# DISCLOSING ALZHEIMER'S GENOMIC RISK TO FAMILY ACCOMPANIED COGNITIVELY IMPAIRED PATIENTS

by
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## ABSTRACT

### Background

More than five million Americans are currently affected by Alzheimer's disease (AD), and that number is expected to triple by 2050. These staggering figures evoke dread; people fear developing the disease as well as the prospect of assuming the physical and emotional burden of caregiving for an affected family member. Current initiatives in AD research are increasingly targeting populations early in disease progression, including individuals who are experiencing mild cognitive impairment (MCI). Increasing reliance on biomarkers and more frequent use of susceptibility genetic testing, however, raises concerns regarding how patients, and particularly those with MCI, will make sense of the abstract and complex nature of the risk information that will be conveyed to them within the context of direct care, as well as research studies. Moreover, the active involvement of family members who often accompany patients with MCI raises questions regarding their role in these visits.

### Methods

This study addresses these questions by providing an in-depth analysis of AD risk communication and its immediate consequences for 79 family-accompanied patients with MCI. This was done by analyzing audio recordings of AD risk disclosure and survey data collected as part of a randomized clinical trial, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL IV) (2009-2012), in which genotype results are/are not included in the AD risk discussion. A variety of coding schemas were applied to the study audio recordings. The Roter Interaction Analysis System (RIAS) was used to quantitatively describing the triadic interaction in AD risk disclosure sessions. Linguistic Inquiry Word Count (LIWC) was used to identify linguistic

indicators of cognitive and emotional processing by patients and family companions. Patient and family companion satisfaction with the AD risk disclosure session was measured by a 10-item satisfaction survey. Multilevel mixed-effect linear regression models were used to identify differences in communication dynamics across the three study groups (genotype nondisclosure group, APOE ε4-negative group and APOE ε4-positive group), as well as to determine the association between genetic counselors' facilitative communication strategies and linguistic indicators of cognitive and emotional processing of patients and companions. Multivariate logistic regression models were generated to examine communication elements of the AD risk disclosure encounter that predict patient and companion satisfaction with the disclosure session.

**Results**

This dissertation demonstrates that genotype disclosure discussions, regardless of patient genotype status, were less patient-centered than non-genotype AD risk discussions. A family companion was more verbally active in the communication processes of patients who receive ε4 positive than ε4 negative genetic test results; they disclosed more medical information, made more positive and orientation statements, and were rated as more nonverbally positive. Genetic counselors' use of facilitative strategies were positively associated with patient and companion word use indicative of cognitive and emotional processing of the AD risk information. Furthermore, patient-centered and psychosocially focused communication pattern was associated with greater patient and family member satisfaction with AD risk disclosure sessions. Companion communication also appeared to play a significant role in enhancing patient satisfaction.

**Conclusions**

This dissertation furthers our understanding of how cognitively impaired patients and family companions communicate in AD risk delivery processes. Consistent with the Social Cognitive Processing Model, the results identified specific counselor's communication strategies that facilitate cognitive and emotional processing of patients and companions in a way that may be linked to therapeutic benefit. The positive satisfaction outcomes associated with patient-centered communication also contribute to the growing literature on patient-centered care. The dissertation results highlight opportunities for healthcare providers, patients and family companions to increase effective interactions in AD risk disclosure settings.

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# CHAPTER 1: INTRODUCTION

## DISSERTATION OVERVIEW

This dissertation consists of five chapters organized around three manuscripts to provide an in-depth analysis of Alzheimer's disease (AD) risk communication and its immediate consequences for 79 family-accompanied patients with mild cognitive impairment (MCI).

Chapter 1 (the current chapter) provides an overview of the study background, conceptual framework, specific aims and hypotheses.

Chapter 2 provides a systematic quantitative evaluation of AD risk communication between genetic counselors and patients with MCI and their accompanying family members. In addition, it compares communication patterns in AD risk disclosure sessions with and without discussions of genetic risks.

Chapter 3 explores the relationship between genetic counselors' use of facilitative communication strategies on verbal indicators of cognitive and emotional processing by patients and an accompanying family member in the context of an Alzheimer's disease risk disclosure session.

Chapter 4 explores communication elements of the AD risk disclosure encounter that predict patient and companion satisfaction with the disclosure session.

Chapter 5 provides a summary of study findings and presents the study's strengths and limitations. It also provides recommendations for future research and the implications of the research for clinical and public health practice.

## LITERATURE REVIEW

### *Transitions in AD research to target at risk populations*

AD is a prevalent, severe and currently incurable neurological condition characterized by progressive declining levels of cognitive function, leading ultimately to disability and death (Green 2005). A major public health concern is the anticipated increase in cases of AD. More than five million Americans are currently affected by AD, and that number is expected to triple by 2050, which may result in estimated $1.2 trillion direct costs to American society of caring for those with AD (Alzheimer'sAssociation 2014). Despite these staggering figures, people not only dread developing the disease themselves, but the prospect of assuming the physical and emotional burden of caregiving is widespread. A Harris poll reported that the number of respondents indicating that they were extremely concerned that they may someday have to provide care for a family member with the disease has doubled in the last five years (HarrisInteractive 2011). Both societal cost and personal devastation make it critical to prepare for the strain that AD will pose on healthcare systems, caregivers and society at large.

Most devastating on both a societal and personal level is that there is no cure for AD. There is a growing consensus that interventions may be more effective before rather than after the degenerative process of AD has progressed (Albert, DeKosky et al. 2011; Sperling, Jack et al. 2011). It is also noticeable that the number of people who have made any plans for the possibility of developing AD keeps growing (HarrisInteractive 2011), over 90% of the public would seek medical advice for themselves or a family member to determine if any noticed symptoms of memory loss or confusion were related to AD (Robert Blendon 2011). Consequently, AD research has become a national priority and the scientific momentum is pushing new research initiatives upstream in the patient's life cycle in consideration of secondary prevention trials that would target large at-risk populations (Sperling, Aisen et al. 2011; Sperling, Jack et al. 2011).

