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Health and Health Care in the U.S. Virgin Islands: Challenges and Perceptions

Abstract: *This research was designed to discover how residents of the United States Virgin Islands think about their health, health status, health problems, and the quality of the health care delivery system. Six focus groups were organized – one for males and one for females on each of the largest islands (St. Thomas, St. Croix, and St. John). Results indicated that Virgin Islanders see a large role for personal responsibility in achieving and maintaining good health, although there are cultural and economic barriers that prevent taking full advantage of available health services. Residents are especially concerned about privacy and threats to confidentiality of patient information that could occur among professionals.*

Key Words: *Health Disparities, Confidentiality, Virgin Islands*

While some scholars have examined health disparities in the Caribbean (Pan American Health Organization 1997; Quinlan 2004, Mahoney 2005), to date there has been limited published scholarly research that addresses health issues and health disparities in the U.S. Virgin Islands (USVI). The available studies are primarily national surveys such as the Behavioral Risk Factor Surveillance System (BRFSS) that included participants from the USVI (Neyer et al. 2007; Casper, Croft, Hong, Fang, & Greer, 2010). What is known is that on at least some important health measures, the USVI compares poorly to the health status of Americans living on the mainland. For example, whereas the estimated 2010 infant mortality rate for mainland Americans was 6.14 deaths per 1,000 live births, in the USVI it was 7.4 (Central Intelligence Agency 2010). How do residents of the USVI view health, their health status, health problems, and the quality of their health care delivery system? In response to an application submitted by the Division of Nursing, University of the Virgin Islands (UVI), in 2004 the National Institutes of Health, National Center on Minority Health and Health Disparities (NIH/NCMHD) awarded a three-year grant to establish "The Caribbean EXPORT¹ Center for Research and Education in Health Disparities." The Export Center provided support for UVI faculty to develop the

capacity and infrastructure to begin to investigate and address health issues and disparities in the USVI. Later, in October 2007, a five-year NCMHD grant was awarded to establish the "Caribbean Exploratory Research Center" (CERC) and continue and expand this work.

The research reported in this paper is a product of that grant. It reports on one method the authors used to gain a preliminary understanding of how Virgin Islanders view health problems, how they define "good" health, what they do to protect and improve their health, and how they view the health care delivery system. We wanted to learn how effective they see mainstream and alternative health care delivery systems in achieving better health. And, as an exploratory study, we also wanted to pinpoint issues that need further study.

The USVI covers 346 square miles, about twice the area of Washington, D.C., with an estimated population in mid-2010 of 110,000 residents, who live primarily on three islands: St. Croix, St. Thomas, and St. John. The 2000 U.S. Census classified 78 percent of the residents as Black (African-Caribbean), 10 percent White, and 12 percent "other." Just under half (49 percent) of the population was born in the Virgin Islands. Native born or naturalized Virgin Islanders are U.S. citizens. Thirty two percent were born elsewhere in the Caribbean. About 13 percent of the population is originally from the 50 states in the U.S., 4 percent hail from Puerto Rico, and 2 percent from elsewhere. Fourteen percent of the population identifies as Hispanic, primarily from Puerto Rico, the Dominican Republic and other Caribbean Islands. In 2002, some 28.9 percent of the population lived below the poverty line (Central Intelligence Agency 2010; Virgin Islands Now 2010). With this rich heterogeneity, any study of health in the Territory, particularly in differences with the 50 American states, is closely interrelated with race and ethnicity.

MAJOR HEALTH CHALLENGES IN THE USVI

A Task Force comprised of key personnel within the Department of Health, experts from many public and private agencies, and community based organizations was convened in 2001 to develop the first strategic plan for the Department of Health, USVI. Utilizing *Healthy People 2010* as the guide (U.S. Department of Health and Human Services 2010), members of the Task Force identified focus areas reflecting the

key health problems affecting the population. The result of the work of this group was to develop a comprehensive plan, *Healthy Virgin Islands 2010* (USVI Department of Health 2003).

The Task Force identified some 28 health concerns and disparities in the USVI. The leading health concerns in the USVI centered on issues of access to quality health services for 1) heart disease and stroke, 2) cancer, 3) diabetes, and 4) HIV infection.

1. **Heart Disease and Stroke:** As with the mainland U.S., cardiovascular diseases are the leading causes of death in the USVI. According to the V.I. Bureau of Vital Statistics, cardiovascular diseases accounts for approximately 34 percent of all deaths in the Virgin Islands, a rate of 191.5 deaths per 100,000 population (USVI Department of Health, 2003).

Risk factors for cardiovascular diseases are widespread in the USVI. Although most of the major risk factors for heart disease and stroke are modifiable or entirely preventable (Chyun, Amend, Newlin, Langerman, & Melkus, 2003), over 80 percent of Virgin Islanders report having at least one major risk factor for heart disease (USVI Department of Health, 2003). These include tobacco use, physical inactivity, poor diet, and high blood pressure, high blood cholesterol, obesity, and diabetes. Several studies have reported racial, ethnic and socioeconomic disparities in the clustering of cardiovascular disease risk factors (Graham-Garcia, Raines, Andrews, & Mensah, 2001; Sharma, Malarcher, Giles, & Myers, 2004).

