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Communication Study

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

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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.

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].

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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 $\geq$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

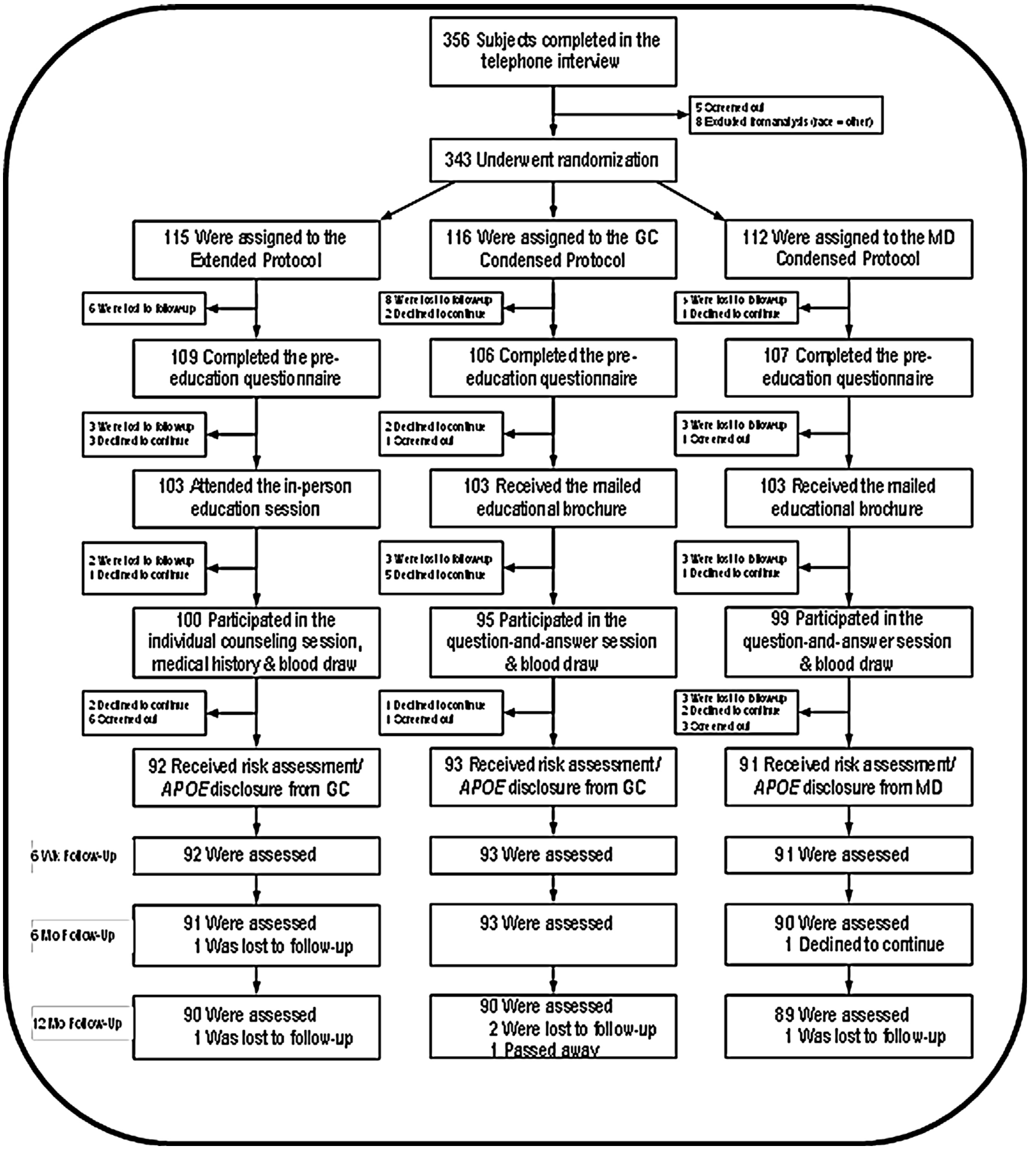

Fig. 1. REVEAL II enrollment and participation flowchart [47].

communication between the participant and provider during the disclosure session (see Appendix A) [23,24]. These composite codes were applied separately to provider and participant talk to analyze their respective contributions to the communication (shown in Table 2) [6]. Recordings were coded by experienced RIAS coders under the supervision of Roter. Intercoder reliability was based on a 10% random sample of recordings ($n = 25$) drawn throughout the coding period for blind double code. Average reliability, using Pearson Correlation Coefficients for categories with a frequency of at least two occurrences per session, was 0.77 across provider categories and 0.88 for patient categories.

2.3.3. *Patient-centered measures*

We focused on the RIAS composite codes that are conceptually associated with Mead and Bower's framework for patient-centeredness [25]. This framework incorporates the concepts of the bio-psychosocial perspective, sharing of power and responsibility between the patient and provider, and the development of a therapeutic alliance in which both parties develop common goals and a personal bond. Therefore, four provider composite codes (biomedical information-giving, psychosocial information-asking, facilitation and partnership building, and positive talk) and five patient composite codes (biomedical information-asking and information-giving, psychosocial information-giving, facilitation and partnership building, and emotional talk) were used as variables in the cluster analysis described below. The remaining composite codes either did not contribute to parsimonious dimensions of patient-centeredness or occurred with very low frequencies. A summary variable was calculated to reflect patient-centeredness consistent with the theoretical conceptualization presented in by organizations such as the National Cancer Institute [26]. The patient-centered composite code is the result of several provider and patient composite codes divided by others. The specific formula is shown in Appendix A. It has been used in previous studies, demonstrating concurrent validity and has predicted patient outcomes [25,27].

