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Communication Predictors of Patient and Companion Satisfaction with Alzheimer's Genetic Risk Disclosure

YUE GUAN ^[b], DEBRA L. ROTER², LORI H. ERBY³, JENNIFER L. WOLFF⁴, LAURA N. GITLIN⁵, J. SCOTT ROBERTS⁶, ROBERT C. GREEN^{7,8,9,10}, and KURT D. CHRISTENSEN ^[b]^{7,8}

¹Behavioral Sciences and Health Education, Rollins School of Public Health, Emory University, Atlanta, GA, USA

²Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

³Social and Behavioral Research Branch, National Human Genome Research Institute, National Institutes of Health, Bethesda, Maryland, USA

⁴Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA ⁵Department of Community Public Health, Center for Innovative Care in Aging, School of Nursing, Johns Hopkins University, Baltimore, MD, USA

⁶Department of Health Behavior and Health Education, University of Michigan School of Public Health, Ann Arbor, MI, USA ⁷Division of Genetics, Department of Medicine, Brigham and Women's Hospital, Boston, MA, USA

⁸Department of Medicine, Harvard Medical School, Boston, MA, USA

⁹Broad Institute of MIT and Harvard, Cambridge, MA, USA

¹⁰Partners Personalized Medicine, Boston, MA, USA

The objective of this study was to identify how features of Alzheimer's disease (AD) genetic risk disclosure communication relate to patient and visit companion satisfaction. We conducted secondary analyses of 79 session recordings from the fourth REVEAL Study, a randomized-controlled trial of AD genetic risk disclosure among patients with mild cognitive impairment. Patient and companion satisfaction were ascertained from postdisclosure surveys. The Roter Interaction Analysis System (RIAS) was used to code triadic communication between the counselor, patient, and companion. High satisfaction was evident for 24% of patients (N = 19) and 48% of companions (N = 38). Multivariate logistic regressions showed that high patient satisfaction was associated with patients' expression of emotions (OR = 1.1, 95% CI: 1.0–1.1) and companions' questions about psychosocial and lifestyle topics (OR = 1.8, 95% CI: 1.1–2.8). High companion satisfaction was positively related to the RIAS overall patient-centeredness score for the session (OR = 4.0, 95% CI: 1.0–15.6) (all *p*-values <0.05). Communication predictors of patient and companion satisfaction. The study results support the growing literature and policy attention directed toward delivering family-centered care.

More than 5 million Americans are currently affected by Alzheimer's disease (AD) and that number is expected to triple by 2050 (Alzheimer's Association, 2017). Approaches to AD care are increasingly focused on identifying individuals at heightened risk for the disease and providing risk estimates based on evidence of cognitive impairment, family history, genetic information, and biomarkers (e.g., amyloid neuroimaging results, genetic variants) (Sperling et al., 2011). *APOE* is a susceptibility polymorphism for late-onset AD, which is the most common form of AD and the most common dementia in the aging population. *APOE* has three alleles: $\epsilon 2$, $\epsilon 3$, and $\epsilon 4$, and each person has two alleles. Hundreds of studies have demonstrated the well-documented association of *APOE* genotype with risk of AD in which 1 copy of the *APOE* $\epsilon 4$ allele

increases the odds of developing disease by \sim 3-fold and 2 copies increase the odds by \sim 12–15-fold (Bertram, McQueen, Mullin, Blacker, & Tanzi, 2007; Farrer et al., 1997). Approximately, a quarter of the general population in the United States carries the risk-conferring *APOE* ε 4 allele (Raber, Huang, & Ashford, 2004). For many older adults, disease risk—whether for AD or other medical disorders—is communicated in both clinical and research settings. However, the abstract and complex nature of probabilistic information conveyed during AD risk disclosure discussions can be cognitively and emotionally challenging for anyone, and especially so for patients with impaired memory (Roberts, Christensen, & Green, 2011).

Older patients are frequently accompanied to medical visits by family members or friends and companions have been shown to play an important and largely positive role in facilitating physician-patient communication (Street & Gordon, 2008; Wolff & Roter, 2008, 2011). Estimates from the Medicare Current Beneficiary Survey showed that 40% of

Address correspondence to:Yue Guan, Behavioral Sciences and Health Education, Rollins School of Public Health, Emory University, 1518 Clifton Road NE, GCR 534, Atlanta, Georgia, 30322, yue.guan@emory.edu

older adults are routinely accompanied to their medical visits and that they report higher satisfaction with physician information-giving and rapport-building when accompanied by a companion (Wolff & Roter, 2011). Older adults also tend to be more satisfied when accompanied by more engaged family companions.