An important goal within this effort involves identifying risk factors associated with AD and at risk population, including asymptomatic adults and patients with preclinical AD. Through the disease paradigm of AD and the disclosure of APOE genotype, the REVEAL Study is the first large scale systematic effort to address AD risk assessment and implications of risk disclosure in regard to this vulnerable population.

***Risk assessment for AD***

The methods of AD risk assessment in this proposed study focus on epidemiological approaches, predictive genetic testing and clinical assessment of MCI. Factors identified from a large body of epidemiological and genetic research have been used in identifying populations at risk for AD and providing quantitative risk estimates.

*Demographic factors*

Several demographic factors may influence the probability of AD. Aging is the most prominent risk factor for AD, with the vast majority of incident cases occurring in later life. Prevalence of AD is thought to double every 5 years beyond the age of 65 years (Kukull, Higdon et al. 2002). Females have a higher prevalence of AD than men (Plassman, Langa et al. 2007). Social epidemiology studies have also suggested that one's educational level, socioeconomic status and lifestyle are associated with AD expression (Stern, Gurland et al. 1994; Evans, Hebert et al. 1997; Lee, Back et al. 2010). Demographic risk factors can be easily ascertained by self-report. Still, the interpretation of epidemiological risk assessment is complicated by selection biases, small ethnic sample sizes and differences in environmental exposures.

*Predictive genetic testing*

AD is unique in that both deterministic and susceptibility genes can confer risk for the disease. Genetic testing already takes place for early-onset, autosomal dominantly inherited forms of AD by looking for mutations in genes like APP, PS1 and PS2 (Campion, Dumanchin et al. 1999). Such familial cases, however, are very rare in the general population, accounting for approximately 2% of all AD cases (Campion, Dumanchin et al. 1999). AD risk can also be conferred by susceptibility genetic testing using APOE genotyping, where the APOE 4 allele increases the risk of AD but is not a definitive predictor of the disease (Farrer, Cupples et al. 1997; Roses 2006). Research has also identified over 550 possible susceptibility genes for AD (Lambert, Heath et al. 2009). However, many of these have been identified via genome-wide association studies and await replication in subsequent studies, and their impact on AD risk is considerably smaller than APOE (Bertram, McQueen et al. 2007).

For most asymptomatic individuals seeking genetic risk for AD, susceptibility testing using APOE genotyping would be more relevant for several reasons. First, APOE is a susceptibility polymorphism for late-onset AD, which is the most common form of AD and the most common dementia in the aging population. Second, approximately a quarter of the general population in the US carries the risk-conferring APOE 4 allele (Raber, Huang et al. 2004). Third, hundreds of studies have demonstrated the well-documented association of APOE genotype with risk of AD in which one copy of the APOE 4 allele increases risk by 3-fold and two copies increases risk by 12–15-fold (Farrer, Cupples et al. 1997; Bertram, McQueen et al. 2007). The risk of developing AD for a given individual with one or two APOE 4 alleles also varies with age, sex and ethnicity (Farrer, Cupples et al. 1997; Cupples, Farrer et al. 2004).

*Clinical assessment of MCI*

MCI describes a syndrome in which an individual has specified deficits in one or more cognitive domains, but is not impaired in activities of daily living and consequently does not meet criteria for dementia (Petersen, Stevens et al. 2001). Some people who suffer from MCI will return to normal functioning or remain stable for years, but many will develop AD (Luis, Loewenstein et al. 2003; Albert, DeKosky et al. 2011; Reiman, McKhann et al. 2011). A number of studies have examined progression from MCI to AD (Bruscoli and Lovestone 2004). The annual conversion rate from MCI to clinical AD is approximately 10–15% and the lifetime risk is 80% or more. However, individuals who have at least one APOE 4 allele have a much higher risk of conversion from MCI to AD than those who do not (Petersen, Smith et al. 1995; Farlow, He et al. 2004; Petersen and Morris 2005). The designation of MCI is already being used clinically, as reflected by the development of screening practices and clinical guidelines have been published in the US and Europe (Portet, Ousset et al. 2006; Lonie, Tierney et al. 2009). All of these efforts emphasize the implications of using MCI as a phenotypic risk factor of AD.

Since MCI patients are at increased risk of developing AD and since APOE genotyping dramatically modifies the risk estimates of persons with MCI, the significance of efforts to better assess and communicate AD risk to patient with MCI is considerable. The clinical trials conducted by REVEAL investigators are the only ones to date that have used APOE genotype disclosure (including to patients with MCI) and provide us an opportunity to explore disclosure in the context of phenotype-genotype risk interactions.

***Impact of risk assessment for AD***

Disclosure of risk for AD is not typically conducted as part of standard healthcare, because there are still significant concerns about the limitations and even the potential harms. Skeptics express concerns over the limited predictive value of available tests and absent of prevention and treatment options (ACMG/ASHG 1995; Brodaty, Conneally et al. 1995; Goldman, Hahn et al. 2011). In addition, concerns over the ethical and psychological harms of genetic susceptibility testing of AD include the possibility of psychological distress, family discord, social stigmatization, and insurance or employment bias (Kukull, Higdon et al. 2002; Offit 2008; Goldman, Hahn et al. 2011).