2.3.4. *Standardization of RIAS codes*

The number of codes counted per session is a function of the session's length. To account for variation in session length, the proportion of each composite code was calculated by dividing its frequency by the frequency of all the composite codes expressed by an individual. The composite code proportions were then standardized (Appendix A). The use of standardized variables facilitates the detection of meaningful contributions made to the clusters by low-frequency but important expressed thoughts (e.g. provider psychosocial information-giving) [7].

2.4. Data analysis

We used a hierarchical cluster analysis, Ward's method, and squared Euclidian distances to identify clusters with discrete patterns of participant-provider communication. The final cluster solution was determined by (1) the number of cases distributed among clusters so that each cluster had enough cases for comparisons, (2) the explanatory power (R^2) of possible cluster solutions, and (3) an ANOVA with a Bonferroni post hoc test to detect significant differences among the clusters' RIAS composite mean Z-scores.

Chi square tests and ANOVA were used to evaluate participant (i.e. age, gender, race psychosocial well-being, education, and APOE status) and study differences (i.e. provider type, protocol arm and study site) by cluster assignment. SPSS 18.0 was used to conduct all statistical analyses [28].

Because individuals with two ε4 alleles have a greater risk of developing AD than those with only one allele, it is possible that genetic status could influence the nature of disclosure session discussions. There were too few individuals with two ε4 alleles to compare to the other cases in a sensitivity analysis. Therefore, we only conducted a sensitivity analysis comparing participants with one ε4 allele to those with no ε4 alleles.

3. Results

3.1. Demographics and session characteristics

The participants differed along several dimensions (Table 1) They ranged in age from 33 to 86 years (mean = 58.25, sd = 10.4), and had a mean of about 16 years of education (sd = 2.5). Almost 70% were female; 17.6% were African-American and 80.1% were Caucasian. Average depression and anxiety scores were low: mean CES-D was 3.33 (sd = 4.04), and BAI was 5.52 (sd = 4.98). Eleven participants had two ε4 alleles (4.2%), 34.7% had one ε4 allele, and 61.1% had none.

The study included five female genetic counselors and four male physicians. The genetic counselors saw on average 38.8 participants each (range 20–54). The physicians saw an average of 20.8 participants each (range 12–26). Disclosure session length varied between 2.1 and 55.1 min, with a mean of 15.5 min (sd = 9.3), 50% were less than 13 min, and 75% less than 20 min. The genetic counselors' mean session length was 17.1 (sd = 9.7, range 2.1–55.1) min. The mean physician session length was 12.0 (sd = 7.0, range 4.0–42.6) min. The difference in session length between the provider types was statistically significant ($p < 0.001$).

Table 1
Session and participant characteristics ($n = 262$).

Characteristics	Mean (sd)
Participant age (years)	58.25 (10.4) Min: 33, Max: 86, Median: 57
Participant education (years)	16.16 (2.5) Min: 3, Max: 20, Median: 16
Session length (min)	15.5 (9.25) Min: 2.1, Max: 55.1, Median: 12.75
Psycho-social well-being	
CES-D[a] (depression) (score > 16 = clinical depression)	3.33 (4.04) Min: 0, Max: 24, Median: 2
BAI[b] (anxiety)	5.52 (4.98) Min: 0, Max: 26, Median: 4
Characteristics	**Frequency (%)**
Gender	
Female	183 (69.8)
Male	79 (30.2)
Race	
African-American	46 (17.6)
Caucasian	212 (80.9)
Others	4 (1.5)
APOE test results	
Two ε4 alleles	11 (4.2)
One ε4 allele	91 (34.7)
No ε4 allele	160 (61.1)
Provider type conducting session	
Physician	83 (31.7)
Genetic counselor	179 (68.3)

[a] Scores on the Center for Epidemiological Studies Depression Scale (CES-D) range from 0 to 60, with higher scores indicating greater depression. A score of 16 or higher indicates clinical depression.

[b] Scores on the Beck Anxiety Inventory (BAI) range from 0 to 63, with higher scores indicating greater anxiety.

3.2. Communication content

Table 2 shows the distributions of composite codes by participants and providers. Providers expressed 5.2 times more discrete thoughts than the participants. Biomedical information-giving accounted for just over 56% of all provider statements made during each session. Eight percent of their utterances were psychosocially related and fewer than 12% reflected efforts to engage the participants. Only 5.5% of participants' utterances were biomedical questions, while 20.0% involved giving biomedical information. Psychosocial issues accounted for 22.0% of participants' statements, though the providers asked about psychosocial issues infrequently (2.2%). Finally, 39% of the participants' utterances were positive statements to the provider, though most of those were acknowledgment of what the provider had just said.

Table 2
RIAS composite code frequencies and percent of total expressed statements by provider and participant ($n = 262$).

