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Cultural Dynamics in HIV/AIDS Prevention Research Among Young People

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Abstract

In September 2005, the National Institute of Nursing Research (NINR), with the support of several other components of the National Institutes of Health (NIH)1, held a workshop entitled “Cultural Dynamics in HIV Biobehavioral Research.” This Special Issue of the Journal of the Association of Nurses in AIDS Care contains a series of articles developed from that workshop. These articles are derived from those presentations that focused on prevention of infection. The articles do not contain an agenda or recommendations from NINR or any other component of the NIH. Rather, the purpose of this special issue is to share with a broad audience the exciting dialogue that began at the workshop, and which the authors hope will continue for some time in the future. The articles represent an interdisciplinary and global perspective. Issues discussed include behavioral theory, inter-generational communication, historical trauma, modernization, research methodology, and the ethics of community clinic trials.

Keywords

HIV prevention research; cultural dynamics; behavioral theory

Background

Twenty-five years of behavioral and biomedical research have led to breakthroughs in treatment of AIDS, increases in life span, and prevention strategies to reduce transmission of the human immune virus (HIV). However, there are segments of populations, both domestically and internationally, who have not benefited from these breakthroughs. This is especially true of young people. According to UNAIDS (UNAIDS, 2005), 40.3 million people were living with HIV/AIDS in the world in 2005, an increase from an estimated 38 million at the end of 2003 (UNAIDS, 2004). In 2003, more than half of new infections occurred in those aged 24 or younger and this trend continues. A challenge in reaching young people affected by the HIV pandemic is the diversity of cultures in which young people live, learn, work and play. Differences in the cultures of researchers and providers on the one hand, and youngsters on the other, may have created barriers for the optimal implementation of critically needed prevention interventions.

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Purpose

In September of 2005, The National Institute of Nursing Research (NINR) with support from the Office of Rare Diseases (ORD), the Office of AIDS Research (OAR) and the Office of Behavioral and Social Science Research (OBSSR) (all from the National Institutes of Health) convened a workshop, "Cultural Dynamics in HIV/AIDS Biobehavioral Research Among Young People." This Special Issue of the Journal of the Association of Nurses in AIDS Care contains a series of articles developed from that workshop. These articles are derived from those presentations that focused on prevention of transmission and infection (National Institute of Nursing Research, 2005). The articles do not contain an agenda for research or recommendations from NINR or any other component of the National Institutes of Health (NIH). Rather, the purpose of this special issue is to share with a broad audience the exciting dialogue that began at the workshop, and the authors hope will continue.

The workshop explored how incorporating an understanding of cultural dynamics can better inform HIV prevention research among some of the world's most vulnerable populations. It included presenters from such diverse fields as nursing, anthropology, sociology, psychology, social work, and epidemiology. Through individual presentations and facilitated discussions with the audience, the presenters explored the following questions:

- How can the culture concept be operationalized with regard to HIV/AIDS biobehavioral research among young people?
- What are some methods for building or adapting theoretical models of health behavior change in light of the cultures of young people affected by HIV/AIDS?
- What innovations in design are needed to address cultural dynamics in HIV biobehavioral research?
- What are some challenges that have been met when transferring successful interventions across cultures?

The articles in this special issue present specific responses to these questions, illustrated through programs of research in the United States and abroad. The following section summarizes the theoretical discussion which set the stage for the presentations discussed at the end of this Introductory article.

The Culture Concept

Culture is a complex concept that "implies a dynamic and ever-changing process (OBSSR, 2001)." At minimum, it includes beliefs, values, norms and practices held in common among a group of people, but more sophisticated analyses call for "more systematic thinking and empirical research" to integrate cultural constructs into health research (Ibid, p2). Other important dimensions of the culture concept are:

- Since culture is dynamic, understanding large group 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.
- Similarly, there is a culture associated with practice. Practitioners must also be cognizant of the impact of their own beliefs, values and norms, and the manner in which these interact with patients and clients.