However, this situation is likely to change in the coming years for several reasons. First, the potential for the use of APOE genotyping in devising treatment strategies for AD patients are being vigorously pursued through an increasing variety of clinical trials. Several papers suggest the treatment-response differences based upon APOE genotype in clinical trials of symptomatic or as yet unapproved disease modifying medications (Petersen and Morris 2005; Risner, Saunders et al. 2006; Cacabelos 2007). Some studies also show beneficial treatment effects on improving symptoms and delaying progression to AD for individuals with MCI (Levey, Lah et al. 2006). Once disease modifying treatments are approved, genetic testing and other forms of predictive testing are likely to be very important in identifying at risk individuals at an early enough age to intervene.

Second, it appears that there is a growing movement to increase access to personal health information via genetic technologies. Predictive genetic testing for AD is now offered by some direct to consumer genetic testing companies that bypass the healthcare system, although there is much debate over ethical, legal and policy issues (Messner 2011). Interest in genetic risk assessment for AD was assessed by surveys posing hypothetical genetic testing scenarios (Green, Clarke et al. 1997). A survey of 203 first-degree relatives of people with AD found that a majority

of participants expressed intentions to pursue risk assessment with perceived pros outweighing cons (Roberts 2000). A general population telephone survey found that 79% of respondents expressed interest in predictive genetic testing for AD and that they would pay on average more than US$300 for such a test (Neumann, Hammitt et al. 2001). Findings of the REVEAL studies show that many participants believed that information would be helpful even in the absence of proven medical care options to reduce their AD risk. The main motivations for seeking such testing including arranging personal affairs, informing decisions about long-term care insurance, preparing the family for the possibility of illness, and emotional relief if found to be at lower risk (Roberts, LaRusse et al. 2003; Kopits, Chen et al. 2011).

Third, a growing literature suggesting that people seeking risk information for AD through formal education and genetic counseling generally find it useful and do not experience adverse effects. In terms of the psychological impact of APOE disclosure, a prospective longitudinal cohort study of 76 asymptomatic individuals did not find any significant adverse emotional reactions to risk information beyond 1 month (Romero, Garry et al. 2005). REVEAL I study also suggests that the test-related distress experienced by those receiving positive results for a deterministic mutation is similar to the distress experienced by those receiving positive results from genetic susceptibility testing, and that the majority of participants receiving genotype disclosure do not experience clinically significant distress after learning of their test results (Cassidy, Roberts et al. 2008).

Forth, although studies have generally found that genetic risk information by itself is insufficient to promote complex behavior changes such as smoking cessation and alteration of dietary and exercise habits (Marteau and Lerman 2001; Heshka, Palleschi et al. 2008), the impact of AD risk assessment reveals beneficial behavioral change. The REVEAL study shows that higher-risk participants are more likely to report health behavior change (addition of vitamins or nutritional

supplements) than lower risk participants (Chao, Roberts et al. 2008). Another behavior of interest is insurance purchasing. APOE 4 positive participants were five times more likely than controls to report long term care insurance changes during the one year follow-up (Zick, Mathews et al. 2005).

Given these reasons, it seems likely that disclosure of personal AD risk will occur on a more frequent basis. However, little is known about how patients, and particularly those with MCI, will make sense of the abstract and probabilistic nature of the risk information that will be conveyed. This suggests that the process and quality of AD risk disclosure in our proposed study is an important and urgent issue to study.

***Communicating genetic risk to patients with MCI***

The abstract and complex nature of information conveyed during AD risk disclosure can be cognitively and emotionally overwhelming for anyone, and patients with MCI are likely to struggle even more than others to understand this information (Heshka, Palleschi et al. 2008; Roberts, Christensen et al. 2011). It is not enough merely to generate risk estimates for AD, effective ways of conveying risk to patients must also be identified and employed.

In previous work on genetic counseling communication, the majority of genetic counselor dialogue was found to be informational in nature (Pieterse, van Dulmen et al. 2005; Meiser, Irle et al. 2008). For example, Roter and colleagues videotaped and analyzed 177 prenatal and cancer genetic counseling sessions with simulated clients. Nearly half of counselor talk involved the provision of basic biomedical information to the patients, while only 4% was psychosocial, emotional and facilitative talk (Roter, Ellington et al. 2006). Similarly, studies on BRCA1 pretest and result disclosure genetic counseling for African American patients and their families revealed that the didactic teaching is the predominant counseling style (Ellington, Roter et al. 2005;

Ellington, Baty et al. 2006). In relation to AD risk communication, Lerner and colleagues analyzed 262 recorded genotype risk disclosure sessions to asymptomatic adult children of a parent with AD and found that clinicians in these sessions were verbally dominant, and more than half of all provider statements were devoted to biomedical information. In the contrast, little psychosocial and emotionally responsive dialogue (expression of empathy, concern, reassurance or partnership) took place. For the patients, a large proportion of all patient talk (39%) was essentially passive acceptance and agreement with clinical information (Lerner, Roberts et al. 2014). This informational dominated counseling practice is in contrast to how current theory and research suggest that health care providers can be responsive to patients' emotional concerns in order to facilitate patients optimally process information and apply it in their own lives (Ellington, Kelly et al. 2011).

Despite a larger body of literature examining how genetic risk information is communicated to patients with normal cognitive functioning, there are few studies have evaluated medical interactions with cognitive impaired patients. A recent survey of 448 clinicians working with MCI patients found that they report commonly discussing AD risk with these patients but that practices for doing so varied greatly (Roberts, Karlawish et al. 2010). Most research on dementia diagnostic disclosure has used qualitative interviews and post-visit questionnaires to obtain retrospective accounts from patients, caregivers, and physicians to characterize diagnostic conversations, but the descriptions are likely limited by reporter bias (Smith and Beattie 2001; Bamford, Lamont et al. 2004; Aminzadeh, Byszewski et al. 2007). These studies are also limited in small sample size and did not have standardized assessments of clinician communication behaviors.