A similar process appears evident in medical visits of patients with AD. In their analysis of 23 routine AD primary care visits, Schmidt and colleagues found that cognitive impairment was associated with diminished patient contribution but greater family member participation in visit dialog. Moreover, the more verbally active the family member was, the more satisfied patients were with the visit (Schmidt, Lingler, & Schulz, 2009).

The current study makes a contribution to this literature by analyzing audio recordings and survey data of 79 AD risk disclosure sessions with patients who have diagnoses of mild cognitive impairment (MCI) and a visit companion. The session communication was coded and examined in relation to both patient and companion postsession satisfaction. Based on the previous research on physician-patient communication broadly, and specifically in regard to older adults as noted above (Schmidt et al., 2009; Street & Gordon, 2008, 2011; Wolff & Roter, 2008, 2011), we hypothesized that a more patient-centered communication style would receive higher satisfaction ratings from both patients and companions. We also hypothesized that companions' communication behaviors would be associated with patient satisfaction.

Methods

Study Design and Data Collection

Analyses were based on audio recordings of AD risk disclosure sessions collected as part of the fourth independent trial of the REVEAL Study. This randomized clinical trial was designed to evaluate the impact of AD risk communication, conveyed with and without results of genotype (identification of the presence of $\varepsilon 4$ allele in APOE gene), to patients with MCI diagnoses and their visit companions. Patients were eligible for recruitment if they had clinical diagnoses of amnestic-MCI, defined at the time of the study as a clinical state where individuals are memory impaired but are functionally intact and do not meet clinical criteria for dementia (Petersen et al., 2001). The specific criteria are (1) a memory complaint, corroborated by an informant; (2) abnormal memory function, as documented by delayed recall on the Logical Memory II subtest of the Wechsler Memory Scale-Revised; (3) adequate general cognitive function (Mini-Mental State Examination [MMSE] score \geq 20); and (4) no diagnosis of AD and no or minimal impairment in activities of daily living. Study design, recruitment, and data collection of the fourth REVEAL Study have been described in detail elsewhere (Guan et al., 2017). The sample for the current study included 79 AD risk disclosure sessions conducted by 3 genetic counselors; patients were randomly assigned at a 2:1 ratio to either an APOE genotype disclosure group (N = 54) or APOE genotype nondisclosure group (N = 25). Patients assigned to the genotype nondisclosure

group received 3-year risk estimates for conversion to AD based on their age and the diagnosis of MCI. Patients in the genotype disclosure group were given risk estimates based on the same factors in conjunction with their *APOE* genotype. MCI patients with one or two $\varepsilon 4$ alleles are at increased risk of developing AD (Petersen et al., 2005). The current study was reviewed and approved by the Johns Hopkins University Bloomberg School of Public Health Institutional Review Board, as well as institutional review boards at each study site.

Patient and Companion Satisfaction with Provider Communication

The primary study outcomes were patient and companion satisfaction with the AD risk disclosure session administered immediately after sessions ended. The 10-item satisfaction questionnaire was developed by Roter and colleagues in previous genetic counseling studies (Roter, Ellington, Erby, Larson, & Dudley, 2006) and adapted to AD risk disclosure (e.g., "your clinician was able to explain the Alzheimer's disease risk estimate and its meaning in a way that you could understand" and "your clinician acted supportive and gave you the feeling that he/she was a partner with you"). Patients and companions were asked to rate their satisfaction about the communication process using a Likert scale of "strongly disagree = 1" to "strongly agree = 5." Because satisfaction scores were negatively skewed, we created a dichotomous variable "high satisfaction" to compare the highest ranking category (highly satisfied; total satisfaction score = 50) with all other responses for both patients and companions. The scales demonstrated strong internal consistency (Cronbach's alpha = 0.88 and 0.90 for patient and companion satisfaction scales, respectively).

