



AMERICAN NEPHROLOGY NURSES' ASSOCIATION

ANNA'S 46TH NATIONAL SYMPOSIUM

APRIL 19-22, 2015

DISNEY'S CORONADO SPRINGS RESORT, LAKE BUENA VISTA, FLORIDA

Ascribing Meaning to Kidney Disease: A Qualitative Study of African Americans with a First Degree Relative on Hemodialysis

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The progression of chronic kidney disease (CKD) is a major contributor to the increased burden of end stage renal disease in African Americans (AA). Having a family member affected with CKD is associated with a greater likelihood of developing the disease, yet many AA have low perceived CKD risk appraisal. Although studies have examined CKD risk perceptions in AA, none explored it from the voices of AA with a relative affected by CKD. This study used an interpretive phenomenological approach to gain a deeper understanding of the lived experiences of AA adults with a first degree relative on hemodialysis and the health beliefs that influence CKD susceptibility. In-depth face-to-face interviews were conducted with 8 women and 4 men. Participants ranged in ages from 26-65 years old. Interviews were audio recorded and transcribed. Data analysis was conducted using an adapted version of Heidegger's hermeneutic analysis process that involved continuous examination of the whole and parts of data. Two patterns and six major themes emerged. Patterns were: How We Relate and Not Knowing — Now Knowing. Themes were: Communication; Comparison; Bloodline; Kidney Disease is Serious; What is Kidney Disease; and Staying Strong. Emotional closeness, lifestyle similarities and number of affected relatives influenced risk perceptions. Having an affected relative increased perceived CKD seriousness but not perceived health threat. AA adults believed their health behaviors would prevent CKD even though they had low CKD knowledge. Findings from this study provided a better understanding of CKD health beliefs and risk perceptions among AA. Education, practice and research implications include: stronger public health risk campaigns based on the health language of AA; education models that engage patients in discussions about family health history, CKD consequences, and health actions; and a clear definition of what constitute genetic risk for CKD and the relationship between genomics and personal risk appraisal.

Abstract selected for presentation at ANNA's 46th National Symposium, Lake Buena Vista, FL, 2015