

UCLA

UCLA Previously Published Works

Title

Family Wellness, Not HIV Prevention

Permalink

<https://escholarship.org/uc/item/70d7z8bx>

Journal

AIDS and Behavior, 13(3)

ISSN

1573-3254

Authors

Rotheram-Borus, Mary Jane

Swendeman, Dallas

Flannery, Diane

Publication Date

2009-06-01

DOI

10.1007/s10461-008-9515-9

Peer reviewed

Family Wellness, Not HIV Prevention

Mary Jane Rotheram-Borus · Dallas Swendeman ·
Diane Flannery

Published online: 16 January 2009

© The Author(s) 2009. This article is published with open access at Springerlink.com

Abstract HIV exceptionalism (and disease-specific programs generally) garner both unbalanced funding and the most talented personnel, distorting local health priorities. In support of HIV exceptionalism, the successful mobilization of significant global health sector resources was not possible prior to HIV. Both sides of the debate have merits; rather than perpetuating polarization, we suggest that sustained improvements in global health require creating a prevention infrastructure to meet multiple health challenges experienced by local communities. We propose four fundamental shifts in HIV and disease prevention: (1) horizontally integrating prevention at one site locally, with priorities tailored to local health challenges and managed by local community leaders; (2) using a family wellness metaphor for services, not disease prevention; (3) implementing evidence-based prevention programs (EBPP) based on common principles, factors, and processes, rather than replication of specific programs; and (4) utilizing the expertise of private enterprise to re-design EBPP into highly attractive, engaging, and accessible experiences.

Keywords HIV prevention · Disease-specific programs · Families · Chronic illness management · Global health

Foundations, donors, policy makers, and advocates committed to stopping the HIV pandemic face increasing criticism about their funding strategies (Halperin 2008;

Shah 2008; England 2008), and their failure to achieve their 2008 goals (UNAIDS 2007). Counter arguments highlight the successful mobilization of significant global health sector resources that was not possible prior to HIV (England 2007). Yet, the global funding for HIV is absorbing almost all health resources in some countries, especially utilizing the most talented and well-trained professionals for HIV-related challenges (Halperin 2008). HIV services are delivered by health care providers in a system that has been “vertically integrated” (USAID 2008), organized to network HIV services at the level of small rural villages, to townships, provinces, counties, and countries.

Small rural, African villages may suffer from tuberculosis (TB), malaria, and malnutrition, as much as from HIV, and the skills and solutions to these diseases may be highly similar to the solutions to HIV, but these health challenges are often ignored by HIV-specific services. Even when a vertical, HIV care system is established and the need for HIV-related services are met, stigma stops many HIV seropositive persons, as well as persons at high HIV risk, from accessing and sustaining care (UNAIDS 2007). Finally, evidence-based programs are being mandated (Rodriguez-Garcia and Kusek 2007), requiring fidelity or consistency to the model that was originally evaluated with different populations and different cultures (Flay et al. 2004). Even when we have robust strategies that consistently demonstrate positive results across multiple populations and countries (e.g., needle exchanges, methadone maintenance, circumcision, behavior change programs), we have not had the capacity, funding, or the political will to scale the programs globally. In short, HIV health care systems have been built or evolved in most countries that must now convince, cajole, and entice community members to utilize the care. We propose four

M. J. Rotheram-Borus (✉) · D. Swendeman · D. Flannery
Global Center for Children and Families, University
of California, 10920 Wilshire Boulevard, Suite 350,
Los Angeles, CA 90024-6521, USA
e-mail: Rotheram@ucla.edu;
CCHPublications@mednet.ucla.edu

fundamental shifts in HIV and disease prevention to meet these challenges: (1) horizontally integrating prevention at one site locally, with priorities tailored to local health challenges and managed by local community leaders; (2) using a family wellness metaphor for services, not disease prevention; (3) implementing evidence-based prevention programs (EBPP) based on common principles, factors, and processes, rather than replication of specific programs; and (4) utilizing the expertise of private enterprise to redesign EBPP into highly attractive, engaging, and accessible experiences.