Composite code names	Provider composite codes			Participant composite codes		
	Mean (sd)	Range	Mean proportion	Mean (sd)	Range	Mean proportion
Biomedical questioning	3.8 (3.28)	0–16	1.7%	9.1 (9.39)	0–68	5.5%
Psychosocial questioning	4.9 (3.93)	0–21	2.2%	0.9 (1.66)	0–10	0.6%
Biomedical information giving	126.6 (72.61)	0–545	56.8%	33.0 (31.01)	0–214	20.1%
Psychosocial information giving	12.9 (13.75)	0–89	5.8%	36.8 (45.04)	1–389	22.4%
Partnership building	26.2 (21.65)	4–143	11.8%	6.5 (7.00)	0–55	3.9%
Positive talk	28.4 (17.81)	4–106	12.8%	63.3 (42.03)	3–294	38.5%
Emotion talk	8.6 (7.35)	0–53	3.9%	10.4 (9.57)	0–51	6.4%
Negative talk	0.2 (0.58)	0–4	0.1%	9.1 (9.39)	0–68	0.4%
Social talk	0.4 (1.74)	0–17	0.2%	0.9 (1.66)	0–10	0.2%
Procedural talk	10.5 (7.51)	0–40	4.7%	33.0 (31.01)	0–214	2.0%
Total provider or participant talk	222.9 (119.86)	22–824	100%	36.8 (45.04)	1–389	100%

3.3. Identified patterns of interaction

Three individual clusters were identified, representing the following pattern types: (1) Psychosocial patient-centered (PPC), comprising 67 (25.6%) of sessions; (2) Biomedical-Patient-Driven (BPD), representing 90 (34.4%) sessions; and (3) Biomedical-Provider-Teaching (BPT), comprising 105 (40%) of the sessions. $R^2 = 0.26$. The patterns' differences for both providers and participants are depicted in Figs. 2 and 3, respectively. Appendix B shows which composite codes were statistically different and the effect size between each of the patterns. The PPC pattern reflects the counseling model and very little of the teaching model and thus not the psycho-educational model. The BPD pattern resembles the educational model in that there is much biomedical questioning by the patient and information giving by the provider. This process appears to be primarily driven by the patient. The BPT model essentially emulates the teaching model in which the provider dominates the session with biomedical information.

During PPC sessions, providers gave less biomedical information, asked more psychosocial questions, and made more efforts to build partnership than in other sessions. Participants in PPC sessions shared more psychosocial information than participants in the other patterns. There were also a greater number of utterances by the participants as a proportion of provider talk in the PPC sessions compared with the others, suggesting these participants had substantially higher levels of verbal engagement (0.88 vs. 0.67 and .069, respectively, $p < 0.001$). (See Table 3.)

The PPC pattern involves substantially more provider psychosocial question-asking than the other patterns (PPC = 0.798, BPD = −0.331, BPT = −0.225). See Appendix B. In other words, the number of utterances regarding psychosocial questions by

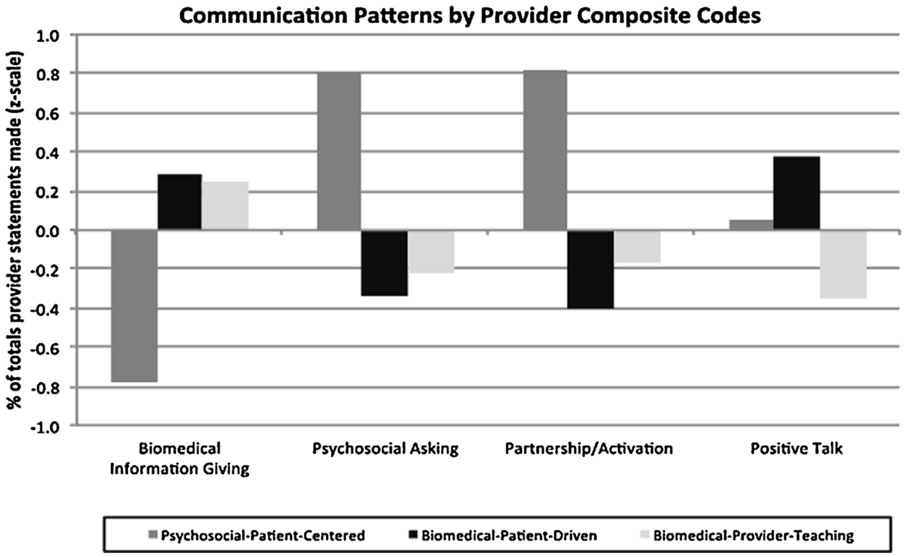

Fig. 2. Comparing provider talk among the three patterns by RIAS composite categories.

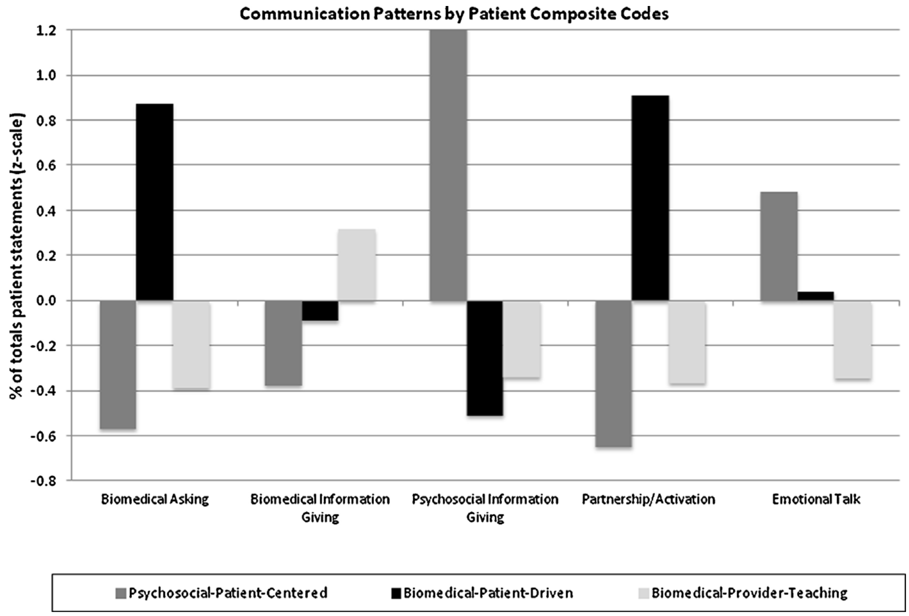

Fig. 3. Comparing participant talk among the three patterns by RIAS composite categories.

