

Using RARE for Insights into Minority Populations Living with HIV/AIDS in Florida

Graham Watts, Institute for Health, Policy & Evaluation Research, Duval County Health Department

William Livingood, Institute for Health, Policy & Evaluation Research, Duval County Health Department

Carolyn Woodhouse, MPH Program Director, East Stroudsburg University, Stroudsburg, PA

Christopher H. Bates, Office of Public Health Sciences/Office of HIV/AIDS Policy, U.S Department of Health and Human Services, Washington, DC

Dawn Goodridge Carney, Institute for Health, Policy & Evaluation Research, Duval County Health Department

Deidre Kelley, City of Jacksonville, Mental Health and Welfare Division, Jacksonville, FL

Abstract

Objective: This study examined the utility of Rapid Assessment Response and Evaluation (RARE) as a tool for gaining insights into the social dynamics underlying HIV/AIDS in predominantly minority communities at high risk of HIV infection. Further, it identified factors influencing access to treatment and services in communities at risk of HIV infection.

Methods: A structured synthesis design was applied to three reports of RARE projects conducted in selected major metropolitan areas on the east coast of Florida. Qualitative analytic techniques were then applied to the RARE reports. Findings in the reports were based on data collected by trained RARE teams using direct observation, focus groups, in-person interviews, and short closed-ended surveys.

Results: Findings indicated that high-risk behaviors for HIV infection are multifaceted and varied across settings. Attitudes about susceptibility to HIV infection, faulty beliefs about the origin of HIV/AIDS, and lack of privacy in accessing services emerged as major barriers of access to treatment and prevention services.

Conclusions: Application of the RARE methodology as a component of needs assessment provides insights about factors that contribute to the HIV epidemic in specific communities and suggests ideas for improving access to quality HIV health care in Florida for specific groups at increased risk of infection.

Introduction

The Rapid Assessment Response and Evaluation (RARE) methodology is not new to public health. Malaria, diarrhea, dengue, and drug abuse have been explored using RARE (Needle et al,

2000). Recently, RARE has been used to develop understanding of HIV/AIDS in high prevalence communities in the United States, including 11 metropolitan statistical areas (MSAs) that implemented studies between 1999 and 2001 (Fitch et al, 2002). For example, a group of HIV service providers, leaders, and community members experienced in HIV prevention services implemented RARE in Seattle, King County. Key project findings were beliefs that HIV was developed by the government to exterminate Black people and persistent negative attitudes toward HIV which promote a culture of shame. Additionally, participants perceived that confidentiality and accessible HIV prevention information were missing (Public Health Seattle & King County, 2004). RARE studies have also been implemented outside the United States. In India, for example, HIV providers have implemented RARE in Mumbai, Chennai, Calcutta, Delhi and Imphal. Like their American counterparts, Indian workers have discovered an attitude of invulnerability to harm despite knowledge of risky behaviors (Dorabjee & Samson, 2000). This study builds on past research by examining the use of RARE methodology to explore how information from RARE provides insights into innovative and community sensitive approaches to preventing HIV/AIDS.

The HIV/AIDS epidemic remains a challenge in the United States. Prevalence of HIV/AIDS is increasing and the burden of the disease is shifting to vulnerable populations such as the poor, who lack access to health care (Centers for Disease Control and Prevention, 2003). These vulnerable populations are typically from communities that are more diverse in terms of social, cultural, political, and economic complexity than mainstream America (Institute of Medicine, 2002). This complexity influences health decisions and behaviors, but its dynamics are not well understood. Further, the lack of understanding regarding multiple etiologies of HIV/AIDS has prompted calls for more research on the community context of the disease. The need for improved understanding of community context has become increasingly clear, even with studies employing optimal experimental research designs (Clayton, Scutchfield & Wyatt, 2000; Livingood & Woodhouse, 2001). In short, understanding the community context, documenting what is known, and broadly disseminating the knowledge are essential for developing insight into effective interventions and strengthening the theoretical base of prevention science.

This study examined the utility of Rapid Assessment Response and Evaluation (RARE) as a tool for gaining insights into the social dynamics underlying HIV/AIDS in communities at high risk of HIV infection. Further, it identified factors influencing access to treatment and services in communities at risk of HIV infection. A thorough understanding of how contextual factors and individual characteristics operate together to influence use or non-use of health care and preventive services can offer useful information to expand health indicator systems and initiate new interventions to address the burgeoning HIV epidemic more comprehensively.

