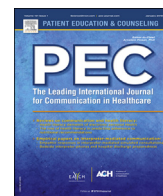




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The impact of genetic counselors' use of facilitative strategies on cognitive and emotional processing of genetic risk disclosure for Alzheimer's disease

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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.

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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 amnesic-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 ≥ 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 $\epsilon 4$ 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 <u>think</u> I wouldn't worry about it at all. -I <u>know</u> what's happening in my brain.
Emotional Expression (EE)	Emotion words including positive emotions (happy, love) and negative emotions (sad, angry, worry)	-I <u>like</u> to walk everywhere. -This makes me <u>happy</u> not only for myself, probably more for my family. -It's a very <u>depressing</u> thought. -She was very <u>sad</u> for her.

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