Table 3
Participant and session characteristics distributions.

Participant and session characteristics	Psychosocial-Patient-Centered (PPC) ($n = 67$, 25.6%)	Biomedical-Patient-Driven (BPD) ($n = 90$, 34.4%)	Biomedical-Provider-Teaching (BPT) ($n = 105$, 40.0%)	Total ($n = 262$, 100%)
Participant age (mean, sd)	58.4 (11.5)	58.4 (10.7)	58.0 (9.5)	58.27 (0.23)
Participant gender ($p = 0.041$)				
Female	51 (27.9%)*	54 (29.5%)	78 (42.6%)*	183 (70%)
Male	16 (20.3%)	36 (45.6%)*	27 (34.2%)	79 (30%)
Participant race ($p = 0.057$)				
African-American	13 (28.3%)	9 (19.6%)	24 (52.2%)*	46 (18%)
All others	54 (25.0%)	81 (37.5%)*	81 (37.5%)	216 (82%)
Psycho-social well-being (mean, sd)				
CES-D (depression)	6.0 (5.2)	5.28 (5.0)	5.41 (4.9)	5.56 (0.15)
BAI (anxiety)	3.8 (3.8)	3.19 (3.9)	3.18 (4.3)	3.39 (0.26)
Highest grade/years college completed (mean, sd)	16.0 (2.5)	16.4 (2.6)	16.0 (2.4)	16.13 (0.10)
Participant APOE status				
Positive	29 (28.4%)	28 (27.5%)	45 (44.1%)	102 (39%)
Negative	38 (23.8%)	62 (38.8%)	60 (37.5%)	160 (61%)
Provider type/gender				
GC	49 (27.4%)	60 (33.5%)	70 (39.1%)	179 (68%)
MD	18 (21.7%)	30 (36.1%)	35 (42.2%)	83 (32%)
Protocol arm				
Extended	27 (30.7%)	28 (31.8%)	33 (37.5%)	88 (34%)
GC condensed	22 (24.2%)	32 (35.2%)	37 (40.7%)	91 (35%)
MD condensed	18 (21.7%)	30 (36.1%)	35 (42.2%)	83 (32%)
Study site ($p = 0.002$)				
Site A	26 (32.5%)*	30 (37.5%)*	24 (30.0%)	88 (31%)
Site B	19 (25.3%)	34 (45.3%)*	22 (29.3%)	75 (29%)
Site C	10 (16.4%)	15 (24.6%)	36 (59.0%)*	61 (23%)
Site D	12 (26.1%)	11 (23.9%)	23 (50.0%)*	46 (18%)
Participant to provider expressed thoughts (mean, sd)	0.88 (0.40)*	0.67 (0.22)	0.69 (0.21)	0.73 (0.29)
Session length in minutes (mean, sd)	16.1 (10.1)	15.0 (9.4)	15.5 (8.7)	15.53 (0.6)

* More cases or percentage than statistically expected in this pattern.

providers in the PPC pattern is 0.798 standard deviations above the mean for all the patterns while the mean number of psychosocial questions by providers in the BPD and BPT patterns are approximately 0.3 and 0.2 below the mean, respectively. The PPC pattern also demonstrated greater patient-centeredness based on the patient-centered composite code (PPC = 0.756, BPD = −0.057, and BPT = −0.449, $p < 0.001$).

Conversely, the BPD sessions included significantly more biomedical question asking (BPD = 0.874, PPC = −0.569, BPT = −0.386), partnership building (BPD = 0.909, PPC = −0.648, BPT = −0.366) and procedural talk (BPD = 0.074, PPC = −0.367, BPT = −0.078) by the participants than either of the other sessions. Communication in these sessions was driven by the participant and tended to be biomedically focused.

The BPT sessions included nearly as many provider statements dedicated to biomedical information-giving as the BPD pattern (BPT = 0.250, BPD = 0.283, PPC = −0.771), but the BPT pattern participants gave significantly more biomedical information than the other two patterns (BPT = 0.317, PPC = −0.376, BPD = −0.090). The BPT pattern participants also made more positive utterances (BPT = 0.429, PPC = −0.611, BPD = −0.046), while expressing far fewer emotional thoughts (BPT = −0.345, PPC = 0.486, BPD = 0.041). Communication in the BPT pattern represents a session that is heavily focused on biomedical information-giving driven primarily by the provider. Although the PPC sessions were on average a minute longer than the other patterns' sessions there was no statistical difference in session length.

3.4. Patient and session characteristics comparisons

Participant age, race, psychosocial well-being (i.e. depression or anxiety levels), and education level were not associated with pattern assignments (Table 3). Genetic status also did not vary significantly by pattern. The sensitivity analysis, in which the 11 participants with two ε4 alleles (4.2%) were excluded, showed no differences in results.

