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The impact of genetic counselors' use of facilitative strategies on cognitive and emotional processing of genetic risk disclosure for Alzheimer's disease

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ABSTRACT

Objectives: To determine the impact of genetic counselor (GC) communication on cognitive and emotional processing of Alzheimer's disease (AD) risk information during discussions with patients with clinical diagnoses of mild cognitive impairment and their companion.
Methods: 79 recordings and transcripts of AD risk disclosure sessions collected as part of the fourth REVEAL Trial were coded using the Roter Interaction Analysis System (RIAS) and the Linguistic Inquiry Word Count (LIWC). Multilevel analyses were used to determine the association between GCs' use of communication facilitation strategies and patient and companion use of words indicative of cognitive and emotional processing.
Results: GC used somewhat more cognitive (14%) than emotional (10%) facilitation strategies. Both patients and companions used more words indicative of cognitive (18% and 17%) than emotional (6% and 5%) processing. GC use of facilitative strategies and patient and companion use of cognitive and emotional processing words were significantly associated in both unadjusted and adjusted models (all p-values < 0.01).
Conclusions: GCs' use of facilitative strategies assist in cognitive and emotional processing in a way that may be linked to therapeutic benefit.
Practice implications: These findings highlight mechanisms through which GCs may assist patients and companions to better understand and cope with risk information.

1. Introduction

Alzheimer's disease (AD) is a prevalent, severe and currently incurable neurological condition characterized by progressive decline in cognitive and physical functioning leading to disability and death [1]. There is growing consensus that interventions to prevent AD are more efficacious the sooner they are implemented [2,3]. As a result, the demand for genetic and other forms of predictive testing to identify at risk individuals is increasing. While several studies suggest that people seeking risk information for AD through genetic counseling generally find it useful and do not experience adverse effects [4–6], no studies have explored how individuals with mild cognitive impairment (MCI) process this information.

Individuals process threatening health information at both an emotional and cognitive level [7,8]. The complex nature of genetic risk information for AD can be cognitively and emotionally overwhelming, and patients with MCI are likely to struggle more than others given cognitive deficits in memory and other domains

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[9,10]. The social cognitive processing model (SCPM), proposed by Lepore and colleagues, suggests that talking with supportive others about stress and its associated consequences validates concerns, helps correct faulty assumptions, promotes accurate understanding and assists individuals in drawing meaning from an event [11]. Individuals who disclose thoughts and feelings to others are less likely to use avoidant coping strategies [12,13] and more likely to make sense of their situation, experience less distress, take informed actions, and even improve physically [14–17].

Despite the growing evidence linking supportive social interactions to cognitive processing and emotional adjustment, we know little about the specific communication strategies that support cognitive and emotional processing within healthcare contexts. A pioneering study in this area by Ellington and colleagues explored the application of SCPM principles to simulated prenatal and cancer pretest genetic counseling sessions [18]. In the study, counselors' contributions to the session dialogue were coded with the Roter Interaction Analysis System (RIAS) to identify facilitative communication strategies and simulated clients' responses during the session were coded using the Linguistic Inquiry Word Count (LIWC) to capture indicators of cognitive and emotional processing[18]. Greater counselor use of facilitative communication (especially asking psychosocial and lifestyle questions, asking for client opinion, probing understanding and use of paraphrase) was associated with higher word use indicative of cognitive and emotional processing during the encounter. Since the study was done in a simulated setting in the context of pretest counseling, it is not clear how the findings might differ from actual sessions in which risk information is disclosed.

A series of subsequent studies that used LIWC to examine pre and post-test genetic counseling for *BRCA1/2* testing explored the relationship between client knowledge, screening behaviors and cognitive and affective word use by both counselors and clients [19,20]. The authors concluded that the some LIWC patterns, particularly by the counselor, are associated with screening behaviors but not an increase in knowledge.

The current study was designed to extend the earlier work of Ellington and colleagues, by applying both the RIAS and LIWC to actual genetic counseling sessions in which AD risk information was conveyed to patients with MCI and a visit companion. In this study AD risk information was conveyed to patients with a clinician-determined diagnosis of MCI and a visit companion. The study makes an original contribution to the genetic counseling field and provides insight into communication dynamics of counseling sessions in which clients with mild cognitive deficits and family members process complex risk information-emotionally and cognitively. Moreover, the study bridges two quite distinct approaches to assessment of medical dialogue, the RIAS and LIWC, suggesting novel intersections that suggest new approaches to the examination of important communication processes.

