breakthroughs, especially young people. This workshop was organized to explore how incorporating an understanding of cultural dynamics can better inform biobehavioral research. In turn, more culturally sophisticated research should lead to appropriate interventions that prevent transmission of HIV among the many populations affected by the disease, and improve understanding of the impact of individual and communal beliefs and values upon the quality of life of those already infected by HIV.

WELCOME

Patricia Grady, PhD, RN, FAAN, Director of the National Institute of Nursing Research (NINR), welcomed participants on behalf of the Institute, and workshop Co-Chairs Martha Hare, PhD, RN and Antonia Villarruel, PhD, RN, FAAN. Dr. Hare articulated the goal of the workshop: *To examine how best to integrate an understanding of cultural dynamics within HIV/AIDS biobehavioral research.* This workshop was interdisciplinary in nature, bringing together experts from the fields of nursing, anthropology, sociology, psychology, social work and epidemiology to explore this topic.

SUMMARY

The **objectives** of the workshop were as follows:

- Operationalize the culture concept in regard to HIV/AIDS biobehavioral research among young people.
- Examine methods for building or adapting theoretical models of health behavior change in light of the cultures of young people affected by HIV/AIDS.

- Assess innovations in design needed to address cultural dynamics in HIV biobehavioral research.
- Consider challenges in transferring successful interventions across cultures.

In order to meet these objectives, the workshop was organized into the following sessions:

- The culture concept in HIV biobehavioral research
- Integrating sociocultural and biobehavioral factors in research on perinatally acquired HIV disease in the U.S.
- Methodological issues: Research among youth at risk of HIV infection, Part I (U.S. focus), and Part II (International focus – Asia and Latin America)
- Ethical and methodological issues in community-based research among young people affected by HIV in southern Africa

Each session included discussion among audience members and panelists, and each day ended with a panel of speakers who responded to audience questions and comments. The workshop ended with a discussion of future directions.

The Culture Concept

There was consensus among participants that sensitivity to culture is crucial in HIV/AIDS research among young people. *Culture includes, at a minimum, beliefs, values, norms and practices held in common among a group of people.* Culture was further explored along a number of dimensions, each of which is important in programs of research on biobehavioral issues in HIV/AIDS.

- Culture is manifested in the intersection of gender, race and class.
- Culture is dynamic. Therefore, understanding processes is critical, and interventions require frequent updating.
- There is a culture associated with research. Investigators must be cognizant of how beliefs, values and norms associated with their own education, training and practice affect the research questions selected, interactions with subjects, and possibly the outcomes of research.
- Every culture has its own history, including the impact of a more dominant culture upon the history of another culture. This can have varied consequences. Historical trauma is the term describing the impact of an historical atrocity (e.g., slavery, genocide) on group identity. It is postulated that this trauma affects the emotional and physical health of members of that group.

Research methods/approaches

Many participants favored a community-based participatory strategy for both descriptive and intervention studies. Examples from such diverse domestic settings as inner city Philadelphia, North Carolina, the Cherokee in the U.S., as well as international settings such as Mexico, Malawi, Vietnam, and Thailand, included strong community input. In one study, recent immigrants to the southeastern U.S. were part of the data collection team for a descriptive HIV prevention study. Subsequently, the community members participated in designing an intervention based upon the findings from these same data. In general, communities want to

know how they will benefit from research, and they want reassurance that successful interventions can be maintained beyond the life of a research study.

One presenter is developing measures of historical trauma based upon research among Native Americans. It is hypothesized that intergenerational suffering, when added to other stressors, may lead to risk-taking behavior that places youth at increased risk of HIV/AIDS. If this proves to be the case, historical trauma can be incorporated into behavioral theory, and interventions that address risk factors associated with historical trauma can be tested.