In studies that did examine specifically the interaction between clinicians and patients with cognitive impairment, Sugarman and colleagues analyzed 26 informed consent encounters for

dementia research. The findings showed that more cognitively impaired patients were less engaged in discussions, devoted a higher proportion of their talk to agreement and asked fewer questions (Sugarman, Roter et al. 2007). Another study analyzed 54 audio recordings where dementia diagnosis was delivered to patients with mild dementia and their caregivers. There is relative high use of positive rapport and facilitative skills by physicians, but relative low emotionally-explicit communication with few statements of empathy or partnership to patients or caregivers (Zaleta and Carpenter 2010). Given these study findings, counselor communication behaviors may not be adequate to facilitate emotional expression and cognitive processing in clients with MCI.

As evidence on how clinicians communicate with patients who have cognitive deficits is rare, this proposed study will address this significant need to provide a systematic evaluation of the ways in which AD risk is shared with patients and family members during a medical visit, with an emphasis on how affective and cognitive markers of exchange are facilitated and expressed. The addition of APOE genotype for risk assessment in the REVEAL IV study also provides an opportunity to compare the communication styles of disclosure sessions with and without genetic risk discussions.

***Involvement of family members in medical visit communication***

Medicare Current Beneficiary Survey (MCBS) shows nearly 40% of community-dwelling older adults reported being routinely accompanied to their medical visits by a family member, usually the spouse or adult children (Wolff and Roter 2008; Wolff, Boyd et al. 2012). While many studies have examined the physician-patient communication, family member involvement in these medical interactions has attracted little research attention.

It is feared that the intrusion of a family member into the doctor-patient interaction may result in a loss of patient autonomy and jeopardize confidentiality (Kapp 1992; Greene, Majerovitz et al. 1994). Indeed, there is some evidence that patients tend to be more passive in their medical visits when a companion is present. Physicians may direct information toward the companion, rather than the patient, and both the physician and companion may ignore the patient in care discussions (Beisecker 1989; Greene, Majerovitz et al. 1994). This may be true for patients with MCI who are accompanied by a family member. Sugarman and colleagues documented that conversations occurred primarily between the clinician and the companion, with patients speaking less (Sugarman, Roter et al. 2007). However, it is impossible to know whether the low levels of patient input into these discussions were a result of cognitive impairment, the participation of a companion, or the complex nature of the communication process.

A recent more detailed analysis of this study data explored the pathways through which these strategies affected patient engagement in the dialogue (Wolff, Clayman et al. 2012). When family members prompted the patients to discuss concerns, state their opinion or ask questions, patients in fact asked significantly more questions of their doctor and were less likely to passively accept physician information. Patients and their family member were also more pro-active in directing the course of the visit by orienting the doctor to their agenda, introducing new topics, and disclosing more psychosocial and biomedical information.

Moreover, observational studies and meta-analyses have provided compelling evidence that the presence of a companion is beneficial to the care process: physicians give more information when family members are present than when patients are unaccompanied (Labrecque, Blanchard et al. 1991; Prohaska 1996) and report that the presence of a companion increases patient information recall (Jansen, van Weert et al. 2010), engagement in medical decision-making (Clayman, Roter et

al. 2005), adherence to medical treatments (DiMatteo 2004), and both patient and physician understanding (Schilling, Scatena et al. 2002). MCBS respondents who reported that an accompanying family member had actively facilitated their medical visit communication were more highly satisfied with physician informativeness and interpersonal skills than those less facilitated by companions or who were alone. These relationships were strongest among beneficiaries who were older, who had poorer physical or mental health and who were least educated suggesting that it is the more vulnerable who benefit the most from active engagement of family in their medical visits (Wolff and Roter 2008; Wolff, Boyd et al. 2012). In view of this evidence, several position papers and commentaries from professional societies have set forth policies to promote the physician-patient-family partnership (AMA 1993).

There are few studies of any kind that investigate how clinicians communicate with patients who have cognitive deficits and are accompanied by a family member. The importance of this work is to not only examine the medical communication between physician and patients with MCI, but also the communication to patient care partners who may be asked to assume a greater caregiving and health decision-making role should conversion to AD occur.

***Physician-patient communication and patient satisfaction***

There is a growing evidence base that links the quality of physician-patient communication to patients' outcomes, including information understanding and recall, treatment compliance, as well as physical and emotional health outcomes (Hall, Roter et al. 1988; Stewart 1995; Di Blasi, Harkness et al. 2001; Griffin, Kinmonth et al. 2004). In view of this evidence, "Health People 2020" has set goals to increase the proportion of patients who report that their physicians have satisfactory communication skills (HealthyPeople2020). To achieve this goal, a key first step is to identify

satisfactory communication strategies that are already in use, so that education and training efforts can be constructed to maximize their use.

Prior research has demonstrated that psychosocially oriented patient-centered communication have a positive impact on patient satisfaction with provider behavior and with patient expectations being met (Stewart 1995; Aruguete and Roberts 2002; Beck, Daughtridge et al. 2002; Zachariae, Pedersen et al. 2003; Roter DL 2006). Family members who accompany older patients to medical visits are most often spouse or adult children and these visit companions play an important and largely positive role in facilitating physician-patient communication. Estimates from the Medicare Current Beneficiary Survey and meta-analysis of family involvement in patients' general medical visits shows that some 40% of older adults are routinely accompanied to their medical visits and that they report higher satisfaction with physician informativeness and rapport building skills than those who are unaccompanied or accompanied by less active family members (Street and Gordon 2008; Wolff and Roter 2008; Wolff and Roter 2011). However, specific companion communication behaviors in enhancing greater patients' satisfaction has not been well articulated.