There was a significant difference in participant gender across the patterns ($p = 0.041$), with more female participants in the PPC and BPT sessions and more male participants in the BPD sessions (Table 3) Finally, communication patterns were not associated with the type of provider who disclosed the test results or the REVEAL II study arm. However, individual providers were not evenly distributed across the patterns ($p \leq 0.001$). For example, one provider, a genetic counselor, had no PPC pattern sessions, splitting sessions only between BPD and BPT patterns. Sixty-percent of another provider's sessions exhibited the PPC pattern, with 12.5% and 25% of the sessions represented by the BPD and BPT patterns, respectively.

4. Discussion and conclusion

4.1. Discussion

We sought to characterize the patterns of patient–provider communication during genetic counseling sessions during which genetic test results for the risk of developing AD are disclosed, and describe how empirical patterns exemplify conceptual models of genetic counseling. We found three distinct patient–provider communication patterns reflecting aspects of the teaching and counseling models of genetic counseling, but not the psycho-educational model [2]. The first, a Psychosocially oriented, Patient-Centered pattern (PPC) incorporates more discussion about psychological issues than the other patterns with minimal discussion about biomedical topics. It most closely reflects the counseling model. The Biomedical-Provider-Teaching (BPT) pattern exemplifies the biomedical focus of the teaching model in which communication is verbally and thematically dominated by the provider and the biomedical paradigm. The Biomedical-Patient-Driven (BPD) pattern has not previously been described in the genetic counseling literature, but is similar to a consumerist communication pattern exhibited in primary care medicine [29]. In this pattern, participants are more dominant, asking more biomedical questions and encouraging the development of a partnership. There are also very few psychosocial statements made.

4.1.1. Contribution to the literature

We found that several elements of patient–provider communication occurring during AD risk disclosure (e.g., emphasis on biomedical talk, provider verbal dominance, little attention to psychosocial issues and provider association with a predominant communication style) are similar to genetic counseling for other disorders [6,7,10,29–31], as well as in communication in other medical settings [29,32–35]. Other genetic counseling studies that have clustered RIAS codes produced four session patterns, rather than three, that reflected somewhat similar elements of the counseling and teaching models [6,7], as well as the psycho-educational model identified by Roter et. al.

The BPD pattern is a unique finding, whereby participants drove the communication by asking biomedical questions. It is akin to Ellington et al.'s client-focused biomedical pattern [7] except that in the BPD pattern the participants acted like assertive consumers, mostly asking questions rather than providing requested biomedical information and were actively developing a partnership with the provider.

It is difficult to directly compare cluster analysis results between studies due to a variety of design differences, such as the choice of RIAS composite codes used for analysis. A standard set of codes would enable comparisons and perhaps a "meta-analyses" eventually. Our selection of the composite codes specifically followed Mead and Bower's patient-centered framework [25]. The study samples, providers, or the contexts in which the genetic counseling was conducted may also contribute to the different results. For example, the different outcomes between our study and Roter et al.'s [6] is likely due to their use of simulated clients who were instructed not to initiate questions.

Two major components of genetic counseling communication – education and psychosocial support – are intended to help patients make informed medical and social decisions and adapt to significant medical challenges. However, the marked imbalance between the two, demonstrated by the BPT pattern and to some extent the BPD pattern, is likely to grow as providers are asked to explain more complicated technical information about test results while facing growing pressure to reduce session time [20,36].

4.1.2. Patient characteristics and communication patterns

We explored associations between the communication patterns and participant characteristics. Only patient gender differed by communication pattern. This finding was consistent with other related studies where women have been found to more often express their feelings and ask questions, while men tend to focus on biomedical information and information-giving [37,38]. Accordingly, there were more female and fewer male participants in the PCC and BPT pattern session than expected, while the opposite was found in the BPD pattern sessions.

We also found a positive but nonsignificant association between African-American participants and the BPT sessions. Studies have repeatedly shown that African-Americans are less likely to be involved in patient-centered medical interactions [39]. Younger and more educated patients are generally more likely to be associated with patient-centered communication [40], but we did not find that to be the case. Our sample had a preponderance of older, well-educated participants, reducing our opportunity to see age and education effects. This may account, however, for the higher proportion of BPD pattern visits in this study, compared with the aforementioned primary care study in which the patients were less well-educated and were studied at a time when patients were not so encouraged to ask doctors questions [29].

4.1.3. Distribution of patterns by provider

Our findings are consistent with previous studies that have documented that providers tend to have individual, habitual styles of communication [7]. Although the patterns in this study are characterized by a combination of participant and provider input, they were driven primarily by the provider. Efforts to train providers to be more flexible with their communication styles may be indicated, as are further examinations of whether this predominance of style affects patient outcomes.

4.1.4. Limitations

Our findings may not apply to other genetic counseling encounters, due to the constraints of REVEAL II as a controlled trial. The providers were instructed to follow a prescribed topic protocol, although they were given latitude to incorporate their style of communication and address the specific needs of individual participants. This tailoring was evident from the range in session length and the variety of topics emphasized by each provider. The mean length of the disclosure sessions, even those conducted by the genetic counselors, were shorter than the generally expected 45–60 min, which may be another consequence of the REVEAL II discussion guide. Perhaps susceptibility testing for AD requires less biopsychosocial counseling than other conditions such as hereditary breast cancer or prenatal diagnosis. Although the participants were largely self-referred and may have had different motivations and levels of concern than a typical at-risk individual, they were demographically similar to the broader population of individuals who seek genetic risk testing [41]. We were unable to determine whether provider gender was associated with communication patterns as all the genetic counselors were female and the physicians were male.