Perinatally Acquired HIV Disease

In 2003, the estimated number of cases of perinatally acquired HIV disease in the United States neared zero, after a peak of well over 800 cases per year in the early 1990s. This was due to successful biomedical interruption of mother-to-child transmission before and during childbirth. Subsequently, children with perinatally acquired HIV disease have benefited from highly active antiretroviral treatment (HAART), and many are now reaching adolescence and young adulthood. These young people are affected by a variety of cultural dynamics associated with their age group, gender, ethnic origin, socioeconomic status, and HIV status.

An analysis of data from the Pediatric AIDS Clinical Trials Group used a working definition of quality of life that includes objective measurement of specific indicators, as well as subjective experience within the patient's cultural and historical context. Findings confirmed that severity of illness is the main predictor of both HIV-related symptoms and impaired social functioning. Furthermore, family stressors also had a strong impact on overall quality of life. While these findings may not be surprising, they point to ways of developing interventions that incorporate social, behavioral and biological variables, perhaps through examining the mediators or moderators associated with the predictors of symptom burden, impaired social functioning, or improved quality of life.

Another presenter offered a "biopsychoneurosocial paradigm" to conceptualize the multiplicity of issues that face young people born with HIV infection. These include family history, repeated environmental stressors, lack of effective treatment during early childhood, and developmental stressors associated with puberty and adolescence. These issues are further complicated by the need to develop (or maintain) trust between provider and patient, and conflicting cultural norms (e.g., ethnic, professional).

The issue of disclosing HIV status to adolescents who were never told that they were born with the disease provides an example of possible conflict between different cultural perspectives. Providers cannot disclose if parents do not agree, yet lack of disclosure can have serious public health consequences, especially if the adolescent is beginning to engage in behaviors that lead to disease transmission. Provider knowledge of public health consequences is embedded within a culture that favors leadership by biomedical providers in health care decision-making. At the same time, parental beliefs about their own role in discussing sensitive issues with their child are frequently complicated by emotional issues related to their role in transmission of the disease. Thus, there are numerous variables in the decision to disclose HIV status to the perinatally infected child. Presenters conceptualized disclosure as a process that occurs over a period of time as the child matures, and as the

family grows to trust the health care team. Research is needed with regard to the components of the process, and the best strategies for building trust between providers and parents/caretakers, empowering adolescents, and protecting the health of potential partners.

At this time, there are limited data from behavioral interventions for adolescents with perinatally acquired HIV disease. Based on the Collaborative HIV Prevention and Mental Health Program (CHAMP) for HIV negative youth, CHAMP+ is targeted to the entire family. The intervention format provides a safe place to deal with issues of family dynamics, treatment adherence, decision-making, avoiding risky behaviors and stigma. It also provides social support to parents and to young people. Pilot data from the research study reveal that stigma and specific aspects of medication management are key issues for the teens and parents.

Research Methods/Approaches

The rich discussion revealed that research should consider the intersection of culture, human development, and ethics. It was suggested that future research incorporate assessment of post-traumatic stress disorder for its possible impact on behavior, including response to disclosure. Another emergent area is the relationship between disclosure and subsequent quality of life.

Prevention of Transmission Among Youth

A key issue of the workshop was whether it is necessary to develop interventions *de novo* –or whether adaptation is sufficient - when intervening to prevent transmission among young people from varied ethnic groups and those who live in different parts of the world. A related issue is whether theory should continually be revised based upon ongoing findings from fields like human development, sociology, psychology and anthropology. In order to address these issues, findings from studies in the U.S. and abroad were presented, followed by discussions that incorporated theoretical concerns and recommendations for research strategies.

Intervention studies sought to integrate cultural or traditional values in ongoing programs of research. In an HIV prevention intervention among young Latino parents in Los Angeles, for example, researchers appealed to maternal and paternal feelings of protectiveness. This intervention is unique in that it seeks to increase the young fathers' stake in the family. An intervention among youth in Mexico is targeted to parent/teen dyads and is shown to reinforce already strong traditional family values as young people maintain sexual abstinence.