While several studies have examined the impact of family member presence on patient satisfaction with visit communication, there has been less attention paid to companions' perspective on the communication process. One study by Schmidt and colleagues analyzed 23 routine AD primary care visit found that the more family caregivers contributed to visit interaction, the more satisfied they were with the visit (Schmidt, Lingler et al. 2009). Prior research on patient-companion agreement have shown that patients and companions almost never show perfect agreement and they are less likely to agree about subjective issues, such as satisfaction with care (Epstein, Hall et al. 1989; Neumann, Araki et al. 2000; Castle 2005; Eggenberger, Heimerl et al.

2013). Specifically, the level of patient-caregiver agreement on satisfaction is less among patients with worse health status, and family caregivers tend to rate higher satisfaction with care (Epstein, Hall et al. 1989; Castle 2005). In the context of AD risk disclosure, when patients are likely to have mild cognitive impairment, companions can offer a unique and perhaps more accurate perspective on care quality to complement the patient's assessment (Lynn Snow, Cook et al. 2005; Pickard and Knight 2005). It is thus critical to evaluate companions' ratings of session satisfaction and how it differs from patients' assessment.

## CONCEPTUAL FRAMEWORK

### *Social cognitive processing model*

Individuals process threatening health information at both an emotional and cognitive level (Leventhal 1997; Miller SM 2000). The social cognitive processing (SCP) model, proposed by Lepore and colleagues, suggests that cognitive processing occurs within an intrapsychic and interpersonal context (Lepore 2001). In this model, cognitive processing refers to an internal psychological activity that fosters a better integration of the stress information within the individual's working schema. Social interactions, as a means to moderate one's cognitive processing, may play a crucial role in the success or failure of individual's cognitive processing of a stress.

The SCP model suggests that the act of talking with supportive others about the event and its associated consequences may encourage the individual to make meaning from the event in the face of someone who validates their concerns, helps correct faulty assumptions, and promotes an accurate understanding of the event (Lepore, Ragan et al. 2000; Lepore 2001). Consequently, individuals can disclose their thoughts and feelings, begin to make sense of their situation, and thus

reduce distress, take informed actions, and even evidence some physical benefit (Lepore, Ragan et al. 2000; Kennedy-Moore 2001; Austenfeld and Stanton 2004; Lepore SJ, Kernan WD et al. 2009). For instance, supportive social responses to the disclosures of prostate cancer patients (Lepore 1998) and bereaved mothers (Lepore 1996) facilitated talking and reduced avoidant thinking and behaviors.

On the other hand, individuals who are encountered with unsupportive and critical social responses may have difficulty in cognitive processing. Individuals will be less likely to disclose, reflect, feel validated, and process their stressful experience with others (Lepore, Ragan et al. 2000; Lepore 2001), which may prevent adequate psychological adjustment. Inhibition of talking and thinking about stress also can interfere with cognitive processing by limiting individual's access to new information and alternative perspectives, which may be critical for cognitive integration of stress-related information (Lepore, Ragan et al. 2000).

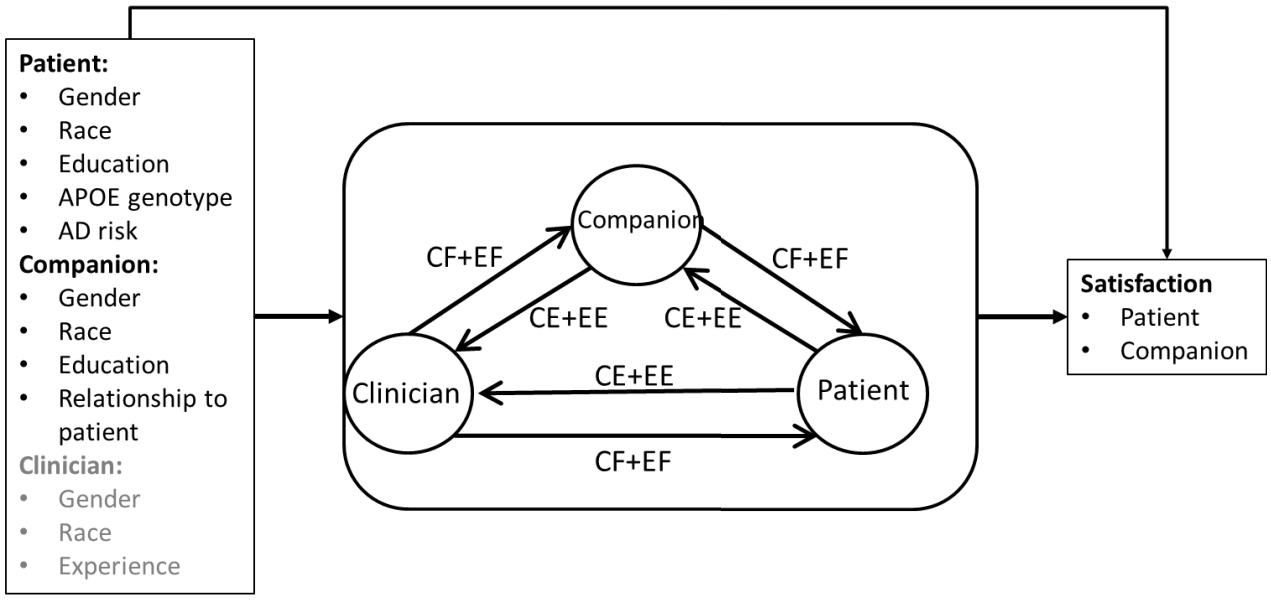
Despite the growing evidence linking supportive social interactions to cognitive processing and emotional adjustment, we know little about the mechanisms that underlie this phenomenon. Ellington and colleagues explored the application of the SCP model principals of the facilitation of cognitive-emotional processing of health information to simulated genetic counseling sessions. They coded and analyzed simulated genetic counselor-client interactions to understand the communication components that are consistent with the SCP model tenets. The results revealed that genetic counselor attempts to promote client emotional expression and insight may predict client cognitive and at least some emotional processing (Ellington, Kelly et al. 2011).

