Communication Study

Distinct communication patterns during genetic counseling for late-onset Alzheimer's risk assessment ☆

Barbara Lerner [a,*], J. Scott Roberts [b], Michael Shwartz [c], Debra L. Roter [d], Robert C. Green [e], Jack A. Clark [f]

[a] VA Boston Healthcare System, Boston, USA
[b] University of Michigan School of Public Health, Ann Arbor, USA
[c] Boston University School of Management, Boston, USA
[d] Johns Hopkins Bloomberg School of Public Health, Baltimore, USA
[e] Brigham and Women's Hospital and Harvard Medical School, Boston, USA
[f] Edith Nourse Rogers Memorial Veterans Hospital, Bedford, USA

ARTICLE INFO

ABSTRACT

Objective: To identify and characterize patient–provider communication patterns during disclosure of Alzheimer's disease genetic susceptibility test results and to assess whether these patterns reflect differing models of genetic counseling.

Methods: 262 genetic counseling session audio-recordings were coded using the Roter Interactional Analysis System. Cluster analysis was used to distinguish communication patterns. Bivariate analyses were used to identify characteristics associated with the patterns.

Results: Three patterns were identified: Biomedical-Provider-Teaching (40%), Biomedical-Patient-Driven (34.4%), and Psychosocial-Patient-Centered (26%). Psychosocial-Patient-Centered and Biomedical-Provider-Teaching sessions included more female participants while the Biomedical-Patient-Driven sessions included more male participants ($p = 0.04$).

Conclusion: Communication patterns observed reflected the teaching model primarily, with genetic counseling models less frequently used. The emphasis on biomedical communication may potentially be at the expense of more patient-centered approaches.

Practice implications: To deliver more patient-centered care, providers may need to better balance the ratio of verbal exchange with their patients, as well as their educational and psychosocial discussions. The delineation of these patterns provides insights into the genetic counseling process that can be used to improve the delivery of genetic counseling care. These results can also be used in future research designed to study the association between patient-centered genetic counseling communication and improved patient outcomes.

Published by Elsevier Ireland Ltd.

1. Introduction

Recent advances in genetic and genomic testing are leading to a proliferation of genetic risk information for common adult-onset diseases such as cardiovascular disease, type 2 diabetes and late-onset Alzheimer's disease [1]. The subsequent increase in clinical testing for conditions with limited treatment or prevention options, although controversial, is focusing greater attention on how to meet patients' medical, psychosocial, and decision-making needs when disclosing the test results during genetic counseling encounters. The actual genetic counseling communication process itself remains poorly characterized [2].

Historically, two models of genetic counseling communication have been recommended: the *teaching and counseling* models [3]. The teaching model focuses on medical and technical aspects of assessing genetic risk, is heavily didactic, and the provider serves as authoritative educator [4]. The counseling model incorporates more psychosocial discussion [3], with a focus on the patient's needs, perspective, and experiences. This model supports patient participation and the development of a patient–provider relationship; there is little emphasis on teaching or informing. Each model has been criticized as insufficient to meet patients' needs. A third, synthesizing *psycho-educational model* that combines elements of both has been promoted as more patient-centered [2].

Experimental data examining the genetic counseling models are limited [5]. Observational studies of communication processes indicate that counselors most frequently employ practices corresponding to the teaching model [6–9]. Many genetic counseling programs for predisposition testing have been structured around a two-session process: pre-test education followed by test results disclosure. Providing an appropriate balance of teaching and counseling is important during the initial session, as well as during the disclosure session, when test results could indicate risk of disease and of transmission to offspring. While examination of disclosure sessions has been suggested [7], it has not been the specific focus of a study until now.

Several genetic counseling studies have used the Roter Interactional Analysis System (RIAS) to describe patient–provider communication during the initial counseling session [6,7,10]. RIAS provides a useful method for profiling communication attributes, allowing better characterization of interaction through identification of multidimensional patterns. It highlights elements of patient-centered communication intrinsic to genetic counseling. Using RIAS codes and cluster analysis, Ellington et al. identified four communication patterns during pre-test breast cancer counseling sessions [7]. Two represented permutations of the counseling model and two reflected the teaching model emphasizing biomedical information. Roter et al. identified similar patterns in the prenatal and hereditary breast cancer settings [6]. The majority of these sessions were categorized into one of two teaching patterns. The remainder exhibited two variants of the counseling model, both correlated with higher levels of client satisfaction.