Roter Interaction Analysis System

Audio recordings of risk disclosure dialog were coded using Roter Interaction Analysis System (RIAS), a widely used quantitative coding system for medical dialog that has demonstrated high reliability and predictive validity for patient satisfaction, utilization, and adherence (Cooper et al., 2011; Mead & Bower, 2000; Roter & Larson, 2002). The unit of analysis is a complete thought communicated as a single word, simple sentence, or a clause in a complex sentence. Statements are coded directly from recordings and assigned to 1 of 37 mutually exclusive code categories. Examples of the RIAS composite codes are published (Guan et al., 2017) and included in the supplementary materials.

Three measures of communication processes were also examined: (1) session length in minutes; (2) the sum of each speaker's (genetic counselor, patient, and visit companion) statements as an indication of total dialog; and (3) patientcenteredness communication, which was operationalized as the ratio of psychosocial and emotional to instrumental exchange. In the current study, the numerator of this latter measure is the sum of patient and companion psychosocial and lifestyle disclosure, questions, emotional statements and active engagement statements, and genetic counselor psychosocial and lifestyle questions, information and counseling and activation/facilitation statements. The denominator consists of genetic counselors' medical questions and orientations, as well as patient, companion, and genetic counselors' statements relating to medical information. Value greater than 1 indicates a more patient-centered session. A random 10% sample of audiotapes (n = 8) was selected for double coding to establish interrater reliability. Pearson correlation coefficients averaged 0.83 across genetic counselor categories and 0.93 for patient categories, indicating high levels of interrater reliability.

Baseline Measures

Patient and companion characteristics, including age, gender, race, level of education, and caregiver relationship to patient, were assessed by self-report. For the purposes of this study, a family history of AD/dementia was defined as self-report of the number of relatives diagnosed with AD or dementia. General cognitive function of the patient was assessed by the MMSE (Folstein, Folstein, & McHugh, 1975) with possible scores ranging from 0 to 30. A score greater than or equal to 24 typically indicates normal general cognitive function, while 20–23 suggests mild memory problems. *APOE* genotype was dichotomized to the presence or absence of at least one copy of the *APOE* $\varepsilon 4$ allele, as MCI patients with an $\varepsilon 4$ allele are at increased risk of converting to AD compared to patients without an *APOE* $\varepsilon 4$ allele.

Data Analyses

The primary outcomes are high patient and companion satisfaction. The likelihood-ratio tests used to estimate the influence of patient clustering within genetic counselors were not significant; therefore, logistic regressions were used to determine the contribution of each speaker's communication to patient and companion satisfaction (in separate models). To identify potential confounders, adjusted multivariate regression models were generated including patient and companion factors (i.e., patient age, gender, educational level, patient-companion relationship, visit length, MMSE score, 3-year AD risk, and *APOE* genotype). Patient and companion characteristics found to be statistically significantly (p < 0.05) related to either communication behaviors or satisfaction included patient and companion gender, years of education, and patient 3-year AD risk. These variables were subsequently included as control variables in the final multivariate logistic regression models. Log like-lihood chi-squared tests were used to compare the fit of adjusted models against a model that included only the intercept. We asserted statistical significance only in instances where both the overall model and the predictor of interest were significant at p < 0.05. In all analyses, two-tailed tests and *p*-values <0.05 were used to draw conclusions regarding statistical significance. Data were analyzed using STATA Version 12.0 (STATA Corp, College Station, Texas).

Results

Sample Characteristics

Sample characteristics are presented in Table 1. Three genetic counselors participated in this study, representing three study sites (Boston, Philadelphia, and Ann Arbor); all the genetic counselors were female Caucasians. The number of patients seen by each genetic counselor was 4, 35, and 40, respectively.

The 79 patients comprising our study sample averaged 76 years of age, with the majority of patients being male (56%) and Caucasian (96%). The mean level of education among patients was 16 years. More than half of the patients (N = 49, 62%) have at least one relative diagnosed with AD or dementia. The majority of patients (86%) showed normal cognitive function based on MMSE scores (MMSE \geq 24), and 11 patients scored in the range of MCI (MMSE 20-23). The average 3-year risk estimates of progressing to AD provided to all patients were 37% and ranged from 8% to 57%. Of the 54 patients in the genotype disclosure group, 57% (N = 31) carried at least one $\varepsilon 4$ allele; 10 (32%) had the $\varepsilon 4/\varepsilon 4$ genotype, and 21 (68%) had the $\varepsilon 3/\varepsilon 4$ genotype. Among those who did not have the $\varepsilon 4$ allele (43%, N = 23), 20 had the $\varepsilon 3/\varepsilon 3$ genotype and 3 had the $\varepsilon 2/\varepsilon 3$ genotype. The $\varepsilon 2/\varepsilon 4$ and $\varepsilon 2/\varepsilon 2$ genotypes were not observed in our study.

