

**COMMUNICATION DURING THE DISCLOSURE OF GENETIC
SUSCEPTIBILITY TO ALZHEIMER'S DISEASE: PATTERNS AND PROVIDER
FLEXIBILITY AND THEIR EFFECT ON PATIENT OUTCOMES**

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ABSTRACT

Introduction:

Patient-provider communication when disclosing predictive test results is a cornerstone of genetic counseling. Ideally, it facilitates patients' comprehension, adaptation, and decisions. Ideally it involves counselors who are flexibly attentive to patients' preferred styles and needs. However, the dynamics of these discussions are not well characterized. In this dissertation I present three related studies of communication used when disclosing the risks for developing late-onset Alzheimer's disease (AD). The first study describes three discrete patterns of patient-provider interaction within disclosure sessions and identifies factors associated with these patterns. The second study evaluates patient outcomes associated with these interaction patterns. The third study develops a definition of provider flexibility in test-result disclosure and explores associations between flexibility and patient outcomes.

Methods:

Genetic counseling sessions (n=262) in which patients were told their APOE (apolipoprotein E) genotype were recorded and coded using the Roter Interactional Analysis System (RIAS), as part of an experimental study of providing genetic risk information to unaffected offspring of AD patients. Cluster analysis was used to define discrete communication patterns. Regression models evaluated associations between identified patterns and patient outcomes (i.e. psychosocial adaptation, information recall and satisfaction) at four points during the following year and between provider flexibility (the degree of variance in a provider's use of affective and task-oriented language and patient outcomes).

Results:

Three distinct patterns were identified: A) counseling/patient-centered (25.6% of sessions), B) traditional biomedical focused (40.0%), and C) patient-driven biomedical focused (34.4%). Neither psychological measures nor risk recall differed by pattern. Patients in Pattern B sessions were more likely to recall test result information than the other patients (OR=2.07, p=0.037). Patients in Pattern A sessions tended to express greater satisfaction with provider behavior ($\beta=0.14$, p=0.054) and expectations ($\beta=0.18$, p=0.009) than the other patients. Greater provider communication flexibility was not associated with improved outcomes, although lower flexibility was associated with greater satisfaction with expectations.

Conclusions and Implications:

This study underscores the importance of patient-centered communication when discussing complicated genetic risk test results. Such communication results in improved patient satisfaction and subsequently patient behavior. Patient-centered communication is crucial to the success of patient care in the era of genomics/personalized medicine.