4.2. Conclusion

Patient satisfaction immediately following the visit is strongly associated with communication styles that incorporate a balance between biomedical and psychosocial talk [42]. Patient-centered communication also appears to lead to improved patient health outcomes, and adherence [43–46]. In this study the PPC pattern demonstrated the most patient-centered communication, but was the least frequent pattern. It is important to confirm a relationship between the patient-centered characteristics of this pattern and better patient outcomes compared to the other patterns. Future analyses of REVEAL data will examine these associations. Such a finding may provide the impetus to develop health communication programs for providers that emphasize patient-centeredness as characterized by the PPC pattern.

4.3. Practice implications

Patients have preferences for the style of communication with providers. Attaining a patient-centered interaction has been recognized as an important goal in the delivery of health care [36], but these ideals for genetic counseling are not yet reality. Providers interested in delivering patient-centered care need to increase their efforts to balance the content and amount of verbal exchange with their patients. Patient-centered care requires that the provider engage patients in the counseling process by ascertaining communication preferences and encouraging them to share concerns and ask questions in proportion to his or her preferences [25,26].

Understanding the effect these patterns have on patient care can be used to improve counseling by genetics providers and other clinicians engaged in the delivery of genetic services. Results from this study supply the basis for research to discern which specific components of the genetic counseling communication process are associated with satisfaction with encounter, understanding of test results, and psychosocial adjustment to risk status.

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Appendix A

List of the RIAS composite codes the unique RIAS codes combined to create them. Bolded individual codes were associated with the composite codes used in the cluster analysis.

Composite code	Individual RIAS code	
	Patient	Provider
Biomedical asking	**All questions-medical, all questions-therapeutic, bid for repetition, all questions-other**	Closed question-medical, closed question-therapeutic, closed question-other, open question-medical, open question-therapeutic, open question-other, bid for repetition
Psychosocial asking	All questions-lifestyle, all questions-psychosocial	**Closed question-lifestyle closed question-psychosocial, open question-lifestyle, open question-psychosocial**
Biomedical information giving	**Gives information-medical, gives information-therapeutic, gives information-other**	**Gives information-medical, gives information-therapeutic, gives information-other, counsels-medical/therapeutic**
Psychosocial information giving	**Gives information-lifestyle, gives information-psychosocial**	Gives information-lifestyle, gives information-psychosocial, counsels-lifestyle/psychosocial
Partnership building	**Asks for service, asks for reassurance, asks for understanding, checks for understanding**	**Asks for opinion, asks for permission, asks for reassurance, asks for understanding, back-channels, checks for understanding**
Positive talk	Laughs, tells jokes, approval, compliment-general, shows agreement, understanding	**Laughs, tells jokes, approval, compliment-general, shows agreement, understanding**
Emotion talk	**Empathy/legitimation statements, concern, worry, reassures, optimism**	Empathy/legitimation statements, concern, worry, reassures, optimism, partnership statements, self-disclosure
Negative talk	Disagreement, criticism	Disagreement, criticism
Social talk	Personal remarks	Personal remarks
Procedural talk	Transitions, gives orientation, instructions, unintelligible utterance	Transitions, gives orientation, instructions, unintelligible utterance
Patient centered	Provider psychosocial asking + Provider psychosocial information giving + Provider emotional talk + Patient psychosocial asking + Provider partnership building + Patient psychosocial information giving + Patient emotional talk + Patient biomedical asking/Provider biomedical asking + Provider procedural talk + Provider biomedical information giving + Patient biomedical information giving	

Appendix B

ANOVA results for RIAS provider composite codes by communication pattern.

	RIAS composite codes (*Z*-scores)	Communication patterns					
		Psychosocial-Patient-Centered (PPC) (*n* = 67, 25.6%)	Biomedical-Patient-Driven (BPD) (*n* = 90, 34.4%)	Biomedical-Provider-Teaching (BPT) (*n* = 105, 40.0%)	*F*	Bonferroni post hoc comparison	Effect size (Cohen's *d*)
Provider communication	Biomedical questioning	0.060	−0.204	0.137	3.03	[*]c	BPD:BPT – 0.4
	Biomedical information giving	−0.771	0.283	0.250	33.49	[**]a,b,c	PPC:BPD – −1.1 PPC:BPT – −1.1 BPD:BPT – 0.04
	Psychosocial questioning	0.798	−0.331	−0.225	36.92	[***]a,b	PPC:BPD – 1.1 PPC:BPT – 1.0
	Psychosocial information giving	−0.014	−0.116	0.109	1.24	NS	
	Partnership building/activation	0.811	−0.408	−0.168	40.37	[***]a,b	PPC:BPD – 1.2 PPC:BPT – 0.9
	Positive talk	0.050	0.375	−0.353	14.28	[***]a,b,c	PPC:BPD – 0.3 PPC:BPT – 0.5 BPD:BPT – 0.8
	Emotional talk	0.022	−0.004	−0.011	0.02	NS	
	Negative talk	−0.05	0.213	−0.150	3.37	[*]c	BPD:BPT – 0.4
	Social talk	−0.025	0.071	−0.045	0.35	NS	
	Procedural talk	−0.076	−0.063	0.103	0.93	NS	

Letters show which pattern comparisons are statistically different for the composite code. a: PPC vs. BPD; b: PPC vs. BPT; c: BPD vs. BPT; NS = not significant.

[*] $p \leq 0.05$.

