

Community-Based Research



Yesterday

In 1932, Franklin Delano Roosevelt said, “The success or failure of any government in the final analysis must be measured by the well-being of its citizens. Nothing can be more important to a state than its public health.”

Until recently, medical research primarily addressed the needs of the majority population, with little examination of the cultural or gender-based influences on disease rates or health outcomes among diverse communities.

Today

As the U.S. population continues to grow in diversity, health disparities have been noted between different population groups. Health care scientists increasingly recognize of the impact of race, culture, gender, socioeconomic status, living conditions, and geography on the health of individuals and communities.

Many communities which may include minority, low-income, rural, or non-English-speaking groups, as well as others such as the disabled or the homebound, are considered medically underserved. Barriers resulting from language, isolation, and cultural differences often limit access to health care. Reaching these underserved communities often requires specialized interventions.

Community-based research promotes collaborations between health care scientists and community leaders in the design and implementation of research projects. The goal is to foster sustainable efforts at the local level to facilitate the translation of research advances into improved health for all. The following are some examples of community-based research:

- **Reaching inner-city African -American men with high blood pressure.** Among ethnic groups in the U.S., African-Americans have the highest rate of high blood pressure, and they tend to develop the condition at a younger age. Young, African-American men from inner-city neighborhoods are at particular risk for uncontrolled high blood pressure, which can cause damage to the kidneys, eyes, and heart. Many have never had contact with health care providers. An intervention delivered at the community level by a nurse-led multidisciplinary team helped men in one urban area bring their blood pressure under better

control through lifestyle changes and careful medication management. At a five-year follow-up, most of the men had sustained their improved blood pressure control and showed less evidence of heart damage.

- **Supporting chronically ill rural women.** Chronically ill women who live in rural areas often lack access to health care. The internet-based *Women to Women (WTW)* (<http://www.montana.edu/cweinert/wtw.html>) project helped a group of rural-dwelling women living with chronic conditions such as diabetes, arthritis, heart disease, or multiple sclerosis, improve their disease self-management. *WTW* provided a website that included an on-line chat room with other chronically ill women, health promotion and teaching activities, and a discussion board facilitated by a health care expert. The *WTW* participants reported improved self-esteem, social support, and health-care empowerment, and also showed declines in depression, stress, and loneliness.

Reducing high-risk sexual behaviors in adolescents. The rate of teen pregnancy in the U.S. is higher than in almost all other developed countries, and over 400,000 teenage mothers give birth each year. The Teen Pregnancy Prevention Initiative (<http://www.hhs.gov/ophs/oah/prevention/research/index.html>), a program within the U.S. Department of Health and Human Services, supports the use of the most effective community programs to reduce high-risk sexual behaviors. Selected programs developed through NIH-funded research include:

- *“Be Proud! Be Responsible!”* Originally focused on adolescent African-American males, this community-based program has been effective in promoting abstinence and safe-sex behaviors in diverse populations (http://www.hhs.gov/ophs/oah/prevention/research/programs/be_proud_responsible.html). It has been further adapted for use in the programs below.
- *“Be Proud! Be Responsible! Be Protective!”* Addressed toward adolescent mothers and pregnant teens, this program emphasizes maternal protectiveness to motivate participants to take responsibility, make healthy decisions, and be aware of the effects of risky sexual behavior on their children and their communities

http://www.hhs.gov/ophs/oah/prevention/research/programs/be_proud_responsible_protective.html).

- “*Cuidate!*” Offered in both English and Spanish, this program utilizes important cultural beliefs and attitudes in the Latino community, such as the importance of family, to communicate risk-reduction strategies and to increase knowledge and self-efficacy skills for adolescent Latinos (<http://www.hhs.gov/ophs/oah/prevention/research/programs/cuidate.html>).
- **Promoting Physical Activity in American Indian Youth.** In recent years, childhood obesity has emerged as a major public health concern. American Indian (AI) populations in particular have experienced an alarming increase in obesity, along with type 2 diabetes, among children. In a community-based research project on an Indian reservation, focus groups of school-aged youths identified motivations for and barriers to engaging in sports and exercise programs. These results can help in the development of culturally appropriate ways to motivate more AI children to stay active and healthy.
- **Helping caregivers of persons with Alzheimer’s disease.** Alzheimer’s disease (AD) is a serious brain disorder that causes a deterioration of memory and thinking skills, along with unpredictable behaviors. In the U.S., over 70% of the 4.5 million persons with AD remain at home, with a spouse, family member, or friend serving as an informal caregiver. Caring for someone with AD, though, can be very burdensome. The *Resources for Enhancing Alzheimer’s Caregiver Health (REACH)* (<http://www.edc.pitt.edu/reach/>) program taught caregivers about AD, and provided strategies to help them manage troublesome AD behaviors. *REACH* also emphasized ways for caregivers to manage their stress, maintain social support, and enhance their own self-care activities. In one study, compared to caregivers who received basic AD education, *REACH* caregivers reported better physical, emotional, and overall health, and lower depression.

Tomorrow

NIH-supported researchers will continue to explore new strategies for conducting research at the community level in order for the entire population to benefit from improved strategies in health promotion and disease prevention. For example, the Internet is expanding the concept of community, while offering new ways to access remote or widely dispersed populations.

- Ongoing research with the *WTW* project for chronically ill rural-dwelling women is exploring the effectiveness of a shorter and simpler web-based intervention on disease self-management, psychosocial adaptation, and quality of life. In addition, the researchers are analyzing responses by the women participants to help address the most frequently discussed problems.
- Adolescents with diabetes can better manage their disease when they are trained in coping skills such as communication, problem-solving, and conflict resolution. This training has been adapted to a web-based program called *TeenCope* (http://nursing.yale.edu/Centers/ECSMI/P30/grey_3.html). The program provides a fun and creative way for these teens to learn coping skills, and allows them to connect with others through a discussion board. *TeenCope* is currently under study.

In addition, new and emerging forms of social media promise to link diverse and underserved communities to available health care resources, as well as to help health care providers expand their reach.

- Scientists developed a brief educational video on issues of sexual pressure, trust, and decision-making, designed to be viewed in private on a small handheld device such as a cell phone. Young African American and Latina women who viewed the video thought it addressed important problems, and helped them be more assertive about insisting on safe sex practices with their partners. Further testing of this and related forms of health information sharing is underway.
- Twitter is a very popular form of social media in which individuals can share short messages known as “tweets.” Researchers reviewed publicly available tweets that contained information on antibiotics. While many messages described the general use and side effects of these medications, others offered information and advice which was sometimes misleading or erroneous. These findings could help in the design of communication programs or information campaigns to help persons with health concerns find accurate information and reliable sources.

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