In sum, the SCP model proposes that interpersonal interactions play a significant role in adjustment following a stressful experience. During an AD risk disclosure discussion, clinicians have an opportunity to promote, through their communication behaviors, patient and family

companion's insight and emotional expression. Moving beyond the earlier work of Ellington and colleagues, for the purpose of this study, we will adapt the SCP model principals to capture not only clinician but also family member communication that act to facilitate the patient's emotional adjustment to and cognitive understanding of the risk information.

***Conceptual framework***

**Figure 1. 1. Conceptual Framework: Clinician-Patient-Companion Triadic Interaction**




As illustrated in Figure 1.1, the conceptual framework suggests communication behaviors that are consistent with tenets of the cognitive-emotional processing model. *Cognitive Facilitation (CF)* consists of question asking in the biomedical realm, checks and paraphrasing, cueing interest for further elaboration, as well as asking for opinions, reassurance and understanding. *Emotional Facilitation (EF)* consists of both psychosocial and lifestyle questions, statements of approval and

compliment, and emotional talk (statements of partnership or alliance, expressions of reassurance, concern, empathy and legitimization). *Cognitive Expression (CE)* relates to statements of insight, understanding, and disclosure of relevant information indicative of problem solving, brainstorming and decision making, reflecting in words that indicate causal linkages such as "because" or "effect" and words that relay more tentative associations such as "think" or "realize". *Emotional Expression (EE)* consists of emotional and psychosocial disclosures. The communication assessment approaches, RIAS and LIWC, described in later chapters, will be used to capture the genetic counselor, patient and family member communication elements listed in the model.

Furthermore, the conceptual framework postulates that communication behaviors during AD risk disclosure are related to patient and family companion satisfaction post session. In addition, a variety of patient factors, including age, gender, educational level, cognitive function and AD risk, are likely to influence both communication processes, as well as satisfaction judgments of the care experience (Roter DL 2006). Similarly, the characteristics of the accompanying family member are pertinent to communication behavior in the medical visit, including relationship to the patient (spouse or adult child/other relative), gender and educational level (Wolff and Roter 2011). Genetic counselor's gender, race and years of experience are also related to communication style (Roter DL 2006), but were tested in the current study due to small variance of the data.

## SPECIFIC AIMS

The purpose of this dissertation to provide an in-depth analysis of risk communication and its consequences for family-accompanied patients with MCI during AD risk disclosure discussions.

**Aim 1:** To describe the triadic interaction of genetic counselor, patient and accompanying family member during AD risk disclosure encounters with particular attention to how cognitive and emotional markers of exchange are facilitated and expressed.

**Aim 2:** To contrast communication style of risk disclosure discussions in which genotype results are disclosed (or not) to family-accompanied patients with MCI.

**Aim 3:** To explore the relationship between genetic counselors' use of facilitative communication strategies on verbal indicators of cognitive and emotional processing by patients and an accompanying family member.

**Aim 4:** To identify features of the risk disclosure encounter that predict patient and family companion satisfaction with disclosure sessions.

## STUDY HYPOTHESES

The study hypotheses are framed by an application of the cognitive-emotional processing principals and existing evidence based on studies of physician-patient communication.

***Hypothesis 1:*** *The genotype discussions would be less patient-centered and have a more didactic teaching style characterized by greater provision of basic biomedical information and less psychosocial, emotional and facilitative talk compared to non-genotype AD risk discussions.*

***Justification:*** According to the broader genetic counseling literature, and as described in the analysis of APOE genotype disclosure to asymptomatic adult children of an AD parent, genetic risk discussions are clinician dominated, with patients asking few questions and expressing relatively little emotion. A large proportion of all patient statements are passive acceptance and agreement with clinical information (Ellington, Baty et al. 2006; Roter, Ellington et al. 2006; Meiser, Irle et al. 2008; Lerner, Roberts et al. 2014). We anticipate higher genetic counselor dominance and lower

levels of family companion and patient engagement in genotype inclusive discussions over those focusing solely on cognitive impairment because the more abstract and technical nature of the genetic information is likely to overwhelm the discussion and be received in a similarly passive way as it was for other genetic counseling clients.

***Hypothesis 2:*** *Greater use of a patient-centered communication style and use of more emotional and cognitive facilitation strategies by genetic counselors will be associated with higher level of emotional and cognitive expression from patients and their visit companions.*

***Justification:*** As conceptualized in our adaptation of the SCP model, we think genetic counselors have an opportunity to promote, through their communication behaviors, patient and companion expressions of insight and emotion. Based on Ellington's earlier study of the genetic counselor-simulated client interactions, they found that genetic counselor attempts to promote client emotional expression and insight may predict client cognitive and at least some emotional processing (Ellington, Kelly et al. 2011). The result suggests a direction for the hypothesis testing in this proposed study.

***Hypothesis 3:*** *Genetic counselors who demonstrate a more patient-centered communication style and make more attempts to facilitate emotional and cognitive expressions will receive higher satisfaction ratings from both patients with MCI and companions.*

***Justification:*** The communication style is thought to influence the care experience reflected in patients' and companions' satisfaction about the visit. Previous work on physician-patient communication showed that psychosocially oriented patient-centered communication have a positive impact on patient satisfaction with provider behavior and with patient expectations being met (Stewart 1995; Beck, Daughtridge et al. 2002; Zachariae, Pedersen et al. 2003; Roter, Ellington et al. 2006).