Horizontally Integrating Prevention Services into One Local Site Managed by Local Leaders, with a Link to Health Care is Useful

Tuberculosis, malaria, malnutrition, alcohol abuse, depression, suicide, and trauma destroy as many lives as HIV, often in a shorter time frame. There is ample evidence that these and other health challenges intersect with HIV and exacerbate each other, rooted in their common biological causes or co-infection, and shared distal or structural factors, such as poor health care infrastructure, poverty, warfare, and societal upheavals or transformations (Singer and Clair 2003). Yet, prevention for each disease is often embedded in health care systems via separate, vertically integrated units. With total health budgets in Sub-Saharan Africa averaging about \$80 per person across the region (World Health Organization 2006), it is impossible to build parallel health systems to prevent and treat multiple diseases. There must be horizontal integration of services for HIV, TB, malaria, alcohol abuse, nutrition, and mental health problems, for example, especially in rural environments with few resources.

Furthermore, prevention is best delivered to families (Rotheram-Borus et al. 2005), rather than to individuals in age and gender segregated groups, which is the typical organization in HIV services. In several countries, the health system integrates care locally by having a generalist responsible for a geographic area: for example, in China, the village doctor addresses all local health problems and difficult problems are referred to more specialized services serving a larger geographic area. Such generalists are needed in prevention.

However, the healthcare sector is not likely to be the optimal site for prevention. Systems for delivering healthcare are stressed and not consumer-friendly. One billion people do not have access to healthcare globally (Shah 2008). If available, clinic waiting lines are long, difficult to access, and often expensive. Consumers often struggle to know whether a problem is severe enough to require treatment; the responsibility and choice for seeking

care is with the consumer. Deciding to seek care, families often face a complex process that involves getting referrals to the right clinic, long waiting times for appointments, taking time off from work or taking children out of school to accommodate available appointment times, paying high rates that are frequently not covered by insurance, and uncertainties around the duration of appointments and whether specific concerns will be addressed successfully. These are difficult challenges to overcome.

It is noteworthy that countries with the greatest turn-arounds in the HIV epidemic have local health planning committees and health advocates that are not based in the healthcare system. For example, rather than the ABC (abstinence-be faithful-use condoms) Campaign, Kirby (2003) has argued that local community planning groups in Uganda, following Adi Amin's exit, were responsible for decreasing HIV seroincidence in the mid 1990s. In Thailand, there is a hierarchical community surveillance system that goes down to the level of one health monitor for every ten persons (Jiraphongsa 2007). China, a country without a generalized HIV epidemic, despite high rates of sexually transmitted diseases (STD), has hierarchically-linked leadership structures: village leaders, women caucus representatives, and village doctors. When these leaders are placed in charge of HIV prevention planning, initiation of drug use decreases (Wu et al. 2002). There may be substantial benefits to charging local leaders with the responsibility for addressing HIV and other diseases in their community. Local leaders can target and be responsible for their community's specific health risks, whether the problem is malaria, tuberculosis, alcoholism, or HIV.

Promoting a family's healthy routines from cradle to maturity is the best strategy for protecting family's health. While linkage to healthcare is needed, prevention is likely to be more accessible and less stigmatizing, if not nested within the healthcare system.

There are many vehicles that can deliver the evidence-based prevention programs (EBPP) necessary to establish healthy daily routines. Family wellness centers in communities are one vehicle, staffed by the community members whose families are thriving (Marsh et al. 2004), and supported by culturally adapted programs for experiential workshops and exhibits, prevention programs, and recreational and vocational programs that engage the community. An alternative strategy is home visiting programs by Mentor Mothers, similar to the nurse home visiting program of Olds (2002). The proliferation of the internet and mobile phones is creating new opportunities and vehicles to promote wellness, even in the most remote, rural areas. Soon, expert information, consultation, and support will be available worldwide "virtually", revolutionizing daily lives (Sorensen et al. 2008).

