U.S. Blacks More Distrustful of Clinical Research

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LOS ANGELES — Older African Americans distrust clinical research significantly more than do older whites, according to results of a mail survey presented by Dr. Raegan W. Durant at the annual meeting of the Society of General Internal Medicine.

The study was designed to determine whether African Americans’ distrust of clinical research arises from attitudes toward physicians and the health care system in general, or from their relationships with individual physicians.

The investigators conducted a mail survey of 3,000 community-dwelling whites and African Americans over the age of 50 years in the greater Boston area, said Dr. Durant of Beth Israel Deaconess Medical Center, Boston. Participants answered seven previously validated questions from a distrust index that measured attitudes about clinical research. Societal distrust was defined as negative historical and cultural perceptions of physicians and clinical research in general. Interpersonal distrust was defined as five or more distrustful responses to the seven questions.

Individuals’ trust in the primary care provider (PCP) was measured with the eight-item trust subscale from the Primary Care Assessment Survey. Respondents were grouped into quartiles. Independent variables included race, gender, age, education level, type of insurance, knowledge of the Tuskegee Syphilis Experiment, and personal experiences with discrimination in health care. Bivariate and multivariate analyses examined the associations among these factors and responses to the distrust index.

The analyses included 498 whites and 329 African Americans. White participants were significantly older and better educated. African American participants were significantly more likely than whites to have experienced discrimination in health care (43% vs. 15%, respectively).

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Interpersonally, a large percentage of both whites (59%) and African Americans (49%) had participated previously in a clinical trial. African Americans were more likely than whites to believe that health care providers might use them as “guinea pigs” without permission (54% vs. 28%) or to think that physicians prescribe medications to experiment on people without permission (58% vs. 41%). There was no significant difference between whites and African Americans in the percentage that believed that their physicians had ever treated them as part of an experiment without their giving permission (2.9% vs. 1.6%, respectively). Interpersonal distrust did not differ significantly between African Americans and whites.

In a multivariate model, African Americans and respondents with the least trust in their PCPs were more likely to think that they might be used as “guinea pigs” without permission (odds ratios, 2.7 and 2.8, respectively). African American race and being in the lowest quartile of trust in one’s PCP were also associated with having concerns about experimental use of prescription medications (odds ratios, 1.9 and 1.8, respectively).

Neither familiarity with the Tuskegee Syphilis Experiment nor experience with discrimination in health care was significantly related to concerns about unwanted experimentation in multivariate models.

Because this study population was well educated overall and a large percentage had previous clinical trial experience, the results may not be representative of other populations. There may also have been some selection bias, as more whites (65%) responded to the survey than did African Americans (44%).

“This [distrust] is a real dilemma,” Dr. Durant said. “We may not ever be able to impact society.” Societal distrust in clinical research among minorities may hamper future research in many therapeutic areas.