Description of RARE Methods

In the United States, Rapid Assessment Response Evaluation (RARE) is a recently developed public health tool for understanding community complexity (Needle et al., 2003). It is a rapid reconnaissance process, using a structured array of methods promoted by the U.S. Department of Health and Human Services, Office of HIV/AIDS Policy. An in-depth explanation of the philosophical tenets, history, structure, and assumptions of RARE are described in public health literature (Needle et al., 2003) and in a manual of the Department of Health and Human Services,

Office of Public Health & Science (Rapid Assessment, Response, & Evaluation Project: RARE, 2001). Briefly, key tenets and assumptions of RARE include--speed, practicality, multiple methods, diverse data sources, inductive reasoning, contextualizing behavior, community participation, and action research.

RARE is the application of anthropological methods of inquiry to a specific health problem (Rapid Assessment, Response, & Evaluation Project: RARE, 2001). However, the techniques of RARE are employed in a much shorter time frame and use far less in-depth study than is normally associated with anthropology and ethnography. Essentially, RARE is an abbreviated application of an anthropological approach that is used to learn more about people and issues that are unique to their settings within a very limited time frame. This approach holds increased promise to yield more in-depth understanding of the factors that are associated with specific health outcomes. RARE is both an approach to data collection and an approach to community development. The RARE data collection strategy has five components: 1) Rapid Assessment Surveys, 2) Cultural Expert Interviews, 3) Focus Group Interviews, 4) Direct Observations, and 5) Geo-Mapping (Rapid Assessment, Response, & Evaluation Project: RARE, 2001).

Rapid Assessment Surveys are short, closed-ended questionnaires that are used with small groups of individuals. Volunteers who complete the surveys provide data that help fill information gaps that remain after other aspects of the RARE methodology have been successfully implemented.

Cultural Expert Interviews consist of in-depth, one-on-one consultations. Participants include policy makers and community leaders, service providers, and individuals from vulnerable, neglected subgroups that are often marginalized. Findings provide evidence about the characteristics of people who are at risk for adverse health outcomes and determining unmet need by looking at availability and accessibility of services.

Focus Group Interviews are an extension of cultural expert interviews using a small group of three to five persons. Members of the group include community activists, gatekeepers, and community “movers and shakers”. A facilitator who remains value neutral moderates the discussion, which allows participants to provide a range of opinions about risk and protective factors of the affected or at-risk subgroup, the availability and accessibility of existing services, and what needs to be done to fill service delivery gaps. Using focus group interviews as a data collection strategy allows the RARE teams to generate new insights for understanding the community’s beliefs about health and social behaviors and provide an additional check on the validity of the data collected by other methods.

Direct Observation or Fieldwork is a technique for examining social environmental processes. Observers are native members of the community, so they gain ready access to socially sanctioned activities without inducing the Hawthorne effect and are able to get an unfettered glance of substance use, commercial sex work (prostitution), and other contextual factors of HIV infection.

Geo-Mapping is used to conduct visual analyses of data. Data inputs include geographic explanations of health or disease such as arrest rates or hospital admissions, prevalence rates, or

socio-demographic factors. These data are subsequently translated into visual maps, which spatially identify differences in locations.

The RARE strategies for data collection are integrated with principles of community ownership, reflected in community based participatory research and empowerment evaluation (Minkler & Wallerstein, 2003; Fetterman et al, 1996). Local community leaders guide the project, including the selection of the specific study communities. The data collection teams are people from the local communities, reflecting the demographics and culture of the communities being studied. The RARE approach has well-developed programs for training data collection teams, equipping indigenous community members with the requisite skills for trustworthy data collection, analysis, and interpretation.

Application of RARE Methods in Florida – Study design, data collection, and analysis

Study Design

This study's design was comprised of five steps: 1) gathering RARE reports that described lack of access to HIV/AIDS primary medical care in three metropolitan statistical areas of Eastern Florida, 2) repeatedly reading the RARE reports and noting language indicative of metaphors that described access to HIV/AIDS primary medical care, 3) summarizing implicit and explicit metaphors embedded in the RARE reports in a cogent and credible manner, 4) identifying relationships between metaphors reported across reports, and 5) translating the effort into an abbreviated but meaningful synthesis.