Table 1. Sample characteristics of patients and companions

	Patient $(N = 79)$	Companion $(N = 79)$
Age, mean (SD), range	75.7 (7.4), 57–89	68.0 (13.3), 22–93
Female, %	35 (44.3)	56 (70.5)
Race, %		
African-American	3 (3.8)	3 (3.8)
White	76 (96.2)	76 (96.2)
Education years, mean (SD)	16.2 (2.9)	16.2 (2.6)
MMSE score, mean (SD)	26.9 (2.1)	
Family history of AD/dementia, %	49 (62.0)	
3-year AD risk, mean (SD)	37.3 (13.7)	
Relationship to patient, %		
Spouse		51 (64.6)
Child		19 (24.1)
Other (friend, other relative)		9 (11.3)

Per study requirement, all patients were accompanied to the session by a family member or friend. Visit companions (N = 79) were on average 68 years of age, predominantly female (70%), and well-educated with an average 16 years of education. They were predominantly spouses (65%) or adult children (24%) with the minority described as "other," including siblings (1%), significant others (2%), and close friends (8%).

Patient and Companion Satisfaction on Interpersonal Communication

Patients and companions in this study were satisfied with the communication of the AD risk disclosure; the average satisfaction scores were 46 (SD = 4, range: 36–50) and 47 (SD = 4, range: 30–50) out of 50 for patients and companions, respectively. In particular, 24% of patients (N = 19) and 48% of companions (N = 38) scored as being highly satisfied with the communication process. The simple observed agreement between patient and companion on high satisfaction was 53%; however, the kappa (0.04, SE = 0.10) indicated only poor to slight agreement when accounting for chance (Landis & Koch, 1977).

Communication Behaviors Predicting Patient and Companion Satisfaction

Table 2 displays the frequency of statements made by genetic counselors, patients, and companions across the RIAS categories and summarizes the odds ratios from logistic regression models (both unadjusted and adjusted for covariates) to identify communication behaviors that are related to patient and companion satisfaction. The adjusted multivariate logistic regression models include patient and companion gender, years of education, and patient 3-year AD risk.

In unadjusted analyses, patients were more often highly satisfied with the AD risk communication when genetic counselors made more positive statements (OR = 1.02, p = 0.04) and when companions asked more psychosocial questions (OR = 1.60, p = 0.03). After adjusting for the covariates, companions' psychosocial question-asking continued to have significant positive association with patient satisfaction (OR = 1.75, p = 0.02); and patient expression of emotion emerged as a significant positive predictor of their high satisfaction (OR = 1.06, p = 0.04).

Companions were less likely to be highly satisfied the more facilitation statements (OR = 0.92, p = 0.046) they made in unadjusted models. In the final adjusted models, companions had almost four times the likelihood of being highly satisfied with the AD risk communication process in sessions with a high patient-centered communication ratio (OR = 3.97, p = 0.048).

Discussion

In general, our findings demonstrate that indicators of patientcentered communication were associated with both patient and companion satisfaction with AD risk disclosure sessions; psychosocially focused questions asked by companions and expression of emotion by patients were associated with greater patient satisfaction, and the summary measure of visit patient-centeredness was predictive of greater companion satisfaction.

We found that patients' active participation in the AD risk communication process positively influenced their satisfaction; when patients expressed emotion (e.g., expressions of reassurance, concern, empathy and legitimization), they were more likely to score as highly satisfied. Prior research has shown that active patient involvement in medical encounters, including emotional and psychosocial disclosure, has been associated with greater satisfaction, as well as other desirable outcomes including increased adherence and positive treatment outcomes (Tennstedt, 2000). The interactions that occur when these types of disclosures are made can convey therapeutic value, enhance trust, and strengthen the therapeutic alliance between patients and health-care providers (Kennedy-Moore, 2001).