- Culture, gender, race/ethnicity, and social class are not distinct concepts. In fact, research needs to elucidate the independent and interdependent contributions of the variables that exist among these intersecting concepts.
- Every culture has its own history. For many vulnerable groups, this has included the dominance of one culture over another or even historically traumatic events such as warfare, slavery or genocide. Some social scientists are investigating the manner in which an historical trauma affects group identity and whether this also affects the emotional and physical health of members of that group.
- Research methods and approaches that incorporate community participation are often desirable, and these strategies may be used in both descriptive and intervention studies. Although not all studies require full participation from the community, community members should be apprised of how their community will benefit from research, and should be reassured that successful interventions can be maintained beyond the life of a research study.
- Culturally appropriate theory-based measures are needed. Examples are tools to measure specific attitudes, beliefs, and norms associated with relationships, gender and power, and sexual behavior (Madden, Ellen, & Ajzen, 1992; Parrado, Flippen, & McQuiston, 2005; Villarruel, Jemmott, Jemmott, & Ronis, 2004).
- Theory-based interventions are also needed. The consensus among workshop participants was that it is probably unnecessary to develop theory *de novo* to address any problem that affects diverse populations. However, it is prudent to critically examine theoretical constructs in light of the social and cultural context of each study population. For example, Hutchinson, Jemmott et al. demonstrate in this special issue how the Theory of Planned Behavior (Madden, Ellen, & Ajzen, 1992) can be expanded through social ecological theory to incorporate culture-specific influences and beliefs in HIV prevention intervention design.

Prevention of HIV Transmission Among Youth

The remainder of this issue is devoted to the topic of preventing HIV infection and transmission among adolescents and young adults. The eight articles span the globe from the United States to Mexico, Jamaica, southeast Asia and Africa. Authors report on interventions utilizing a variety of theoretical constructs for teen parents, abstinent youth, gay youth, and young people facing severe social and economic dislocation.

The US-based studies were fielded in both urban and rural settings. Welle and Clatts extend the qualitative methodological toolkit through a narrative device known as scaffolding, which is the creation of a platform for relating critical life events. Their descriptive study among East coast urban gay, lesbian, and bisexual youth, identified the potential for utilizing the deep life history approach as a way to intervene among sexually active adolescents who have had little trust for adult authority figures. Lowe developed a brief intervention for Cherokee youth to build self-reliance that was sensitive to the impact of historical trauma, and enhanced the protective factors of individual and group resilience. Lesser, Koniak-Griffin, and collaborators are testing an HIV prevention intervention that aims to enhance maternal and paternal feelings of protectiveness among young Latino parents in Los Angeles. Their intervention is unique in that it seeks to increase the young fathers' stake in the family.

Gallegos, Villarruel et al. present baseline data from a study designed to increase communication between teens and parents on topics important to preventing HIV. This study demonstrates that female parents with higher educational attainment consider themselves to be more frequent communicators of sexual information than other respondents. However, other variables, such as feeling comfortable in communicating with adolescents, or the teens'

perception that the parent was knowledgeable, were not affected by gender or education. Hutchinson, Jemmott et al. demonstrate how they have extended their own work with inner city US teens to teens in Jamaica, a setting where HIV is spreading largely through heterosexual contact.

The spread of HIV/AIDS in resource-poor settings is primarily from heterosexual transmission. In some cases, the behaviors responsible for this transmission are affected by the disruption of traditional cultural values, or by the lack of knowledge and comfort experienced by adults in responding to the questions and experiences of young people. Kaljee et al. found evidence in Vietnam of a bifurcation between traditional norms and those held by young people, and difficulties in communication between the generations. Fongkaew, Fongkaew and Muecke have been intervening with adolescents to counteract a perception that having sex is a way of "being modern." Youth trained as peer leaders teach teens to value tradition, while also learning knowledge and skills for HIV risk prevention.

In sub-Saharan Africa, there are communities where as many as 1/3 of young women ages 20-24 are infected with HIV. The burden of infection in women has a strong negative impact on families, and ultimately on society (Department of Economic and Social Affairs, 2004). Kaponda's team has been working in Malawi, a country that is extremely poor. They have used a four-step process for developing a culturally and developmentally appropriate intervention acceptable to both young people and elders even in remote villages. Finally, MacQueen and Abdool Karim take a step back and consider the ethical and methodological issues that need to be considered in fielding large scale HIV prevention trials among adolescent and young adult women.

Conclusion

The reader is invited to explore the rich material provided by the authors in this special issue, and to apply the findings to their own research and practice settings. It is hoped that readers will come away from these articles with a deep appreciation of culture as a dynamic process that affects, and is affected by, human behavior.

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