[**] $p \leq 0.01$.

[***] $p \leq 0.001$.

ANOVA results for RIAS patient composite codes by communication pattern.

	RIAS composite codes (Z-scores)	Communication patterns					
		Psychosocial-Patient-Centered (PPC) ($n = 67$, 25.6%)	Biomedical-Patient-Driven (BPD) ($n = 90$, 34.4%)	Biomedical-Provider-Teaching (BPT) ($n = 105$, 40.0%)	F	Bonferroni post hoc comparison	Effect size (Cohen's d)
Patient communication	Biomedical questioning	−0.569	0.874	−0.386	88.63	***a,c	PPC:BPT – 1.5 BPD:BPT – 1.4
	Biomedical information giving	−0.376	−0.090	0.317	11.19	***b,c	PPC:BPT – 0.7 BPD:BPT – 0.4
	Psychosocial questioning	−0.013	0.121	−0.096	1.15	NS	
	Psychosocial information giving	1.216	−0.509	−0.339	137.63	***a,b	PPC:BPD – 2.3 PPC:BPT – 2.1
	Partnership building/ activation	−0.648	0.909	−0.366	104.64	***a,b,	PPC:BPD – −1.2 PPC:BPT – −1.1
	Positive talk	−0.611	−0.046	0.429	26.60	***a,b,c	PPC:BPD – −0.6 PPC:BPT – −1.1 BPD:BPT–0.5
	Emotional talk	0.486	0.041	−0.345	15.83	***a,b,c	PPC:BPD – −0.4 PPC:BPT – −0.9 BPD:BPT – 0.5
	Negative talk	0.076	−0.094	0.032	0.64	NS	
	Social talk	−0.134	0.012	0.076	0.91	NS	
	Procedural talk	−0.367	0.364	−0.078	11.68	***a,c	PPC:BPD – −0.7 BPD:BPT – 0.4
Both	Patient centeredness	0.756	−0.057	−0.449	38.18	***a,b,c	PPC:BPD – −0.9 PPC:BPT – −1.4 BPD:BPT – 0.5

Letters show which pattern comparisons are statistically different for the composite code. a: PPC vs. BPD; b: PPC vs. BPT; c: BPD vs. BPT.

$^{*}p \leq 0.05$.

$^{**}p \leq 0.01$.

$^{***}p \leq 0.001$.

References

[1] Green ED, Guyer MS, National Human Genome Research Institute. Charting a course for genomic medicine from base pairs to bedside. Nature 2011;470:204–13.

[2] Biesecker B, Peters J. Process studies in genetic counseling: peering into the black box. Am J Med Genet 2001;106:191–8.

[3] Kessler S. Psychological aspects of genetic counseling. IX. Teaching and counseling. J Genet Couns 1997;6:287–95.

[4] Djurdjinovic L. Psychosocial counseling. In: Baker D, Schuette J, Uhlmann W, editors. A guide to genetic counseling. 1st ed., New York: Wiley-Liss; 1998. p. 127.

[5] Wang C, Gonzalez R, Merajver SD. Assessment of genetic testing and related counseling services: current research and future directions. Soc Sci Med 2004;58:1427–42.

[6] Roter D, Ellington L, Erby LH, Larson S, Dudley W. The Genetic Counseling Video Project (GCVP): models of practice. Am J Med Genet C Semin Med Genet 2006;142C:209–20.

[7] Ellington L, Baty B, McDonald J, Venne V, Musters A, Roter D, et al. Exploring genetic counseling communication patterns: the role of teaching and counseling approaches. J Genet Couns 2006;15:179–89.

[8] Smets E, vanZwieten M, Michie S. Comparing genetic counseling with non-genetic health care interactions: two of a kind? Patient Educ Couns 2007;68:225–34.

[9] Lobb EA, Butow P, Barratt A, Meiser B, Tucker K. Differences in individual approaches: communication in the familial breast cancer consultation and the effect on patient outcomes. J Genet Couns 2005;14:43–53. PMID: 15789155.

[10] Pieterse A, Dulmen Av Ausems M, Beemer F, Bensing J. Communication in cancer genetic counselling: does it reflect counselees' previsit needs and preferences. Br J Cancer 2005;92:1671–8.

[11] Hardy J. Amyloid, the presenilins and Alzheimer's disease. Trends Neurosci 1997;20:154–9.

[12] Alzheimer's Association. 2013 Alzheimer's Disease Facts and Figures; 2013;9.

[13] Green R, Cupples L, Go R, Benke K, Edeki T, Griffith P, et al. Risk of dementia among White and African American relatives of Alzheimer's disease patients. J Am Med Assoc 2002;287:329–36.

[14] Lautenschlager N, Cupples L, Rao V, Auerbach S, Becker R, Burke J, et al. Risk of dementia among relatives of Alzheimer's disease patients in the MIRAGE study: what is in store for the oldest old? Neurology 1996;46:641–50.

[15] Roses A. Apolipoprotein E genotyping in the differential diagnosis, not prediction, of Alzheimer's disease. Ann Neurol 1995;38:6–14.

[16] Raber J, Huang Y, Ashford W. ApoE genotype accounts for the vast majority of AD risk and AD pathology. Neurobiol Aging 2004;25:641–50.

[17] Roberts J, Christensen K, Green R. Using Alzheimer's disease as a model for genetic risk disclosure: implications for personal genomics. Clin Genet 2011;80:407–14.