Other examples from outside of the U.S. point to the impact of economic change, and disruption from the ongoing AIDS pandemic upon traditional cultural values. Research in Vietnam provides evidence of a bifurcation between traditional norms and those held by young people. Interventions that target communication between the generations, and prevention education, should be tested. A nursing scientist from Thailand has been intervening with adolescents to counteract a perception that having sex is a way of "being modern." Youth are trained as peer leaders, and taught to value tradition, while also learning the scientific underpinnings of maintaining a healthy lifestyle.

In sub-Saharan Africa, there are communities with as many as 1/3 of young women ages 20-24 infected. The burden of infection in women has a strong negative impact on families, and

ultimately on society. In Malawi, a country that is extremely poor, social disruption in villages is so great that many children are unsupervised. These children may voluntarily engage in risky behaviors, or may be exploited by others. Therefore, researchers have been testing a community-level intervention to reach members of even remote villages. Where South African girls have been found to be at serious risk of molestation, some interventions teach basic safety, such as protecting oneself on the walk to and from school.

Intervention development becomes increasingly challenging when accounting for variables and constructs that have received little attention in the past. Examples include “fluid” sexual identity, the researcher/subject relationship, historical trauma, and addressing structural constraints (e.g., political structures) on individual interventions. A qualitative study of adolescents in the urban U.S. who are coming to terms with their sexual orientation revealed that sense of self can change over time. Initial distrust of adults – perhaps generated from experience with parents - can also have a strong impact on ability to engage in a research project. Once engaged, however, participation in research seemed to have an impact on self-concept, possibly mediated by the relationship with the researcher. The impact of the researcher/subject relationship, and of sharing one’s life history, upon behavior may be a fruitful area of investigation for intervention development.

A prevention intervention among Cherokee youth used the concept of “culture loss” or dispossession (a form of historical trauma) to identify the underlying reason for health disparities. The theory-based intervention seeks to re-instill traditional values in order to decrease substance abuse and stress and increase self-reliance. Data show that participants in the intervention group do meet these outcomes, despite the fact that hoped for decreases in stress did not hold throughout the 90-day follow-up period.

Theory development

Commonly used theories in HIV prevention research include:

- social learning theory
- social cognitive theory
- theory of reasoned action
- theory of planned behavior
- protection-motivation theory

Some researchers favor a single theory for an intervention, others combine theoretical frameworks, while others may find it necessary to make further modifications based upon the results of qualitative studies.

One team of U.S. researchers has designed successful theory-based, developmentally appropriate HIV risk reduction interventions targeted to individuals, families, or systems (i.e., clinics, faith-based organizations), within the US and abroad. They found that it is critical to select the theoretical framework that addresses the desired behavior change within the context that the intervention will be tested. According to this team, entirely new constructs are not needed, but formative research must be conducted to inform choice of theory, and, when translating a previously tested intervention, modifications in approach for the new context. For example, if adapting a successful curriculum for U.S. inner city teens to the Caribbean, it is essential to consider whether the variables tested in that curriculum are all applicable to the

new context, and if others must be added. Or, if attempting to reach families through churches, rather than individual teens in a community-based organization, then the values of the church, such as abstinence, may need to be emphasized.

Research Methods/Approaches

Presenters and audience members¹ discussed ways of enhancing current approaches to descriptive and intervention research, and strategies for disseminating and sustaining successful interventions. One concern revolved around a need for methods that achieve cultural sensitivity, in particular measurement innovation and development. Workshop participants also pointed out that for both descriptive and intervention research, attention should be paid to subpopulations. Examples include U.S.-based Latino youth whose families originated in different Latin countries, or gay youth from varied ethnic groups. Discussions revealed that next steps involve (1) testing interventions for efficacy and effectiveness in practical conditions such as schools, clinics and community agencies, and (2) trials of sustainability. Appropriate methodologies for effectiveness trials, and for preparing communities to sustain interventions on their own are needed.