Genetic counselors' communication did not play a significant role in affecting patient satisfaction, a relationship that has been seen in other studies (Roter et al., 2006). We speculate that feelings of vulnerability associated with mild memory loss may have led patients to depend more on the visit companions during communication between themselves and the counselor, thereby diminishing counselor influence. In our study, patient satisfaction may have been less a function of counselor communication than the cues patients took from their companions' exchanges with the counselor, as suggested by the positive relationship between the number of psychosocial and lifestyle questions that visit companions asked and patient satisfaction. It is also possible that there was simply not enough variation the way counselors communicated results to predict patient satisfaction.

Our findings confirm the important role of the companion's facilitation of visit communication in enhancing patient satisfaction. This finding builds upon prior research that has identified a variety of communication behaviors performed by companions during medical visits that are associated with patient report of satisfaction with care, including asking questions (Wolff & Roter, 2008). Observational studies and metaanalyses have provided compelling evidence that the presence of a companion is beneficial to the care process: physicians typically provide more information when companions are present than when patients are unaccompanied (Prohaska, 1996), and the presence of a companion increases patient information recall (Jansen et al., 2010), participation in medical decision-making (Clayman, Roter, Wissow, & Bandeen-Roche, 2005), adherence to medical treatments (DiMatteo, 2004), as well as both patient and physician understanding of one another (Schilling et al., 2002). The presence of companions may be particularly important when the patient has memory impairments, given the challenges associated with processing complex health information.

We found that the more patient-centered the session was, the greater the likelihood that the companion would be more satisfied with session communication. This result extends previous findings that a higher frequency of patient-centered

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$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	1.0		.00 - 1.02	1.01	1.00 - 1.02	1.00	0.99 - 1.01	1.00	0.99 - 1.02
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$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	1.0		.00 - 1.10	1.05	1.00 - 1.10	1.02	0.98 - 1.07	1.03	0.98 - 1.08
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$\begin{array}{cccccccccccccccccccccccccccccccccccc$	1.0		00-1.11	1.06^{*}	1.00 - 1.13	1.03	0.98 - 1.09	1.05	0.99 - 1.11
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	0.6		.35-1.09	0.53	0.28 - 1.03	0.87	0.67 - 1.14	0.95	0.71 - 1.27
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nts 2.1 1.02 0.84–1.25 1.05	1.0	-	.84–1.25	1.05	0.86 - 1.29	06.0	0.75 - 1.09	0.95	0.79 - 1.15

Table 2. Patient and companion satisfaction with AD risk disclosure

*p < 0.05. Adjusted odds ratios control for patient and companion gender, years of education and patient 3-year AD risk. p-Values for the overall fit of adjusted models ranged from 0.07 to 0.48.

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behaviors is associated with greater patient satisfaction (Beck, Daughtridge, & Sloane, 2002; Roter DL, 2006; Zachariae et al., 2003). The discrepancies in satisfaction between patients and companions might be due to their different expectations for the session. Studies have shown that patients and companions almost never show perfect agreement and they are less likely to agree about subjective issues, such as satisfaction with care (Castle, 2005).

A growing literature has shown that physicians and other health professionals can be taught to understand and implement a variety of patient-centered techniques, including demonstrating empathy, asking for patient understanding, and conveying reassurance (LA et al., 2011). When working with patients with dementia, communication skills training is particularly important for health professionals and family caregivers (Doyle, 2009). Systematic reviews in dementia care have demonstrated significant positive effects of communication skills training on professional and family caregivers' communication skills, competencies, and knowledge (Eggenberger, Heimerl, & Bennett, 2013; Wolff et al., 2014). There is far less literature describing effective strategies for patients with MCI. Our findings provide additional direction and rationale to develop tailored health communication programs for not only physicians and family caregivers but also for patients with mild cognitive deficits, as well.

Some caution is necessary in interpreting our results given the exploratory nature of this study, and the associations found in this descriptive study do not necessarily indicate a causal relation. Satisfaction is a complex construct that may be influenced by unmeasured factors external to the disclosure session communication, and the lack of variance in our satisfaction measure may have limited our ability to detect associations. There is also the possibility that participants may have felt pressure to overstate their satisfaction immediately after the disclosure session. The nonsignificant results could also be due to the small sample size. Furthermore, patients enrolled in the REVEAL trial may differ from a broader population of older adults with mild memory problems considering their high levels of education and motivations to seek genetic testing. Our findings may not apply to other AD risk disclosure sessions, due to the structured nature of the REVEAL protocol and the limited number of genetic counselors that took part in the study.