Data Collection

Data for the synthesis were derived from three RARE Reports: Rapid Assessment Response Evaluation Final Report, Jacksonville, Florida, 2002; Rapid Assessment Response & Evaluation, Team Report for Miami-Dade County; and Rapid Assessment Response & Evaluation, Palm Beach County HIV/AIDS Crisis Response Team, 2001. The U.S. Office of HIV/AIDS Policy trained field research teams from Duval (N=7), Palm Beach (N=19), and Miami-Dade (N=11) counties. The process for selecting teams included holding trilateral discussions between the Office of HIV/AIDS Policy, the Chief Elected Official (e.g., Mayor) of the affected Metropolitan Area, and Health Department Officials. Further, it included selecting a local field team based on holding trilateral discussions and these criteria: Indigenous to the affected community, infected or affected by the HIV/AIDS epidemic; a history of community or public health involvement in HIV/AIDS treatment or prevention; diverse disciplinary background such as medicine, anthropology, public health, social work, and health education; and potential for training as measured by continuing education credits or formal certifications completed. Each trained team selected a leader and identified areas where visible sex or drug trafficking were endemic and where previous public health work indicated myths about HIV/AIDS infection and transmission.

In Duval County, a total of 15 focus groups (at least 5 individuals in each), 26 one-on-one interviews, and 133 rapid assessment surveys were completed in 2002. In Palm Beach County, a total of 19 focus groups (each consisting of 4 to 13 individuals), 34 one-on-one interviews, 16 area observations of pre-identified sex and drug trade zip codes, 50 rapid assessment surveys (3

to 5 questions), and 20 geographic maps were completed in 2001. The Miami-Dade metropolitan area also collected data using similar techniques. Throughout the data collection process the field researchers preserved the integrity of the environmental context by using language and idiomatic expressions recognizable to collaborators, negotiating police presence during observations, using two-paired observers, wearing comparable dress to the study group, and making observations or dialoguing with participants during periods of peak sex and drug activities.

Data Analysis

Qualitative data analysis of RARE Reports is a structured synthesis (an adaptation of processes described in Noblit and Hare's [1988] meta-ethnography). This interpretive process was applied to reports of RARE projects conducted in three major metropolitan areas on the East coast of Florida. It involved data reduction, data tabulation and cross-case conclusion development (Gibson, 1998). Data reduction began with identification of themes as the units of analysis. After repeated reading, comparing, and analyzing to understand the nature of barriers and supports for accessing HIV/AIDS primary medical care and support services, researchers abstracted themes related to HIV transmission or access to HIV/AIDS primary medical care from words used in the reports or from ideas embedded in text.

Next themes were listed, compared, and organized into categories, thus enabling the reduction of many themes into a concise inventory that covered key issues. This inventory of themes was subsequently organized in tabular form. Cross-case conclusion development included looking for themes that were unique and common across counties. A comparison of the similarities and differences between themes derived from each setting revealed community characteristics and exposed insights for addressing issues that affect persons living with HIV/AIDS.

Results

The identification of barriers associated with access to treatment and services in communities at risk of HIV infection are summarized as themes, units of analysis of this study, in Table 1. We identified two thematic patterns, which we called *unique* and *shared* themes.

Shared themes are those that were common to two or more counties. Respondents from three counties (Miami-Dade, Duval, and Palm Beach) shared four themes: Lower socio-economic status, anomie (feeling trapped, hopeless, and powerless), survival needs (food, shelter, transportation), and privacy. Respondents from two counties (Miami-Dade and Duval) shared three themes: Inconsistent condom use, institutional distrust (as reflected in assertions which stated that HIV is an invention of the government), and low perceived threat of infection. Respondents from two counties (Palm Beach and Miami-Dade) shared one theme, community outreach, and respondents from two counties (Duval and Palm Beach) also shared one theme, access to care.

Unique themes *were those that were not shared with another county*. These themes appeared only twice. Respondents from Duval County had two unique themes: Interagency collaboration and modeling (imitating observable behaviors). In contrast, respondents from Palm Beach County had three unique themes: Alternative therapies (reliance on non-traditional HIV/AIDS

remedies), invincibility (low perceived susceptibility to infection), and vengeance (deliberately exposing sex partners to HIV).