Consistent with tenets of the SCPM, we hypothesized that greater use of facilitative strategies by genetic counselors would be positively associated with patient and companion word usage indicating emotional and cognitive processing.

2. Methods

2.1. Study design and data collection

Analyses were based on audio recordings and transcripts of AD risk disclosure sessions collected as part of the fourth REVEAL Study, a multisite randomized clinical trial designed to compare the impact of AD risk communication, conveyed with and without genotype results, to patients with MCI diagnoses and their visit companions. Patients were eligible for recruitment if they had clinical diagnosis of amnestic-MCI, defined as (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) [21]; 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 is described in detail elsewhere [22].) The sample for the current study included 79 AD risk disclosure sessions conducted by genetic counselors; patients were randomly assigned 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 having a clinical diagnosis of MCI. Patients in the genotype disclosure group were given risk estimates based on these same factors in conjunction with their *APOE* genotype. Patients with one or two *ε4* alleles are at increased risk of converting to Alzheimer's disease. The current study was reviewed

Table 1
Application of the SCPM to the AD risk disclosure session.

SCP constructs	Coding categories	Examples
Genetic counselor facilitative communication strategies operationalized with RIAS codes		
Cognitive Facilitation (CF)	Ask medical questions, and ask for opinion, reassurance and understanding.	-What do you recall in terms of being told about MCI? -Does that make sense? -Were you expecting that?
Emotional Facilitation (EF)	Ask psychosocial questions, reassures, partnering, self-disclosure, show approval and compliment, show concern or worry, empathy and legitimization.	-Do you feel that the knowing that you have one copy of E4, does that change at all how you're feeling about this, your personal inner thoughts? -It's hard to lose people you care about. -If you think of any questions, feel free to ask.
Patient and companion communication indicators operationalized with LIWC		
Cognitive Expression (CE)	Cognitive mechanisms (think, because, know, consider)	-I *think* I wouldn't worry about it at all. -I *know* what's happening in my brain.
Emotional Expression (EE)	Emotion words including positive emotions (happy, love) and negative emotions (sad, angry, worry)	-I *like* to walk everywhere. -This makes me *happy* not only for myself, probably more for my family. -It's a very *depressing* thought. -She was very *sad* for her.

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.

2.2. Roter interaction analysis system (RIAS)

Audio recordings of risk disclosure dialogue were coded using RIAS, a widely used and well validated system for empirically describing medical visit communication [23]. 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 one of thirty-seven mutually exclusive and exhaustive code categories. The code categories used in the current analysis were combined to reflect cognitive and emotional facilitative communication strategies as listed in Table 1. A random 10% sample of audiotapes (n = 8) was drawn throughout the coding period for double coding to establish inter-coder reliability. Pearson correlation coefficients averaged 0.83 across genetic counselor communication categories.

2.3. Linguistic inquiry word count (LIWC)

The LIWC is a text analysis tool that identifies words indicative of emotional and cognitive expressions [24] theoretically derived and consistent with the tenets of the SCPM. Table 1 displays the LIWC categories used in the current study indicative of cognitive processing including words that indicate understanding and recognition of causal linkages such as “because” or “effect” and words that indicate insight and relay more tentative associations such as “think” or “realize”. Words reflecting emotional processing include both negative emotions (e.g., guilt, anger, worry) and positive emotions (e.g., happiness, love). Audio recordings of the AD risk disclosure sessions were transcribed and the transcripts were prepared in accordance with recommendations from the manual accompanying the LIWC software (2007 version) including eye ball method of checking use and meaning of counted words and edit “filler” words without obvious significance (i.e., “you know”).

2.4. Data analyses

Descriptive statistics were used to present an overall picture of GC use of facilitative communication strategies during the session and both patient and companion use of words indicative of risk information processing. To determine how genetic counselors’ facilitative communication behaviors predicted patient and companion processing, we ran separate multilevel mixed-effect linear regression models with each word category as the dependent variable and genetic counselor communication behaviors as the independent variable, with a random effect to account for clustering at the genetic counselor level. In the adjusted models, we included patient and companion gender, patient-companion relationship, patient MMSE score, patient group (genotype nondisclosure, genotype disclosure: $\varepsilon 4$ negative, and genotype disclosure: $\varepsilon 4$ positive), and total word count of the three speakers as control variables. Interactions between counselor’s communication behaviors and patient group were checked statistically. In all analysis, 2-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).