Wellness, Embedded in Families' Healthy Daily Routines, Prevents HIV and Other Diseases Requiring Behavioral Adaptations

The world has attacked the HIV pandemic by trying to eliminate the specific sex and drug behaviors that transmit the virus. This frame defines HIV infection as a public exposure of illicit acts and maintains stigma (Beaudoin 2007), results in population's perceptions of HIV as just punishment (Li et al. 2007), and contributes to low uptake of HIV-related services, even when available (Kaisernetwork.org. 2005).

However, increasing evidence demonstrates that risky acts are low when a person has long-term goals, hopes to achieve the goals, and a sense of meaning in life (Harrison 2008). Across cultures, healthy daily routines are embedded in a family life that has meaningful, supportive interactions, and allocation of family resources consistent with a family's values (Weisner 2002). Focusing on healthy daily routines enables family members to help each other create pro-social roles and identities for themselves and their children, and to acquire the healthy habits that buffer and sustain an individual through hard times. When encountering risky situations (offers of drugs or bartering unprotected sex), the short term reward is refused as motivations for long-term goals are stronger (McClure et al. 2004). Building families' capacities to identify their deepest values and life goals, and supporting a family's responsibility to promote their children's health and well-being over time, serves as a foundation for combating HIV. Such an approach simultaneously sidesteps the stigma that is generated with a laser focus on sex and drug behaviors. Promotion of a long, healthy, and meaningful life and building wellness for one's family are far more motivating than disease prevention.

A Family Wellness framework also places sex and drug use among a cluster of behaviors that can build or derail family health. Five behaviors account for more than 50% of all morbidity and mortality globally: what we eat, how much we eat, exercise, smoking, and alcohol use (McGinnis and Foege 1993). Chronic diseases resulting from these five behaviors will increase by 54% over the next 20 years, further bankrupting the healthcare system, especially in the developing world (DeVol and Bedroussian 2007). Eating, exercising, smoking, and drinking, as well as forming meaningful social and sexual partnerships, are routines rooted in family's everyday lives. Small changes in a family's behaviors reverberate to make huge differences cumulatively over time in the health outcomes of each family member. Healthy daily routines create alternatives to risk and are typically incompatible with risky acts and drug use. Building health daily routines is an alternative strategy for delivering HIV prevention.

EBPP Across a Broad Range of Risky Acts Share Common Components and Processes that Facilitate Synergistic Learning and Make Local Adaptation Easier

In the 1970s, EBPP focused on building generic skills: ways of thinking, feeling, and acting (Ingram et al. 2008). Researchers found that unless the specific information about each type of risk (drug use or smoking) was included in the EBPP, the program was ineffective. For the last 35 years, the field of health promotion has been increasingly compartmentalized to address ever more narrow outcomes. Prevention researchers specialize in shifting narrowly defined outcomes. HIV researchers typically address sex, but only occasionally drug use in the same program. Drug abuse prevention often ignores sexual relationships. Obesity prevention programs might only address caloric intake (eating), but ignoring caloric output (exercise) renders the program ineffective.

Yet, it has been demonstrated that EBPPs result in gains that are quite broad. Bonding children to their school environments and building social skills among early elementary school children has a 15 year impact and reduces sexual and drug risk behaviors among late adolescents (Hawkins et al. 2005). Having a nurse visit children during their early life, building a mother's skills and bonds with her baby, reduces incarceration 15 years later (Olds et al. 2002). Intervening with mothers with AIDS and their adolescent children improves the early outcomes of their grandchildren, who are often born after the death of the HIV + mother (Rotheram-Borus et al. 2006). The information, skills, and support provided in narrowly targeted EBPP benefit children and families in unexpected ways showing a synergistic benefit.

