

Outreaching to save lives

Minority participation in clinical trials is low. There are people who are trying to change this.

By Pablo Jaime Sainz

Julius Phillips stands in front of a room full of African-American men telling them about the risks of prostate cancer.

He gives his presentation in an informal way, as if he was chatting with a group of friends.

The men seem at ease, comfortable listening to what Phillips has to say.

At the end of his talk, he invites them to participate in a clinical trial focusing on prostate cancer among African-American men.

Even if none of the men sign-up for the clinical trial on the spot, Phillips knows he has reached one of his goals: Educate the public about conditions affecting the community.

Julius Philips is a Project Coordinator for Community Outreach for the San Diego EXPORT Center, a partnership of organizations focusing on community minority health and health disparities research.

His job consists of encouraging minority groups, especially African-Americans and Latinos, to participate in clinical trials sponsored by the University of California, San Diego (UCSD).

His mission is important, because, historically, minority participants have been underrepresented in clinical trials, he said.

“In theory, what we do is go out and promote clinical trials among minorities. In reality we do much more than that: we are health educators. That’s what I consider myself,” said Phillips, who started his nursing career in the Navy. “We present the information about the condition so that the public can make informed decisions about what it is.”

Phillips' work has become so much part of the community he works in, that when there's a public event; organizations invite him to speak about health issues.

Health fairs, community clinics, other health care organizations, and street festivals, are all places where he presents information on topics such as heart disease, obesity, and cancer.

"Although it's not something tangible, I know we're making a difference," he said.

But Phillips' task is no easy one.

During the first year of the San Diego EXPORT Center outreach program, Phillips, along with another outreach worker, attended 118 events where he reached out to 4,195 people, the vast majority of them minorities.

Of the 4,195, only 245 actually signed up to participate in a clinical trial.

According to Phillips, the barriers that prevent African-American and Latinos from participating in clinical trials include time commitment and lack of information.

He said that time commitment is an issue because many clinical trials require participants to commit to 2, 3, or even up to 5 years.

"Lack of information is another issue because many people believe that researchers are going to do all sorts of experiments with you," Phillips said. "People have misconceptions about what a clinical trial is."

But the major barrier for minority participation is, believe it or not, geography, Phillips said.

"UCSD is so isolated from the people it wants to serve," he said. "Many times people don't have the transportation to go to La Jolla. Taking the bus? If getting them to participate in a clinical trial was a problem, now imagine telling them that in order to participate they also have to be on a bus for hours."

White males have the highest participation rates in clinical trials, while African-Americans and Latinos are less likely to participate. “The truth is that clinical trials results most of the time give out information pertaining only to White males, because they are generally the ones who have the most participation in clinical trials,” he said. “Clinical trials need more diversity, more minority participation in order to turn out more inclusive results.”

In an effort to encourage minority participation, almost every research grant requires scientists to include a certain number of minority participants, Phillips said.

“In the past, researchers never bothered to go out into the community. That’s starting to change,” he said. “Even if it forces [researchers] to do it, quotas are needed in order to reflect our population.”

Because of cultural and language barriers, sometimes it can be difficult for researchers to reach out to minority groups, Phillips said.

“Some researchers don’t understand cultures other than their own; others just don’t care. Many of them, though, have a fear of going out to the African-American community. They feel unease,” he said.

It’s because of this, that outreach workers reflect the communities they want to reach.

“We have the same issues. We, as health educators and outreach workers, are reducing the gaps between UCSD and the community,” said Phillips, who, together with another outreach worker, Julio Sesma, can be promoting up to 13 clinical trials at a time.

Phillips said that changing health disparities through clinical trials not only depends on the institutions doing the studies.

“Health disparities among minority populations need to change,” he said. “But everything doesn’t depend on researchers. I believe that the first step to stop these disparities starts with the

people themselves. If you have diabetes, it depends on you to start looking for ways to improve your health. Don't assume the institutions are going to go out looking for you," Phillips said. "If you never participate [in clinical trials] researchers will never know how to treat conditions affecting your community."

(Info Box)

Phillips has some advice for people considering participating in a clinical trial:

- Talk to the researcher who's doing the study. Get all the information you can about the study. Ask for details.
- Know your rights and responsibilities.

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