Table 2
Sample characteristics of patients and companions.

	Patient (N = 79)	Companion (N = 79)
Age, mean (SD)	75.7 (7.4)	68.0 (13.3)
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, mean (SD)	26.9 (2.1)	–
Family history of AD/dementia, %	49 (62.0)	–
3-year risk, mean (95%CI)	37.3 (13.7)	–
Relationship to patient, %		
Spouse	–	51 (64.6)
Child	–	19 (24.1)
Other (friend, other relative)	–	9 (11.3)

3. Results

3.1. Sample characteristics

Three genetic counselors participated in this study, one from each of three study sites (Boston, Philadelphia, and Ann Arbor). The counselors were female Caucasians aged 26 through 48 and they conducted between 4 and 40 disclosure sessions.

As displayed in Table 2, the 79 patients comprising our study sample averaged 76 years of age with the majority 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%) had 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 eleven patients scored in the range of mild impairment (MMSE 20–23). The 3-year risk estimates of progressing to AD averaged 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.

All patients were accompanied to their risk disclosure session by a family member or friend (referred to hereafter as visit companion). Visit companions (N = 79) were on average 68 years old, 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%).

3.2. RIAS analysis of genetic counselor talk

The length of risk discussions ranged from 9.7 to 63.5 min with a mean of 27.0 min (SD = 9.7). Genetic counselors verbally dominated the sessions typically contributing 63% of session statements. As displayed in Table 3, on average, the majority (83%) of counselor talk was directed to the patient with 15% directed to the companion. Counselor use of cognitive facilitation strategies comprised 14% of their session talk and emotional facilitative strategies comprised 10%. As is evident in Table 3, these strategies were more commonly directed toward patients than companions.

3.3. LIWC analysis of patient and companion word use

Patients talked more than their visit companions during the session, which was demonstrated by the total word count (mean = 699.8 and 501.1 for patients and companions, respectively). As shown in Table 4, patients and companions contributed to the discussion similarly in terms of word use across cognitive and emotional domains; 16.6% of patient words and 16.3% of companion words were indicative of cognitive processing and 7.2% of patient words and 6.7% of companion words reflected emotional processing. Also evident in Table 4, is that patients and

Table 3
Descriptive analysis of genetic counselor (GC) use of cognitive and facilitative strategies.

RIAS Codes	Mean number of RIAS codes (SD)	Range	Average% of Total GC Talk	Range
All GC talk	351.1 (96.9)	138–729	NA	NA
GC talk to patient	288.6 (81.3)	126–602	83%	49%–98%
Cognitive facilitation	36.1 (28.6)	3–152	10%	2%–26%
Emotional facilitation	27.6 (13.4)	7–80	8%	2%–16%
GC talk to companion	55.3 (43.4)	6–215	15%	2%–50%
Cognitive facilitation	12.9 (10.1)	0–45	4%	0%–10%
Emotional facilitation	7.8 (6.8)	0–32	2%	0%–7%

companions employed greater use of positive than negative emotion words.

3.4. The impact of genetic counselor facilitation on patient and companion word use indicative of cognitive and emotional processing

Table 5 illustrates the regression coefficients from the linear mixed effects models (both adjusted and unadjusted for covariates) for cognitive and emotional words regressed on genetic counselors' use of facilitation strategies. In all unadjusted models, facilitation of emotional and cognitive processing is positively correlated with both patient and companion word use indicative of cognitive and emotional processing of session information ($p < 0.001$).