EBPPs' broad and long-term gains may emerge from the similarity of their common components. All EBPP share the same general theory: habits change slowly over time in relationships with opportunities and practice, and are reversed in the same way (Rotheram-Borus et al. 2008). EBPPs always: (1) present a framework to understand the problem; (2) build cognitive, affective, and behavioral skills; and (3) create new sources of sustainable social support (Rotheram-Borus et al. 2008). Each program also provides two components unique for every targeted behavior: educational information about the specific action that must be applied to the person's life; and a structural analysis that addresses the environmental barriers to implementing the targeted action. For example, condom protected sexual risk acts require knowledge about appropriate use of condoms, the ability to use condoms correctly, and access to condoms. The shared components of EBPPs suggest that the conceptualization, skills, and support generated by each EBPP could potentially reverberate and

create synergy, as the same skills are practiced for multiple targeted actions. Promoting wellness creates the opportunity for the same conceptualization, skills, and support to reduce risk and increase resiliency in multiple domains. Success in reducing one risk act makes changes in other risk acts easier. Furthermore, each of these behaviors is embedded in a daily routine that both complements and interacts with the actions of other family members and friends. Improvements by one network member radiate throughout a system. Each EBPP creates a structured setting, change agents, and a program that can be replicated with local adaptation to the vehicle and language that transmit change. Specific strategies found in EBPPs (e.g., monitoring the frequency of a targeted action) significantly reduce the frequency of the action (McDonald et al. 2002). Every community can implement a monitoring strategy for persons at risk, families, or neighborhoods. Local leaders do not need to implement the monitoring system in exactly the same way as a specific EBPP has previously implemented. Processes such as self-monitoring are the types of principles that can be consistently replicated with fidelity (Flay et al. 2005). Trying to replicate specific scripts or activities are far less likely to be relevant across communities, countries, or regions. New standards of evidence (Flay et al. 2005) are needed to be able to scale EBPP globally, a standard based on common factors, processes, and principles (Rotheram-Borus et al. 2008; Ingram et al. 2008).

Utilizing the Expertise of Private Enterprise to Design Prevention Programs Can Increase Their Demand and Uptake

While scientists have identified the critical components for establishing healthy behaviors among family members, existing EBP are underutilized (Rotheram-Borus et al. 2006). Private enterprise, not science, knows how to engage families over time and to influence their preferences, habits, and establish loyalty. In contrast to the underutilization of EBPP, McDonald's and Kentucky Fried Chicken have significantly influenced the daily lives of almost all Americans: every child has about 3.5 meals weekly at McDonald's (Schlosser 2001). Children's loyalty to McDonald's is cemented by the age of 9 years and lasts a lifetime. McDonald's has a great deal to teach scientists and the global health community about how to promote healthy lifestyles. If public health specialists could socialize children to healthy daily routines for eating, exercising, and goal setting by age 9, there would be dramatic and sustained drops in our healthcare expenditures and improvements in our quality of life.

Private entrepreneurs replicate and diffuse quality products in hundreds of thousands of sites simultaneously;

can health providers deliver health programs with fidelity globally? In order to achieve this goal, we advocate employing the product development and marketing expertise of the private enterprise world to increase the uptake, scalability, and sustainability of EBPP (Rotheram-Borus et al. 2006). In particular, rather than a focus on memorizing health information, marketers are likely to create engaging, concrete experiences that capture our attention and imagination—a recipe for sustained motivation over time.

Summary

HIV has spread unchecked, affecting almost 40 million families (World Health Organization 2006). HIV/AIDS and other diseases will continue to impact families throughout the twenty-first century. Having local leaders share responsibility for promoting family wellness and healthy daily routines may be far more likely to defeat HIV than expensive, high-end solutions in the healthcare sector. Given the failure of our current approaches to stop HIV, radically different conceptualizations and prevention strategies are needed. Family Wellness, Mentor Mothers, and internet-based innovations are potential strategies that can create health promoting communities. A social space for dialog and critical thinking is needed in communities in order to build knowledge and skills in both formal and informal networks (Campbell et al. 2007). Prevention sites can then enable a family's negative habits to be broken and healthy routines to be cemented.