2. **Cancer** is the second leading cause of death in both the mainland U.S. and the USVI. The *Cancer Facts and Figures 2003* from the American Cancer Society reports that about one-fifth of all deaths in the U.S. stem from cancer, and that cancer will eventually inflict one in every three Americans alive today. The mortality data in the USVI mirror national trends, with breast and prostate cancers being the most common for female and male cancer deaths respectively (USVI Department of Health, 2003).
3. **Diabetes:** According to the results of the Behavioral Risk Factor Survey 2009, 8 percent of Virgin Islanders have been told they have diabetes. Diabetes in the USVI affects more Black and Hispanic residents and is more common among older adults and persons with lower education and income levels (USVI Department of Health, 2003). These data show a need for healthier nutrition practices and more physical activity.
4. **HIV Infection:** At the end of 2007, there were 31.4 people per 100,000 residents living with AIDS in the USVI, compared to 12.5 in the U.S. as a whole (Centers for Disease Control, 2010). Because of the lack of information about risk and transmission of the disease, and sexual mores, there is a high rate of other STDs as well, which increases the risk of HIV transmission. HIV infection is a stigmatized disease in the Territory, leading many to avoid testing for HIV, so that by the time they present for care, many patients have severe immuno-suppression, or AIDS. The most common risk factor for HIV infection in the USVI is unprotected heterosexual sex, and the number of men and women who have the disease is nearly equal. Substance abuse is also an important factor in transmission.

Persons of Afro-Caribbean descent make up 68 percent of those diagnosed with HIV, similar to their representation on the overall USVI population. On the other hand, approximately 28 percent of those diagnosed with HIV are Hispanic, a proportion that is double their proportion in the population. An estimated 55 percent of those patients were infected through heterosexual transmission, and women make up 43 percent of the patients in care.

These data provide only a rough sketch of the top health challenges facing residents of the USVI. We now turn our attention to a study that examined how USVI residents view their health and health care.

METHOD

Sample and Data Collection

The data reported below were obtained from six focus group sessions that were conducted on the three largest islands in the USVI. The purpose of the focus groups was to elicit perceptions of health and health care from diverse segments of the population. After securing the requisite approval from the Institutional Review Board at the University of the Virgin Islands, each group met for three hours in facilities owned by the University of the Virgin Islands that were located on major bus routes. A total of 29 respondents (9 male and 20 female) participated in the six groups: 14 from St. Croix, 7 from St. Thomas, and 8 from St. John. The number of participants and duration of each session were sufficient for our research objectives and consistent with prevailing standards (Fern, 2001).

Participants varied in age and education, and had a range of ethnic heritages that were similar to the age, education and ethnicity distributions in the wider population. One focus group was organized for each gender on each island. A male native Virgin Islander conducted the men's groups, while the women's groups were led by a woman of Caribbean heritage who had lived in the USVI for 25 years.

Data Analysis

General questions, all of which were posed in each of the focus groups, were developed by CERC faculty and staff. The entire sessions of the focus groups were audio recorded and transcribed. The facilitators compared the raw data to the transcribed data for accuracy. Responses were read by each focus group facilitator and categorized according to area or theme, resulting in six general categories, to be discussed below.

RESULTS

The results of the Focus Groups' discussions can be divided into six general areas:

1. **What constitutes good health?** There was consensus both between and within groups that "health" was not simply the absence of disease or disability. Instead, typical responses defined "health" as:
 - "feeling good, energized, without *dis-ease*; i.e., not in pain or discomfort"
 - "in physical, mental, and spiritual balance"
 - "being physically fit"
 - "meeting accepted standards for levels for blood pressure, sugar, cholesterol, and weight"
 - "good stress management"
 - "strong self-esteem"

In the USVI, where geographical proximity leads to lifelong relationships perhaps more so than on the mainland, having positive relationships with others was also seen as an important dimension of good health. Indeed, two older participants stated that to them,

"health" meant an ability to help others. All participants acknowledged that one's perception of health was dependent on culture and lifestyle, so, indeed, health was not understood as a monolithic or one-dimensional concept. For some, the definition of health was strongly linked to their religious beliefs.

2. **Health Care Problems:** What are the most crucial health care problems? The five most important health issues identified by members of the focus groups were Diabetes, Heart Disease, HIV/AIDS, Asthma, and Hypertension. The majority of participants expressed concerns about limited resources and high costs, such as the Medicare gap, high cost of insurance and co-pay, large number of uninsured residents, and the overall cost of services.

Female respondents tended to focus on problems with health care delivery, such as Medicare caps and providers' rejection of Medicare services for the elderly. One group of women singled out the vulnerability of uninsured preschoolers as a special problem. Several women, especially in the group on St. Croix, expressed concerns with cleanliness (e.g., hand washing; maintenance of sanitary facilities). Women on all three islands expressed concerns about the use of outdated equipment at health facilities and that inadequate maintenance of equipments leads to too many breakdowns. In contrast, the male respondents tended to focus more on specific threats to health: alcoholism, cardiovascular disease, prostate problems, gambling, and obesity. Men voiced a stronger distrust of health care personnel than women, although (as will be discussed below) all groups brought up issues of trust, confidence, concern about professional qualifications and cultural competence, and the fear that their health information would not be treated with privacy and confidentiality.