***Hypothesis 4:*** *We anticipate that visit companions will play a significant role in bridging patient-genetic counselor communication and that their communication will be associated with patient satisfaction.*

***Justification:*** Estimates from the Medicare Current Beneficiary Survey and meta-analysis of family involvement in patients' general medical visits shows that patient accompanied by a supportive family member report higher satisfaction with physician informativeness and rapport building skills than those who are unaccompanied or accompanied by less active family members (Street and Gordon 2008; Wolff and Roter 2008; Wolff and Roter 2011). These relationships were strongest among beneficiaries who were older and had poorer physical or mental health suggesting that it is the more vulnerable who benefit the most from active engagement of family in their medical visits (Wolff and Roter 2008; Wolff, Boyd et al. 2012).

# CHAPTER 2: MANUSCRIPT ONE

**Disclosing Alzheimer's disease risk to cognitively impaired patient and family companion: an assessment of the triadic communication pattern**


## ABSTRACT

**Objectives:** To provide a systematic quantitative evaluation of Alzheimer's disease (AD) risk communication between genetic counselors and patients with mild cognitive impairment (MCI) and their accompanying family members, and to compare communication patterns in AD risk disclosure sessions with and without discussions of genetic risks.

**Methods:** Seventy nine audio recordings of AD risk disclosure sessions collected as part of a randomized clinical trial, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL IV), were analyzed for this study. The Roter Interaction Analysis System (RIAS) was used to quantitatively describing AD risk communication among the genetic counselor, patient and accompanying family member. One-way ANOVA and Chi-square test were used to compare baseline characteristics between the genotype nondisclosure group and the ε4-negative and ε4-positive subgroups. Multilevel analysis was conducted to identify differences in communication dynamics across the three study groups.

**Results:** The AD risk disclosure sessions (regardless of patient genotype status) were counselor-driven and psychosocially focused. Our findings indicate genotype disclosure discussions were less patient-centered than non-genotype AD risk discussions ($p<0.001$). Companions in the ε4 positive group were more verbally active ($p=0.04$), disclosed more medical information ($p=0.049$), made

more positive (p=0.049) and orientation statements (p=0.04), and were rated as more nonverbally positive (p=0.006) than those in the ε4 negative group.

**Conclusions:** This study furthers our understanding of how cognitively impaired patients and family companions communicate in AD risk delivery processes, and contributes to an evidence base that can guide communication training for the benefit of patients and their families.

## INTRODUCTION

Prevention and early address of Alzheimer's disease (AD) is a national priority. New research initiatives are increasingly characterized as secondary prevention trials that target at risk populations, including individuals who are either asymptomatic or experiencing mild cognitive impairment (MCI) (Sperling, Aisen et al. 2011; Sperling, Jack et al. 2011). Despite growing reliance on biomarkers and susceptibility genetic testing to assess AD risk (Farrer, Cupples et al. 1997; Roses 2006), there is limited literature describing how this risk is communicated to patients, especially those with MCI.

Despite a large body of literature examining how genetic risk information is communicated to patients with normal cognitive functioning, there are few studies that have evaluated medical interactions with cognitively impaired patients. Understanding complex and unfamiliar concepts associated with genomic risk is difficult for many patients but it is especially challenging for older, less literate and more medically complex adults and certainly challenging for patients with cognitive deficits (Heshka, Palleschi et al. 2008; Chen, Farwell et al. 2009; Roberts, Christensen et al. 2011; Wolff and Roter 2011). The few studies that have specifically examined the interaction between clinicians and patients with cognitive impairment have found low levels of substantive engagement. One such study by Sugarman and colleagues analyzed 26 informed consent encounters for dementia research and found that more cognitively impaired patients in the study asked fewer questions and were more passive in agreeing with clinician statements than those with less impairment (Sugarman, Roter et al. 2007). Another study analyzed 54 visit recordings in which a dementia diagnosis was delivered to patients with mild dementia and an accompanying family member. That study found relatively high use of positive exchange and facilitative skills by clinicians, but low levels of emotionally explicit communication directed to patients or family

members (Zaleta and Carpenter 2010). These findings suggest significant communication challenges in assisting patients with MCI in emotional and cognitive processing of risk information.

Family members frequently accompany patients with the MCI to medical visits and often assume caregiver and decision-making roles. As reflected in the studies mentioned above, there is little in-depth analysis of their engagement in AD disclosure sessions that include genetic information. The current study provides a systematic quantitative evaluation of AD risk communication between genetic counselors and patients with MCI, and their accompanying family member. This is done by analyzing audio recordings of AD risk disclosure collected as part of a randomized clinical trial, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL IV) (2009-2012) in which APOE genotype results are/are not included in an AD risk discussion.

Of particular interest to this study is a comparison of communication style in the risk disclosure sessions with and without reference to genetic risk information. We expect that the genotype discussions would be less patient-centered and have a more didactic teaching style characterized by greater provision of basic biomedical information and less psychosocial, emotional and facilitative talk compared to non-genotype AD risk discussions. We also expect that the presence of a family companion would influence the communication processes of patients receiving ε4 positive rather than ε4 negative genetic test results.