Open Access This article is distributed under the terms of the Creative Commons Attribution Noncommercial License which permits any noncommercial use, distribution, and reproduction in any medium, provided the original author(s) and source are credited.

References

- Beaudoin, C. E. (2007). HIV prevention in sub-Saharan Africa: a multilevel analysis of message frames and their social determinants. *Health Promotion International*, 22(3), 198–206. doi:10.1093/heapro/dam019.
- Campbell, C., Nair, Y., Maimane, S., & Nicholson, J. (2007). 'Dying twice': a multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology*, 12(3), 403–416. doi:10.1177/1359105307076229.
- DeVol, R., & Bedroussian, A. (2007). *An unhealthy America: The economic burden of chronic disease*. Los Angeles, CA: The Milken Institute.
- England, R. (2007). The dangers of disease-specific programmes for developing countries. *BMJ (Clinical Research Ed.)*, 335(7619), 565. doi:10.1136/bmj.39335.520463.94.
- England, R. (2008). The writing is on the wall for UNAIDS. *BMJ (Clinical Research Ed.)*, 336(7652), 1072. doi:10.1136/bmj.39569.497708.94.

- Flay, B. R., Biglan, A., Boruch, R. F., Castro, F. G., Gottfredson, D., et al. (2005). Standards of evidence: criteria for efficacy, effectiveness and dissemination. *Prevention Science*, 6(3), 151–175. doi:10.1007/s11121-005-5553-y.
- Flay, B. R., Graumlich, S., Segawa, E., Burns, J. L., Holliday, M. Y., & Aban Aya Investigators. (2004). Effects of 2 prevention programs in high-risk behaviors among African American youth. *Archives of Pediatrics and Adolescent Medicine*, 158(4), 377–384. doi:10.1001/archpedi.158.4.377.
- Halperin, D. (2008, January 1). Putting a plague in perspective. *New York Times* [Editorial].
- Harrison D. (2008, March 18). A life worth living is a powerful incentive for youngsters to avoid getting HIV. *Cape Times*.
- Hawkins, J. D., Kosterman, R., Catalano, R. F., Hill, K. G., & Abbott, R. D. (2005). Promoting positive adult functioning through social development intervention in childhood. *Archives of Pediatrics and Adolescent Medicine*, 159(1), 25–31. doi:10.1001/archpedi.159.1.25.
- Ingram, B. L., Flannery, D., Elkavich, A., & Rotheram-Borus, M. J. (2008). Common processes in evidence-based adolescent HIV prevention programs. *AIDS and Behavior*, 12(3), 374–383. doi:10.1007/s10461-008-9369-1.
- Jiraphongsa, C. (2007). Report at the AIDS in Asia Network Meeting, National Institute of Hygiene and Epidemiology (NIHE), Vietnam. December 16–18.
- Kaisernetwork.org (2005). 16th annual black church week of prayer for healing of AIDS begins March 7. Retrieved 26 March 2008.
- Kirby, D. (2003). Presentation on USAID's ABC Study at USAID, Washington, DC October.
- Li, L., Wu, Z., Wu, S., Zhaoc, Y., Jia, M., & Yan, Z. (2007). HIV-related stigma in health care settings: A survey of service providers in China. *AIDS Patient Care and STDs*, 21(10), 753–762. doi:10.1089/apc.2006.0219.
- Marsh, D. R., Schroeder, D. G., Dearden, K. A., Sternin, J., & Sternin, M. (2004). The power of positive deviance. *British Medical Journal*, 329(7475), 1177–1179. doi:10.1136/bmj.329.7475.1177.