Additional regression models were created to adjust for potential confounders as described earlier. The associations between counselor use of facilitative strategies and patient expressions of cognitive and emotional words were modified by patient group (p-value for interaction < 0.05). Subgroup analyses suggested that in multivariate adjusted models, the positive effect of counselors' cognitive facilitation on patients' cognitive ($\beta = 4.9$, $p < 0.001$) and emotional ($\beta = 1.1$, $p < 0.001$) expressions were significantly stronger if the patient was at higher risk of developing AD ($\varepsilon 4$ positive), compared to those in the genotype nondisclosure group ($\beta = 3.1$, $p < 0.001$ and $\beta = 0.6$, $p = 0.003$ for cognitive and emotional expressions, separately). Similarly, counselors' use of emotional facilitation had a more significant effect on patients' cognitive ($\beta = 5.3$, $p < 0.001$) and emotional expressions ($\beta = 1.1$, $p < 0.001$) in the $\varepsilon 4$ positive group compared to the genotype nondisclosure group ($\beta = -1.5$, $p = 0.40$ and $\beta = -0.4$, $p = 0.40$ for cognitive and emotional expressions, separately). The positive effect of counselors' facilitation (cognitive or emotional) on patients' expressions were not different between the $\varepsilon 4$ positive and the $\varepsilon 4$ negative group (all p-values > 0.05). The interaction effects were not significant for companion word use.

In the final adjusted models, genetic counselors' use of facilitative strategies had a significant positive impact on patient and companion use of both emotional and cognitive processing words (all p-values < 0.01).

4. Discussion and conclusion

4.1. Discussion

This study provides an exploratory analysis of how patients with a diagnosis of mild cognitive impairment and their visit companions process cognitive and emotional information conveyed during AD risk disclosure sessions. As hypothesized, genetic counselors' use of facilitative communication strategies was positively associated with linguistic indicators of affective and cognitive processing during the disclosure sessions by patients and companions.

Consistent with the tenets of the SCPM, and the earlier study by Ellington and colleagues, when genetic counselors ask questions, check for understanding and express concern, reassurance and empathy, patients and their visit companions use more cognitive and emotional words indicative of processing. This effect was evident even after controlling for factors that have been shown to influence clinician-patient interactions (e.g. gender, cognitive function and *APOE* genotype) [25]. The disclosure of thoughts and feelings has been shown to have therapeutic benefits through the conversion of a stressful event (e.g. AD risk disclosure) into a linguistic structure which in itself may promote understanding of a stressor and a reduction of associated negative emotion [26,27]. This interpretation is supported by studies linking emotional disclosure to positive patient outcomes, including improved reported physical health and psychological well-being [14–17,19,28,29]. In one study using LIWC to identify insight and emotional expression correlates of short term outcomes, Kimberly and Ellington (2014) analyzed BRCA1/2 pre-test genetic counseling encounters (N = 90) and found that a higher level of patient emotional expression was positively related to indicators of knowledge gain following BRCA1 genetic counseling sessions [19]. Based upon these findings and others, our results suggest that

Table 4
Descriptive analysis of LIWC word use by patients and companions.

LIWC word category	Mean frequency (SD)	Median	Range	
Total patient word count	699.8 (788.6)	427	(5–4451)	Average% of total patient talk
Emotional expression	39.9 (41.6)	28	(1–264)	7.2%
Positive emotion	30.8 (32.3)	23	(1–199)	5.8%
Negative emotion	9.0 (11.0)	6	(0–65)	1.3%
Cognitive expression	122.6 (146.8)	70	(0–818)	16.6%
Total companion word count	501.1 (395.8)	383	(3–1792)	Average% of total companion talk
Emotional expression	26.7 (17.8)	24	(0–73)	6.7%
Positive emotion	20.6 (13.9)	18	(0–66)	5.4%
Negative emotion	6.0 (5.9)	4	(0–28)	1.3%
Cognitive expression	86.2 (71.9)	62	(0–334)	16.3%

Table 5
Multi-level analysis of Genetic Counselors' cognitive and emotional facilitation and expressions of patient and companion cognitive and emotional processing of risk information.

LIWC word categories	GC Cognitive Facilitation		GC Emotional Facilitation	
	unadjusted coefficient (SE)	adjusted coefficient (SE)[a]	unadjusted coefficient (SE)	adjusted coefficient (SE)[a]
Patient				
Cognitive expression	5.1 (0.3)**	4.6 (0.4)**	8.2 (0.8)**	3.8 (1.0)**
Emotional expression	1.3 (0.1)**	1.1 (0.1)**	2.3 (0.2)**	0.9 (0.3)*
Companion				
Cognitive expression	6.2 (0.4)**	6.1 (0.4)**	7.1 (0.8)**	6.2 (0.9)**
Emotional expression	1.2 (0.1)**	1.1 (0.2)**	1.7 (0.2)**	1.5 (0.2)**

* $P < 0.01$.
** $P < 0.001$.
[a] Adjusted coefficient derived from models that controlled for patient and companion gender, patient-companion relationship, patient MMSE score, patient group (genotype nondisclosure, *ε4* negative and *ε4* positive groups), and total word count of the three speakers.

counselors' supportive communication elicits insightful and emotional disclosure, which may facilitate positive therapeutic effects, such as an increase in knowledge and a reduction in anxiety and distress related to AD risk disclosure.