Aside from hereditary cancer, little is known about the communication exchange during genetic counseling for adult-onset conditions with a genetic predisposition. The interest in genetic counseling for these conditions is rapidly increasing. Therefore, this study examines the genetic counseling communication process in the context of an Alzheimer's disease (AD) genetic test result disclosure session.

AD, the most common form of dementia in adults over age 65 [11], and the prevalence is expected to triple by 2050 to 13.8 million people [12]. It serves as a useful model for exploring genetic counseling communication regarding adult-onset for which no preventive medical interventions are currently available. The ε4 allele in the apolipoprotein E (APOE) gene is associated with up to a 57% lifetime risk of developing AD (depending on the number of ε4 alleles the individual possesses), compared to a 10–15% risk for the general population [13,14]. The ε4 allele occurs with a frequency of about 25% in the U.S. population [15,16]. APOE testing is not typically part of medical care for AD, due to limitations in both the testing and treatment's predictive value options. However, a series of randomized clinical trials, the Risk Evaluation and Education for Alzheimer's disease (REVEAL) Study, has evaluated the safety, efficacy, and psychosocial impact of different methods of providing genetic-based AD risk assessments to first-degree relatives of AD patients [17,18]. This study used data from the second REVEAL trial (REVEAL II). Our goal was to identify whether distinct patterns of communication existed and to what extent the three conceptual models of genetic counseling (i.e. teaching, counseling, and psycho-educational) were represented.

2. Methods

2.1. Study design

The purpose of REVEAL II was to compare the effect of providing APOE genetic risk assessment using an extended "initial" genetic counseling session vs. a briefer educational process [17,19,20].

Details of the parent clinical trial methodology are described in detail elsewhere and briefly summarized here.

Participants were randomly assigned to one of the three study arms. Participants in the *extended* arm met with a genetic counselor for an in-depth group educational session and a private follow-up meeting to discuss remaining questions or concerns prior to determining whether to pursue genotype testing. If testing was conducted, results were disclosed by a genetic counselor. Those assigned to the *condensed* arm received an educational brochure in the mail instead of attending an educational session, and then could meet with a genetic counselor to discuss any questions or concerns before testing. Participants in the *condensed* arm who opted for testing were further randomized to meet with either a genetic counselor or non-genetics physician (e.g., neurology, geriatrics) to receive their test results and personal risk assessment.

2.2. Participants

Individuals with first-degree relatives affected by AD were eligible. Subjects were cognitively intact (confirmed by brief neuropsychological screening) and at least 18 years old. Most were self-referred, having heard about REVEAL through the Internet, community outreach events, word-of-mouth, through other AD research studies, or were recruited through research registries at the study sites.

Of the 356 participants who completed initial telephone interviews, 343 underwent randomization, 12 were screened out, 8 were excluded, 31 were lost to follow up and 20 declined to continue prior to the disclosure session, as depicted in Fig. 1. Of the remaining 276 participants, 262 (94.9%) agreed to have their disclosure session audio-recorded, remained in the study through the six-week post-disclosure data collection period, and thus comprised the sample for the current study.

2.3. Measures

Demographic characteristics including age, gender, race, and education level were assessed by self-report.

2.3.1. Psychological well-being

During the initial recruitment interview, depression and anxiety were measured using a 20-question Center for Epidemiologic Studies Depression Scale (CES-D) [21] and 21-question Beck Anxiety Inventory (BAI) [22]. Scores on the CES-D range from 0 to 60; scores ≥16 indicate clinical depression. BAI scores range from 0 to 63, with higher scores indicating greater anxiety.

For REVEAL II, informed consent was obtained from all human subjects and institutional review boards at each of the four participating sites: Boston University, Weill Medical College of Cornell University, Case Western Reserve University, and Howard University. Boston University and the University of Michigan institutional review boards approved the secondary data analysis presented here. All patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the study.

2.3.2. Patient–provider communication

A set of 37 mutually exclusive, previously derived, RIAS codes were assigned to the smallest meaningful unit of a complete thought (i.e., utterance) [6] These codes capture the socio-emotional and task-focused elements of the medical interaction. The frequencies of the providers' and participants' codes were calculated separately. Then, as part of the RIAS coding process, the conceptually similar codes were combined into 10 previously established and validated composite codes to measure the