The positive satisfaction outcomes associated with elements of patient-centered communication support the growing literature and policy attention directed toward delivering family-centered care (Health & Services, 2012). We also acknowledge the influence of companions in achieving greater patient satisfaction. With the presence and increasing severity of cognitive deficits, the active involvement of companions is critical to facilitate older adults to function successfully in a complex health-care environment. Findings of this study also highlight opportunities for health-care providers, patients, and visit companions to increase effective interactions in AD genetic risk disclosure settings, which may ultimately lead to improved medical care quality and better patient outcomes.

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Additional members of the REVEAL Study Group are Deborah Blacker, Massachusetts General Hospital/Harvard Medical School and Harvard School of Public Health, Boston, Massachusetts; Melissa Butson, Case Western Reserve University, Cleveland, Ohio; Clara Chen, Boston University School of Public Health, Boston, Massachusetts; Robert Cook-Deegan, Sanford School of Public Policy, Durham, North Carolina; Elana Cox, Weill Cornell Medical College, New York, New York; L. Adrienne Cupples, Boston University School of Public Health, Boston, Massachusetts; Jessica Davis, Weill Cornell Medical College, New York, New York; Lindsay Farrer, Boston University School of Medicine and Boston University School of Public Health. Boston. Massachusetts; Grace-Ann Fasaye, Walter Reed National Military Medical Center, Bethesda, Maryland; Patrick Griffith, Morehouse School of Medicine, Atlanta, Georgia; Kristin Harkins, Perelman School of Medicine, Philadelphia, Pennsylvania; Susan Hiraki, GeneDX, Gaithersburg, Maryland; Megan Johnson. Howard University, Washington, DC; Stephanie Johnson, Howard University, Washington, DC; Jason Karlawish, Perelman School of Medicine, Philadelphia, Pennsylvania; Denise Brigham and Women's Hospital, Boston, Perry, Massachusetts; Lan Le, University of Michigan School of Public Health, Ann Arbor, Michigan; Elana Levison, Division of Genetics, New York Presbyterian Hospital, New York, New York; Natalie Bartnik, University of Michigan School of Public Health, Ann Arbor, Michigan); Erin Linnenbringer, Washington University School of Medicine, St. Louis, Missouri; Elisabeth McCarty Wood, Perelman School of Medicine, Philadelphia, Pennsylvania; Thomas Obisesan, Howard University Hospital, Washington, DC; Stephen Post, Stony Brook University, Stony Brook, New York; Kimberly Quaid, Indiana University School of Medicine, Indianapolis, Indiana; Lisa Ravdin, Weill Cornell Medical College, New York, New York; Norman Relkin, Weill Medical College of Cornell University, New York, New York; Charmaine Royal, Duke University, Durham, North Carolina; Robert Stern, Boston University School of Medicine, Boston, Massachusetts; A. Dessa Sadovnick, University of British Columbia, Vancouver, British Columbia; Susan Sami, Case Western Reserve University, Cleveland, Ohio; Pamela Sankar. Perelman School of Medicine, Philadelphia, Pennsylvania; Wendy Uhlmann, University of Michigan Medical School, Ann Arbor, Michigan: Leo Waterston, Brigham and Women's Hospital, Boston, Massachusetts: Peter Whitehouse, Case Western Reserve University, Cleveland, Ohio; and Lori Wright, Medical College of Georgia, Athens, Georgia.

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Conflict of Interest

Debra Roter is the author of the Roter Interaction Analysis System (RIAS) and holds the copyright for the system. Johns Hopkins University also has rights to some enhancements of the system. Neither Debra Roter nor Johns Hopkins collects royalties for use of the system in research as is the case for the current study. Debra Roter is an owner of RIASWorks LLC, a company that provides RIAS coding services for nonuniversity projects and it is possible that RIASWorks would benefit indirectly from dissemination of the current research. Robert Green reports personal fees from Illumina, Helix, GenePeeks, Veritas, and Ohana and is a cofounder with equity in Genome Medical. There are no other conflicts of interest.

ORCID

Yue Guan b http://orcid.org/0000-0001-6377-4626 Kurt D. Christensen b http://orcid.org/0000-0003-4068-776X

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