Our findings also extend the current literature by demonstrating the effects of counselor communication strategies on the way family members and friends who accompany patients to their medical visits cognitively and emotionally process information, with important implications for their role in the delivery of dementia care. Analysis of the Medicare Current Beneficiary Survey shows nearly 40% of community-dwelling older adults report being routinely accompanied to their medical visits by a companion, usually the spouse or adult children [30,31]. Family members frequently accompany patients with the MCI to medical visits and often assume caregiver and decision-making roles. Within this context, facilitating cognitive and emotional processing of family companions is of particular importance in AD risk disclosure given the implications these disclosures for family member risks and future caregiver responsibility.

Taken together, the study findings point to ways GC communication can assist patients and visit companions to process risk information on both a cognitive and emotional level. Counselors in our study used somewhat more cognitive relative to emotional facilitative strategies and patient and companion talk was more indicative of cognitive than emotional processing. These findings are consistent with those of Ellington and colleagues based on simulated prenatal and cancer genetic counseling sessions further validating use of simulations as a way to gain insight into actual practice[18]. Word use by both patients and companions in the current study demonstrates similar patterns reflecting higher levels of cognitive than emotional processing. While we cannot determined causality and do not know if higher levels of emotional facilitation by the counselors resulted in greater patient and companion emotional engagement, or patient engagement spurred counselor facilitation, the former explanation appears most likely.

The genetic counselors in the current study faced several challenges that may have contributed to lower levels of emotional facilitation. The AD risk disclosure is a onetime event, and it may be difficult to integrate expressions of emotion and empathy during the first visit with the patient and the companion. Further, activating the cognitive processes is especially challenging for individuals with cognitive deficits due to difficulty comprehending the implications of AD risks. As a result, genetic counselors may spend more time checking for patient understanding than exploring the patient's emotional response to the information as is evident in other genetic counseling studies in other settings [32]. It is also worth noting that the counselors in this study were instructed to follow the semi-structured risk disclosure protocol and this may have led to a greater focus on delivery of specified information (e.g., review of *APOE* genotype, AD risk estimates presentation) than they might have otherwise.

A limitation of LIWC is the extent to which it can depict the context of interaction since it relies only on counts of word frequency. It is interesting that patients in the genotype nondisclosure group expressed more negative emotion than those who received *ε4* positive results, regardless of the counselors' emotional facilitation efforts. Although patients in the control group (genotype nondisclosure group) were ensured that they would receive their genotype results at 12-month follow-up if they wanted the information, some patients were disappointed and criticized the delay. Although we note this use of negative words was about the study design rather than communication and processing of AD risk, we believe that the negativity still affects the affective tone of the interaction. In addition, our analyses cannot determine the causal pathways that precipitated patient and companion expressions and whether they were self-initiated or motivated by the genetic counselor's communication. Several predictors that may be relevant to the communication process cannot be evaluated in this study due to little variance in patient and genetic counselor race. Furthermore, patients enrolled in the fourth REVEAL Study trial were largely self-referred and well-educated and may have different motivations and levels of concern than a more typical at-risk individual. Our findings may not apply to other AD risk disclosure sessions, due to the constraints of REVEAL as a controlled trial and the fact that only three genetic counselors communicated results in this study. It is possible that study counselors are not representative of the field at large and that their disclosure style may more accurately reflect communication characteristics of research protocol-driven sessions than common practice.

4.2. Conclusion and practical implications

The results of this study support the use of communication strategies that facilitate cognitive and emotional processing. It is significant that the broader literature on cognitive and emotional processing suggests therapeutic benefit, and although not measured, it may be the case in the current study. The current study contributes to a small but important literature, and suggests directions for future educational efforts for genetic counselors and other health care providers as well as empowerment interventions for family members to support the important role they play facilitating understanding and coping with complex health information.

Conflicts 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 non-university 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.

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