- McClure, S. M., Laibson, D. I., Loewenstein, G., & Cohen, J. D. (2004). Separate neural systems value immediate and delayed monetary rewards. *Science*, 306(5695), 503–507. doi:10.1126/science.1100907.
- McDonald, H. P., Garg, A. X., & Haynes, R. B. (2002). Interventions to enhance patient adherence to medication prescriptions: Scientific review. *Journal of the American Medical Association*, 288(22), 2868–2879. doi:10.1001/jama.288.22.2868.
- McGinnis, J. M., & Foege, W. H. (1993). Actual causes of death in the United States. *Journal of the American Medical Association*, 270(18), 2207–2212. doi:10.1001/jama.270.18.2207.
- Olds, D. L., Robinson, J., O'Brien, R., Luckey, D. W., Pettitt, L. M., Henderson, C. R., Jr., et al. (2002). Home visiting by paraprofessionals and by nurses: a randomized, controlled trial. *Pediatrics*, 110(3), 486–496. doi:10.1542/peds.110.3.486.
- Rodriguez-Garcia, R., & Kusek, J. Z. (2007). Planning and managing for HIV/AIDS results, a handbook. World Bank, Global HIV/AIDS Program. From http://siteresources.worldbank.org/INT/HIVAIDS/Resources/375798-1103037153392/Results_Handbook_31Oct2007.pdf. Retrieved 20 December 2008.
- Rotheram-Borus, M. J., Flannery, D., Rice, E., & Lester, P. (2005). Families living with HIV. *AIDS Care*, 17(8), 978–987. doi:10.1080/09540120500101690.
- Rotheram-Borus, M. J., Lester, P., Song, J., Lin, Y. Y., Leonard, N. R., Beckwith, L., et al. (2006). Intergenerational benefits of family-based HIV interventions. *Journal of Consulting and Clinical Psychology*, 74(3), 622–627. doi:10.1037/0022-006X.74.3.622.
- Rotheram-Borus, M. J., Swendeman, D., Flannery, D., Rice, E., Adamson, D., & Ingram, B. (2008). Common factors in effective HIV prevention programs. *AIDS and Behavior*, [Epub ahead of print]. doi:10.1007/s10461-008-9464-3.
- Schlosser, E. (2001). *Fast food nation: The dark side of the all-American meal*. New York: Houghton-Mifflin Books.
- Shah, A. *Health Issues*. From <http://www.globalissues.org/health>. Retrieved 25 March 2008.
- Singer, M., & Clair, S. (2003). Syndemics and public health: Reconceptualizing disease in bio-social context. *Medical Anthropology Quarterly*, 17(4), 423–441. doi:10.1525/maq.2003.17.4.423.
- Sorensen, T., Rivett, U., & Fortuin, J. (2008). A review of ICT systems for HIV/AIDS and anti-retroviral treatment management in South Africa. *Journal of Telemedicine and Telecare*, 14(1), 37–41. doi:10.1258/jtt.2007.070502.
- UNAIDS (2007). *AIDS epidemic update: 2007*. Geneva, Switzerland: UNAIDS.
- USAID (2008). *The capacity project*. From <http://www.capacityproject.org>. Retrieved 25 March 2008.
- Weisner, T. S. (2002). Ecocultural understanding of children's developmental pathways. *Human Development*, 45(4), 275–281. doi:10.1159/000064989.
- World Bank (2008). Trends in HIV/AIDS data—Highlights from world bank research. From <http://econ.worldbank.org>. Retrieved March 31, 2008.
- World Health Organization (2006). *World Health Report 2006: Annex table 3*. Geneva: WHO. Available online at: <http://www.who.int/whr/2006/annex/en/index.html> and in the WHO statistical information system (WHOSIS): core health indicators.
- Wu, Z., Detels, R., Zhang, J., Li, V., & Li, J. (2002). Community-based trial to prevent drug use among youths in Yunnan, China. *American Journal of Public Health*, 92(12), 1952–1957.