Table 1. Themes from RARE Projects in Three Florida Counties

	Themes	Duval	Palm Beach	Miami-Dade
1.	Low socio-economic status	X	X	X
2.	Anomie	X	X	X
3.	Survival needs	X	X	X
4.	Privacy	X	X	X
5.	Inconsistent condom use	X		X
6.	Institutional distrust	X		X
7.	Perceived threat	X		X
8.	Limited community outreach		X	X
9.	Access to care	X	X	
10.	Interagency collaboration	X		
11.	Modeling	X		
12.	Alternative therapies		X	
13.	Attitude of invincibility		X	
14.	Vengeance		X	

Discussion

This research is unique in that it deals exclusively with three RARE reports, which served as the units of analysis, the data sources for the themes. RARE, although not new to public health, is just emerging as a tool for enhancing the response of public health practitioners to HIV/AIDS prevention and treatment. It allows HIV/AIDS program planners to triangulate data from multiple methods and sources to provide a broader and clearer picture of the social and cultural determinants of HIV/AIDS prevention and treatment issues that impact service utilization.

The structured synthesis approach to data analysis employed here relies on data reduction, data tabulation, and cross-case conclusion development. Findings reported here are not entirely new. In particular, attitudes of invincibility toward HIV infection, institutional distrust, and privacy/confidentiality were supported, thus suggesting universality of these themes. If, indeed, persons who feel invulnerable to harm do not perceive their personal risk for infection or reinfection, then checking for perceived risk of HIV infection should be included in HIV testing and counseling. Similarly, the view that government invented HIV for ethnic genocide might inevitably lead to loss of trust in the biomedical system, which offers information, testing, diagnosis, and treatment. This myth is a huge concern for public health workers because institutional distrust is antagonistic to care seeking. Finally, perceived lack of privacy/confidentiality is also a concern because it can affect treatment adherence (Dorabjee & Samson, 2000; Public Health Seattle & King County, 2004).

Some findings of this research differed from findings of prior RARE studies. Needle et al., 2003 found myths, which suggested that protection from HIV infection is enhanced by doubling condoms or having sex with non-injecting drug users who use crack alone. This study did not

identify similar culturally thematic perspectives; however, it did uncover themes such as anomie, vengeance, alternative therapy, and interagency collaboration. Perhaps these themes germane to Florida owe their existence to subgroups of ethnically diverse populations that perceive a distinction between themselves and the moralistic majority.

RARE studies are not developed for generalization beyond the selected study sites. Instead, they are designed to illuminate the social and cultural context of health decisions and behaviors such as using available health services or engaging in safer sex or safer drug use. The occurrence of three universal themes: privacy, attitude of invincibility, and institutional distrust has implications for the design of health service environments. In particular, the privacy theme suggests the need to design health service access points in ways that assure public confidence in accessing HIV/AIDS treatment and services incognito. The failure to provide screening and treatment in settings that clients deem suitably private can increase cognitive and emotional costs of care seeking and potentially lead some clients to under-use available HIV/AIDS services. As a whole, the three themes offer a useful starting point for developing a confirmatory model to examine the usefulness of these RARE themes for informing HIV/AIDS public health practice among Floridians in the 21st century.

Public health practice in the 21st century stands on the threshold of a new beginning. A key aspect of this new beginning includes understanding the geopolitical and sociocultural contexts in which health decision-making and behavior develop (Williams & Janoshik, 2001). It appears that HIV/AIDS prevention research can benefit from integrating models that emphasize beliefs and attitudes with biomedical HIV/AIDS interventions (Baldwin et al, 1996).

Conclusions

The RARE methodology can overcome limitations of traditional needs assessments that rely on sociodemographic data alone. Routine examination of incidence and prevalence surveillance data can have a desensitizing or victim blaming effect because descriptive data alone do not provide insights for cultural or sociological underpinnings of health problems. RARE incorporates different methods and data sources which provide a rich base of information for broadening public health science researchers' and practitioners' understanding of health problems, the people affected by health problems, and the meaning that people give to their behaviors. Insights gathered from RARE could also be used to design programs sensitive to a community's cultural values and underscore the need for broad participation to promote community ownership of solutions to local problems. Programs developed from this perspective can overcome limitations of erroneous assumptions and over-simplistic problem definition, which flourishes when assumptions are not grounded in the cultural context of the community. Despite promising benefits, the temporality (point-in-time), short duration, budget requirement, and collaboration required to successfully conduct a RARE project are key limitations that can compromise data collection.