DISCUSSION

The workshop helped to identify several challenges inherent in a culturally dynamic program of research. In order to meet these challenges, workshop presenters discussed underlying principles during their presentations, and revisited earlier discussions of research methods and approaches during discussions with the audience after each session, and at the end of the workshop.

Overview of Discussion

Topics of discussion ranged from broad issues regarding the experience of HIV among young people, to specific concerns regarding research methodologies among specific groups of youth. In order to attain the goal of integrating an understanding of cultural dynamics within HIV biobehavioral research, it is necessary to address issues common to humans, as well as particular approaches to solving those issues. One approach would be to conduct a meta-analysis of current research on a problem (e.g., empowering young women to avoid risky behavior) in order to elucidate commonalities across cultures, as well as varied patterns among cultures. If such commonalities and patterns yield variables that can be translated to intervention design, formative research could be made more efficient. Still, community buy-in is considered critical for the success of culturally appropriate research. This means empowering the community to bring their ideas to a specific research project and inform the design as it evolves.

Among the most obvious challenges in developing culturally appropriate research, is the sheer number of variables to consider (e.g., individual and communal values, history of discrimination, socio-economic status, language, and religious beliefs). Furthermore, researchers need to consider the impact of the research process upon the community and upon cultural norms and values. Although completely new theory was not considered, it may be necessary to engage in sophisticated model-building with concurrent attention to measurement development and data analysis techniques.

¹ As a group presenters, and audience members, are referred to as participants.

Another step for researchers would be training in the local values and history of the community in order to improve the manner in which risks and benefits are articulated within the local context. One outcome of such training could be development of culturally appropriate informed consent documents and processes. Such training could also sensitize investigators to the impact of structural issues (e.g., economic insecurity), which are beyond the scope of this biobehavioral research agenda, upon the outcomes of interest.

Summary of Directions for Future Research

Below is a list that summarizes discrete suggestions for future research, culled from discussions, and comments from the audience. The list is not exhaustive, and does not reflect a specific research agenda, but is meant to stimulate thought and discussion among members of the HIV/AIDS biobehavioral research community as they develop their own programs of research.

Quality of Life Among Perinatally Infected Youth

- Elucidate the relationship between early disclosure of HIV status to young people, quality of life, and ongoing mental health.
- Develop and test interventions that promote healthy behaviors among perinatally infected young people.

Prevention of Transmission

- Conduct trials of sustainability for efficacious interventions.
- Identify and promote protective factors within individuals, families, schools and communities.
- Test interventions for efficacy and effectiveness in practical conditions such as schools, clinics and community agencies.
- Target interventions to male partners of at risk adolescents.

Theory Development

- Update theories of human development with regard to the experience of young people (e.g., ongoing crisis and uncertainty) growing up in the HIV pandemic.
- Account for the impact of larger group-level processes on individual, family or small group behavior.
- Improve theories of relationships, and the impact of the relationship on HIV risk behavior.

Methodology

- Conduct meta-analyses on issues (e.g., gender and power) that may yield important information across cultures, or that may inform researchers on important differences among cultural groups.
- Develop innovative measures for culturally validated research tools.
- Conduct training on local values and concerns, in order to develop better informed consent materials, and to sensitize investigators to factors that affect the research process.

- Conduct finer grained analyses of the impact of the HIV epidemic on specific cultural groups; e.g., U.S.-based Latino youth whose families originated in different Latin countries, or gay youth from varied ethnic groups.
- Include community members from the outset, and in all phases of, community participatory research.
- Develop methodologies that include indigenous approaches to research.

CONCLUSION

Change is constant among cultures and among individuals. Strategies for addressing the needs of young people affected by HIV may require frequent modification. However, presenters demonstrated that there is a maturing body of research upon which to build interventions to decrease the impact of HIV among society's most vulnerable populations.