Commentary: Pediatric Psychology Research Informing Policy for AIDS-Affected Youth in Africa

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Two articles in this issue of the *Journal of Pediatric Psychology* (JPP) address the impact of HIV/AIDS on children and adolescents in Africa (Cluver et al, in press; Puffer et al., in press), where the AIDS epidemic continues to take a costly toll on families. In Kenya 6.3% of the population has HIV (1.5 million individuals) and these numbers climb in South Africa, where 17.8% of people live with HIV (5.6 million people) (Joint United Nations Programme on HIV/AIDS, 2010). These papers represent important work in the area of pediatric psychology and warrant attention both from researchers in the area of HIV/AIDS and from the field as a whole. As such, we would like to praise some of the unique strengths that these articles contribute to this area of inquiry as well as highlight the importance of these efforts to the field and pediatric psychology in general. Specifically, these works are excellent examples of the importance of working with populations that can be difficult to access, the necessity of considering the cultural framework of research populations, and the potential for connecting research to policy in meaningful ways.

The authors of both studies should be commended for the work presented here. There are relatively few published studies related to families affected by HIV/AIDS in Africa because of the numerous challenges inherent in executing such work. Both studies presented in this issue used methods designed to obtain a representative sample, no easy task in research with vulnerable populations. Obtaining approvals to work with vulnerable youth can be challenging, and designing studies such that communities will be interested and willing to participate is critical to success. Furthermore, Cluver and colleagues conducted longitudinal tracking of orphans, noting challenges due to settlements being destroyed and children living in transient housing and other dangerous living situations. To

retain 71% of this highly unsettled sample after 4 years is a testament to organization, perseverance, and belief in the value of the work being done. Furthermore, this high retention rate speaks to the valuable relationships formed between researchers and families living with this devastating illness. Description of the strategies used to build community connections in future publications will be helpful to advancing these kinds of endeavors in other countries. Without such efforts and long-term bonds, information affecting the welfare of these children would be lacking.

Next, both manuscripts provide excellent descriptions of the cultural contexts in which the studies were conducted, aiding the reader's understanding of the relevance of the work and providing a framework for considering the findings. Understanding cultural norms is critical to HIV/AIDS research. For example, Puffer and colleagues note specific factors of orphans' lives in Muhuru Bay, Nyanza Province that may predispose youth to risk, including economic disadvantages and cultural norms that increase the likelihood of engaging in higher risk sex. These rich descriptions enhance the reader's ability to draw conclusions from the data. A description of cultural norms is also essential for communicating with both international and national audiences where context plays a central role in shaping behavior and may be different from broader societal norms.

While models developed in Western countries are often similar to those used to explain risk behaviors in Africa, important differences exist in the ways these models translate to intervention. For example, parenting interventions with proven efficacy can be challenging to implement when parents are focused on meeting basic needs due to infrastructure limitations. Similarly, individual interventions for adolescents in the United States do not always translate to youth in Africa due to different

motivations. For example, young people in the United States may engage in unprotected sex to meet needs of intimacy or express trust, whereas youth in Africa may have financial motivations for risk behaviors, as reported in the work of both Puffer and colleagues as well as Cluver's previous work (Cluver, Orkin, Boyes, Gardner, & Meinke, 2011). Culturally based power differentials determined by gender also put some young women in Africa at risk for reasons different than those of many women in the United States.

Perhaps most importantly, both studies represent work aimed at guiding policy and funding directives to improve the lives of children whose parents have HIV/AIDS. These studies, developed from policy questions, represent an important model for researchers seeking support in challenging research funding climates. In this issue of *JPP*, Cluver and colleagues note the lack of culturally relevant research examining the impact of having a parent sick with AIDS and posed the question: what is the psychological impact of having a caregiver affected by AIDS and is this impact different than that of other illnesses? They found support for the notion that caregiver AIDS affects children before the death of a parent, similar to U.S. studies (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007; Forehand, et al., 1998). Furthermore, characteristics of AIDS, in comparison to other illnesses, were associated with additional mental health symptoms among children, which has not been examined within the United States. The authors assert likely suspects, such as stigma or changes in family roles, which have been supported in other pediatric studies (Mellins, et al., 2007; Stein, Reidel, & Rotherham-Borus, 1999). This study is exceedingly valuable in that it begins to disentangle the impact of orphanhood from the impact of parental illness from AIDS, providing further support that efforts to intervene with youth whose parents have AIDS must begin *before* the death of a parent.

Similarly, the work of Puffer et al. also addressed a critical policy question: in regions of the world strongly affected by HIV/AIDS, are orphans at any greater risk for HIV than the average young person such that they should be singled out for intervention? This study yielded mixed findings; while orphans did not report more sexual activity, orphan status did moderate relationships between psychosocial variables and self-efficacy, which may be important to later sexual risk. This research suggests that orphan status may confer additional risk, even among this at-risk population. The extent to which this dictates tailored interventions will be the subject of future work.

In the case of these studies, it is easy to identify how research can inform important decisions about how we

support and care for the millions of children affected by HIV/AIDS. Policies to support interventions for AIDS-affected families are needed, both when parents are living and when youth have been orphaned. Both studies identified higher levels of psychological symptoms among youth who had lost a parent, suggesting that interventions to support the mental health of these young people are needed. The impact of such interventions, as Puffer and colleagues also point out, may have wide-reaching effects, including HIV risk. Interventions helping families discuss illness may ease some uncertainties and resulting anxiety among children. Helping families plan for the uncertainties of parental illness and the resultant economic and social losses to children may also be useful. Programs aimed at enhancing independent living skills for youth with ill parents may help buffer the negative sequelae observed in these studies (e.g., transactional sex). In fact, studies in the United States have demonstrated positive impact on adolescent emotional adjustment, substance and sexual risk behavior 6 years after youth with HIV-infected parents participated in a coping skills intervention (Rotheram-Borus, Stein, & Lin, 2001, 2006). Funding interventions that facilitate youth's connections with support systems and enhance existing ones will be valuable. Likewise, teaching youth adaptive coping strategies in the face of stigmatizing and uncontrollable life events will be key. In the current economic climate where focus has been placed on decreasing federal spending overall with a targeted emphasis on reductions to foreign aid (currently about 1% of the U.S. budget), studies that can provide insight into specific targets for both addressing the needs of persons living with HIV/AIDS and preventing future generations from acquiring HIV/AIDS are vital. The need is great for studies examining the cost effectiveness of interventions used in a variety of settings to influence public policy in Africa, the United States, and elsewhere. The opportunity for research on youth affected by HIV and AIDS to have an impact on policy is great, if the barriers to completing useful studies can be overcome.

Finally, these studies also move the field forward by considering the influence of parental illness in a context in which such illness is prevalent. Examining the influence that health conditions have on children in ways besides having the condition themselves is an important role of pediatric psychology. While many children live with caregivers with chronic illnesses, science describing the effects on family process and children's well-being is in shorter supply, both from developed and developing countries. Thus, this research, and the policies that can emanate from it, can inform the ways in which social services support young people living in families affected by illness.

In times of economic challenge, making the important work of these community-based organizations empirically driven is critical to the efficient use of limited resources aimed at promoting global development. Commitment from researchers, such as those presented in this issue of JPP, to answering questions aimed at directing these resources is critical to policy making and is a model for many areas of research.

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