The use of RARE in three metropolitan communities illustrates the utility of RARE methodologies to increase contextual understanding of the AIDS epidemic in vulnerable, non-mainstream communities and cultures. Differences in behavioral patterns among various cultures extend far beyond differences in language to differences in the risk of exposure to HIV

infection. Therefore, new approaches to understanding health risk and health seeking behavior would be a welcome addition to the inventory of public health tools for assessing community needs for health services and developing strategies to reduce conditions that promote health disparities.

Please address all correspondence to Graham F. Watts, Ph. D., 900 University Boulevard North, Suite 604, Jacksonville, FL 32211, Phone: 904-665-1779, Fax: 904-665-3111, email: graham_watts@doh.state.fl.us.

References

Baldwin, J.A., Rolf, J.E., Johnson, J., Bowers, J., Benally, C. & Trotter, R.T. (1996) Developing culturally sensitive HIV/AIDS and substance abuse prevention curricula for native American youth. *Journal of School Health*, 66, 322-327.

Centers for Disease Control and Prevention . Advancing HIV Prevention: New Strategies for a Changing Epidemic -- United States, 2003. *MMWR: Morbidity and Mortality Weekly Report*. 18 Apr 2003: 329-570 (<http://www.cdc.gov/epo/mmwr/mmwr.html>).

Clayton, R.R., Scutchfield, F.D. & Wyatt, S.E. (2000) Hutchinson smoking prevention project: A new gold standard in prevention science requires new transdisciplinary thinking. *Journal of National Cancer Institute*, 92, 1964-1965.

Dorabjee, J. & Samson, L. (2000). A multi-centre rapid assessment of injecting drug use in India. *International Journal of Drug Policy*, 11, 99-112.

Fetterman, D.M., Kaftarian, S.J., & Wandersman, A. (Eds.). (1996). *Empowerment evaluation: Knowledge and tools for self-assessment & accountability*. Thousand Oaks: Sage Publications.

Fitch, C., Rhodes, T., Hope, V., Stimson, V.G. & Renton, A. (2002). The role of rapid assessment methods in drug use epidemiology. *Offprint from Bulletin on Narcotics*, LIV(1 & 2), 61-72.

Gibson, C. (1998). Semi-structured and unstructured interviewing: a comparison of methodologies in research with patients following discharge from an acute psychiatric hospital. *Journal of Psychiatric & Mental Health Nursing*, 5, 469-77.

Institute of Medicine (2002). *No Time to Lose: Getting More from HIV Prevention*. Brief Report. Retrieved January 2004 from <http://www.iom.edu/includes/DBFile.asp?id=4131>

Livingood, W.C. & Woodhouse, C.D. (2001) Hutchinson study, gold standard or spruce goose: An epistemological view of prevention research. *American Journal of Health Studies*, 17, 138-143.

- Minkler, M. & Wallerstein, N. (Eds.). (2003) Community-based participatory research for health. San Francisco: Jossey-Bass.
- Needle, R.H., Trotter II, R.T., Singer, M., Bates, C., Page, J.B., Metzger, D. & Marcelin, L.H. (2003) Rapid assessment of the HIV/AIDS crisis in racial and ethnic minority communities: an approach for timely community interventions. *American Journal of Public Health*, 93, 970-9.
- Needle, R.H., Trotter II, R.T., Goosby, E., Bates C. & Von Zinkernagel, D. (2000). Methodologically sound rapid assessment and response: Providing timely data for policy development on drug use interventions and HIV prevention. *International Journal of Drug Policy*, 11, 19-23.
- Noblit, G.W. & Hare, R.D. (1988). *Meta Ethnography, Synthesizing Qualitative Studies*. Newbury Park: Sage Publications, Inc.
- Public Health Seattle & King County (2004). *Final Report and Recommendations*. Retrieved January 2004 from <http://www.metrokc.gov/health/apu/publications/rare/>.
- Rapid Assessment, Response and Evaluation Project RARE (2001). *RARE Field Assessment Methods Training Workbook*. Office of HIV/AIDS Policy: Washington DC
- Williams, R.L. & Yanoshik, K. (2001). Can you do a community assessment without talking to the community? *Journal of Community Health*, 26, 233-47.