3. **Barriers to good health and good health care:** Next, the focus groups talked about what they saw as barriers to good health and good health care. All groups talked about financial constraints, which were seen as more of a national than a local problem. Three additional types of barriers were identified that are more specific to the USVI.

First, there are barriers to good health that can be addressed by better professional training and education. There was concern that health care providers from the U.S. mainland were not culturally competent, and about significant provider-patient communication obstacles based on patients' use of language that providers may misunderstand. Several female participants felt that male providers were not sufficiently respectful. There was also concern about a declining number of Public Health Nurses, who were active in communities until the mid-1980s, following up on patients discharged from hospitals and on newborn infants and their mothers. Second, some barriers to good health can be addressed by more rigorous enforcement of existing policies. By far the most widespread concern, expressed by several participants in different focus groups, concerned patient confidentiality and privacy. Overall, trust and confidence in the health system is markedly low; concern for confidentiality is high. While part of the problem may stem from insufficient training for health professionals, it is also clear that participants feel that enforcement of rules protecting confidentiality is sorely lacking. In part this may be because health care

staff who are overworked and underpaid can become careless, but the comments indicate that some concerns with confidentiality stem from living in an island community where everyone seems to know everyone else.

Third, some barriers could be addressed by better coordination, planning, and/or financing. Included here is confusion about where best to go to receive specific health services and doubt about the range and limits of services provided by the Department of Health. Some participants did not know which problems were best treated in local clinics or physicians' offices vs. hospital emergency rooms.

4. **Personal Responsibility.** What is the role of personal responsibility in attaining good health? Regardless of whether one uses "mainstream" or "alternative" sources of health care, all respondents agreed that good health requires at least some personal responsibility. For example, the older respondents pointed to health problems caused by fast-food obesity and a declining participation (among all age groups) in physical activities. They stated that behaviors such as going to Church or to the beach were important in achieving and maintaining good health. All participants recognized the importance of healthy diets and proper exercise in achieving good health. Several participants also stated that because of the high cost of health care, they would exhaust home remedies before seeking professional medical health care. All groups reported the use of herbs, bush tea, alternative medical practitioners (usually without disclosure to mainstream health providers), and suggested that the health care establishment develop high standards for, and dispel myths about, complimentary and alternative medicine.
5. **How Health Care Providers are Viewed:** Next, the focus groups were asked to share their feelings about health care professionals' "customer service." Neither surprisingly nor unique to the USVI, several respondents pointed to long waiting times as a problem in clinics, physicians' offices, and hospitals. Some stated that the health care providers do not spend enough time with patients (especially the elderly), and/or that the providers do not give their undivided attention to the patient during the office or clinic visit. Further, several participants saw a need to adjust clinic hours so that services are available in the evenings and on weekends. Others suggested that it was necessary to go off-island (e.g., to Puerto Rico or even to the U.S. mainland) to get decent health care. Some felt there was an insufficient level of cultural understanding and respect throughout the health care system, and insufficient appreciation of the subtleties of the culture in the USVI from non-native health care providers who had been trained off-island. In short, the data revealed a crucial need for better training for health care providers in customer service, which is categorized as inefficient, insensitive, and of such poor quality that staff sometimes make clients feel like "victims."
6. **Sources for Health Information:** Where do people in the USVI obtain health information? Two principal sources were identified: the Health Department and family/friends. Respondents felt that there was plenty of "formal" or written information available, although the information was not always disseminated in effective ways (e.g., in Spanish). Respondents

identified several effective means of communicating health care information: brochures, radio and TV spots, public gatherings (e.g., races and walks), and through churches, barber shops, and beauty salons. Overall, respondents tended to see more health information as an opportunity for empowerment and increasing the level of personal responsibility for health.

CONCLUSIONS

The use of focus groups to learn perspectives on the health concerns of Virgin Islanders proved to be highly valuable. Virgin Islanders provided depth, breath and relevance as they shared insights into health issues impacting the USVI.

Participants clearly expressed an interest in being credible and effective partners in improving health care for all Virgin Islanders. They expressed concerns about limited cultural competence and respect for patients, ineffective skill in communicating with individuals whose cultural beliefs and health practices may be poorly understood and accepted by practitioners with a mainland orientation, and limited customer service skills that are clearly essential to providing high quality care. The CERC is currently conducting studies that examine the efficacy of culturally based health practices, and when and how certain practices might be incorporated into more standard practices and advice from health care professionals.

Participants expressed considerable unease regarding confidentiality and privacy of their and their families' medical information. Confidentiality and privacy protection are extremely important and often difficult in small, isolated islands such as the USVI as well as everywhere in rural areas, small towns and villages, and even in urban housing projects, where individuals tend to assume (and may well be correct) that "everyone knows everyone else's business."

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¹ EXPORT stands for (enters of) Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training. The NCHHD has awarded grants to establish approximately 60 EXPORT Centers throughout the United States.

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