2007

Disparity and diversity workshop

Dione Farria
Siteman Cancer Center

Brian C. Springer
Siteman Cancer Center

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Overview

- Why this course?
- Who are the diverse populations?
- Why is this issue important?
- What is PECaD’s role?
Definition of Diversity

Many distinct characteristics that patients, researchers and staff bring to our institution and its programs. These include:

- Race / ethnicity / national origin
- Gender
- Age
- Sexual orientation
- Socioeconomic background
- Physical abilities
- Religion
- Other differences
Why Is This Important?

- Variations of thinking
- Beliefs and values
- Communication styles
- Behaviors
- Social customs

Understanding and appreciating these differences helps us achieve goals in health, health care, and research.
Why This Course?

- Diversity is widely-recognized as critically important
- Lack of available courses
- Differential awareness
- Internal and external pressures
- Modeled on Necessary Elements course
- Discussion and interaction
- Overview and tools
Course Overview

- Historical perspective
- Communication issues and strategies
- Informed consent issues
- Recruitment and retention strategies
- Community based participatory research
Planning Committee

- Washington University Human Research Protection Office
- Siteman Cancer Center
- General Clinical Research Center
- Center for Clinical Studies/Volunteer for Health
- Saint Louis University School of Public Health
- NCI Cancer Information Service
- Program for the Elimination of Cancer Disparities
Diversity Is Here

- Today, almost 1 in 3 Americans identifies as a racial or ethnic minority.
- Nearly 1 in 5 school-aged children speak a language other than English at home.
- By 2010, nearly ½ of the total workforce will be comprised of women and people of color.
- By the year 2050, 1/4 of the total population will be Hispanic; ½ of the population will be people of color.

National Multicultural Institute, 2006
Diverse Populations

Racial/ethnic minorities

- African-Americans
  » 18% of catchment area
- >50% of St. Louis City
Diverse Populations

Immigrants

- St. Louis is in top 10 for refugee resettlement
- 2nd highest concentration of newly arrived refugees and immigrants to native born residents
- >27 languages in our schools
Diverse Populations

Elderly

- Represent 2/3 of cancer patients but only 20-30% of research participants (NCI)
Diverse Populations

- Low SES
  - Low income
  - Low health literacy
  - Poor education
  - No health insurance

- Rural
  - Transportation
  - Inconvenience
  - Poverty
Why Is This Important?

- Improves external validity
- Many diseases disproportionately affect minorities, elderly or low SES groups
- Different groups can have different outcomes
- NIH Revitalization Act
Barriers
Investigator-Related Barriers

- Lack of awareness
- Lack of effort
- Inadequate resources
Patient-Related Barriers

- **Distrust of Medical Community**
  - Detroit study- 81% of 91 aware of Tuskegee study, ½ would decrease willingness

- **Limited Resources**
  - Lack of reliable transportation
  - Child care
  - No insurance
  - Inflexible work schedule
  - Competing priorities
Patient-Related Barriers

- Poor Health Literacy
  - Limited understanding of clinical trials
  - Forms hard to understand

- English Language
Strategies

Special assistance
  Community Presentations
  Mass Mailings

Lay referral
  Hiring special staff
  Media
Program for the Elimination of Cancer Disparities (PECaD)
Mission

To bring state-of-the-art cancer care to the entire community
What is PECaD?

1 of 25 NCI funded Community Network Programs established to reduce cancer disparities
Key Components

- Programs
- Policy
- Participatory research
- Pipeline
- Provider education
Community Initiatives

- Mammography Outreach Patient Registry
- Radio Education Program
- Prostate cancer screenings
- Partnership with Missouri Screen for Life
- Partnership with Young Choices, Inc
Research Initiatives

- Trial Monitoring Program
- Disparity and Diversity Workshop Series
- Pilot Projects
- Community Protocol Review Committee