[18] Green RC, Roberts JS, Cupples LA, Relkin NR, Whitehouse PJ, Brown T, et al. Disclosure of APOE genotype for risk of Alzheimer's disease. N Engl J Med 2009;361:245–54.

[19] Christensen K, Roberts J, Royal C, Fasaye G, Obisean T, Cupples A, et al. Incorporating ethnicity into genetic risk assessment for Alzheimer disease: the REVEAL study experience. Genet Med 2008;10:207–14.

[20] Roberts JS, Chen CA, Uhlmann WR, Green RC. Effectiveness of a condensed protocol for disclosing APOE genotype and providing risk education for Alzheimer disease. Genet Med 2012;14:742–8.

[21] Radloff L. The CES-D scale: a self-report depression scale for research in the general population. Appl Psychol Meas 1992;1992:343–51.

[22] Beck AT, Epstein N, Brown G, Steer RA. An inventory for measuring clinical anxiety: psychometric properties. J Consult Clin Psychol 1988;56: 893–7.

[23] http://www.riasworks.com/. Retrieved October 21, 2013, 2013.

[24] Roter D. The Roter method of interaction process analysis. Baltimore, MD: The Johns Hopkins University Bloomberg School of Public Health; 2006 . 55.

[25] Mead N, Bower P. Patient-centeredness: a conceptual framework and review of the empirical literature. Soc Sci Med 2000;51:1087–110.

[26] Epstein RM, Street RL. A framework for patient-centered communication in cancer care. Communication in cancer care: promoting healing and reducing suffering. NIH Publication No. 07-6225. Bethesda, MD: The National Institute of Cancer; 2007.

[27] Alegria M, Roter DL, Valentine A, Chen CN, Li X, Lin J, et al. Patient–clinician ethnic concordance and communication in mental health intake visits. Patient Educ Couns 2013. PMID: 23896127 [Epub 2013/07/31].

[28] SPSS Inc.. SPSS 18.0 for Mac; 2010, http://www.ibm.com/SPSS_Statistics.com, Chicago, IL.

[29] Roter D, Stewart M, Putnam S, Lipkin M, Stiles W, Inui T. The patient–physician relationship: communication patterns of primary care physicians. J Am Med Assoc 1997;277:350–6.

[30] Butow PN, Lobb EA. Analyzing the process and content of genetic counseling in familial breast cancer consultations. J Genet Couns 2004;13:403–24.

[31] Ellington L, Roter D, Dudley W, Baty B, Upchurch R, Larson S, et al. Communication analysis of BRCA1 Genetic Counseling. J Genet Couns 2005;14:377–86.

[32] Slingsby BT, Yamada S, Akabayashi A. Four physician communication styles in routine Japanese outpatient medical encounters. J Gen Intern Med 2006;21: 1057–62.

[33] Golsäter M, Lingfors H, Sidenvall B, Enskär K. Health dialogues between pupils and school nurses: a description of the verbal interaction. Patient Educ Couns 2012;89:260–6.

[34] Shaw JR, Bonnett BN, Roter DL, Adams CL, Larson S. Gender differences in veterinarian–client–patient communication in companion animal practice. J Am Vet Med Assoc 2012;241:81–8.

[35] Sondell K, Soderfeldt B, Palmqvist S. Underlying dimensions of verbal communication between dentists and patients in prosthetic dentistry. Patient Educ Couns 2003;50:157–67.

[36] Berwick DM. What 'patient-centered' should mean: confessions of an extremist. Health Aff (Millwood) 2009;28:w555–65.

[37] Roter D, Hall J, Aoki Y. Physician gender effects in medical communication: a meta-analytic review. J Am Med Assoc 2002;288:756–64.

[38] Hall J, Roter D. Do patients talk differently to male and female physicians? A meta-analytic review. Patient Educ Couns 2002;48:217–24.

[39] Roter DL, Stewart M, Putnam SM, Lipkin M, Stiles W, Inui TS. Communication patterns of primary care physicians. J Am Med Assoc 1997;277:350–6.

[40] Swenson SL, Buell S, Zettler P, White M, Ruston DC, Lo B. Patient-centered communication: do patients really prefer it. J Intern Med 2004;19:1069–79.

[41] Roberts J, Barber M, Brown T, Cupples L, Farrer L, LaRusse S, et al. Who seeks genetic susceptibility testing for Alzheimer's disease? Findings from a multisite, randomized clinical trial. Genet Med 2004;6:197–203.

[42] Zebiene E, Razgauskas E, Basys V, Baubiniene A, Gurevicius R, Padaiga Z, et al. Meeting patient's expectations in primary care consultations in Lithuania. Int J Qual Health Care 2004;16:83–9.

[43] Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. Patient Educ Couns 2002;48:51–61.

[44] Robinson JH, Callister LC, Berry JA, Dearing KA. Patient-centered care and adherence: definitions and applications to improve outcomes. J Am Acad Nurse Pract 2008;20:600–7.

[45] Bertakis KD, Callahan EJ, Helms LJ, Azari R, Robbins JA, Miller J. Physician practice styles and patient outcomes – differences between family practice and general internal medicine. Med Care 1998;36:879–91.

[46] Stewart MA. Effective physician–patient communication and health outcomes – a review. Can Med Assoc J 1995;152:1423–33.

[47] Linnenbringer E, Roberts JS, Hiraki S, Cupples LA, Green RC. "I know what you told me, but this is what I think:" perceived risk of Alzheimer disease among individuals who accurately recall their genetics-based risk estimate. Genet Med 2010;12:219–27.