## METHODS

### Study design and data collection

This study uses a sample of audio-recorded AD risk disclosure sessions collected as part of the REVEAL IV randomized clinical trial. Patients and an accompanying family member (referred to as a visit companion) were recruited at four REVEAL study sites (Ann Arbor, Boston,

Philadelphia and Washington, D.C.). Eligible patients were older adults (age range: 55-90 years) who did not have dementia, had received a diagnosis of MCI from a specialist through the REVEAL site's research registry or through clinical referrals or community screening, and had a memory complaint either reported by the patient or an informant. Patients were excluded if they scored in clinically significant ranges on validated measures of cognitive functioning (Mini-Mental State Examination score<=20), depression (The Geriatric Depression Rating Scale score>=12), or anxiety (The State-Trait Anxiety Inventory score>=19).

Patients were randomly assigned in a 2:1 ratio to either APOE genotyping disclosure group (N=75) or APOE genotyping nondisclosure group (N=39). Patients assigned to the nondisclosure group received 3-year risk estimates specific for age and the diagnosis of MCI. Patients in the disclosure group were given the same risk estimates with additional information based on their genotype-specific risk (Figure 2.1 displays sample risk presentations).

The 3-year risk estimate provided to patients was defined as the cumulative risk of developing AD from the age at disclosure over the next three years. These risk estimates were calculated from the Memory Impairment Study, a clinical trial involving 769 amnestic-MCI patients, which provided three-year risk data stratified by APOE genotype (Petersen, Thomas et al. 2005). Patients with one or two ε4 alleles are at increased risk of developing Alzheimer's disease. Although patients were given additional information that the risk for ε4/ε4 may be higher than a single copy of the gene, they were not provided with a specific risk number stratified by APOE genotype. Individuals with the ε2/ε4, ε3/ε4 and ε4/ε4 genotypes were given the same positive genotype risk estimates.

The risk disclosure sessions were led by a study clinician who specialized in genetic counseling, clinical psychology, general practice or neurology. Although study clinicians were

instructed to follow a prescribed topic protocol, they were given latitude to address the specific needs of individual patients.

Of the 114 patients who received AD risk assessment, 79 (69.3%) agreed to have their risk disclosure session audio-recorded and received the disclosure session from a board certified genetic counselor. This group comprises the sample for the current study. The current study was reviewed by the Johns Hopkins University Bloomberg School of Public Health Institutional Review Board.

**AD risk disclosure communication**

Audio recordings of risk disclosure dialogue were coded using the Roter Interaction Analysis System (RIAS), a widely used and well validated system for empirically describing medical visit communication (Roter and Larson 2002). The unit of analysis is a complete thought communicated as a single word, simple sentence, or a clause in complex sentence. Statements are coded directly from recordings and assigned to one of thirty-seven mutually exclusive and exhaustive code categories. The code categories address task-focused categories such as questions and information and counseling statements in topical areas related to medical condition, therapeutic regimen, lifestyle and psychosocial information. Also included are socio-emotional categories that capture positive or negative exchange through approvals, compliments, disagreements and criticisms, as well as socioemotional responses like empathy, concern, reassurance and legitimation. RIAS composite codes and examples are presented in Table 2.1.

Four measures of disclosure processes were also examined: (1) session length in minutes; (2) the sum of each speaker (genetic counselor, patient and family companion) statements as an indication of total dialogue; (3) verbal dominance, which is constructed as the ratio of clinician to participant and companion statements; and (4) patient-centered communication, reflecting the ratio

of socioemotional to instrumental exchange. The numerator of the measure consists of patient and companion psychosocial and lifestyle disclosure, all patient and companion questions and emotional statements plus genetic counselor psychosocial and lifestyle questions, information and counseling and activation/facilitation statements. The denominator consists of the sum of genetic counselors' medical questions and orientations, as well as patient, companion and genetic counselors' statements relating medical information. The measure has been used in a number of studies and it shows predictive and concurrent validity to a variety of patient and physician outcomes (Mead and Bower 2000; Roter and Hall 2004).

In addition to the verbal categories of exchange, a RIAS coder rated each speaker on a 6-point scale (low to high) reflecting both positive (interest, warmth, engagement, empathy, respectfulness and interaction) and negative affect (dominance and hurried for the genetic counselor, anxiety and distress for the patient and companion). These ratings have been found to reflect voice tone that is largely independent of literal verbal content (Hall, Roter et al. 1981).

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 .83 across clinician categories and .93 for patient categories. Reliability for the ratings of emotional tone was calculated as agreement within 1 scale point and these averaged 99% (range 89–100%) for all three speakers.

**Survey measures**

Patient and companion characteristics, including age, gender, race, level of education, numeracy, dyad relationship and family history of AD/dementia were assessed by self-report questionnaire items.

For the purposes of this study, a family history of AD/dementia was defined as self-report of the number of relatives diagnosed with AD or dementia (0 "negative" and >=1 "positive"). Objective numeracy skills were assessed using a validated eight-item scale developed by Lipkus and colleagues (Lipkus, Samsa et al. 2001). Possible scores ranged from 0 to 8 (indicating number of items answered correctly), with higher scores indicating higher level of numeracy. No standard cut-offs are defined for high or low numeracy groups. The mean of the numeracy measure for the study population is 6.3 (SD=1.4). We propose that scores less than or equal to 4, approximately one standard deviation below the mean, be interpreted as low numeracy; scores equal to 8, approximately one standard deviation about the mean, be interpreted as high numeracy; and scores between 5 and 7 be considered average numeracy.

General cognitive function of the patient was assessed by the Mini-Mental State Examination (MMSE) (Folstein, Folstein et al. 1975). A score greater than or equal to 24 indicates adequate general cognitive function, 20 to 24 suggests mild cognitive impairment, 13 to 20 suggests moderate cognitive impairment, and less than 12 indicates severe cognitive impairment.

APOE genotype was dichotomized depending on carrier status of one copy of the APOE ε4 allele, patients with one or two ε4 alleles are at increased risk of developing Alzheimer's disease than patients without a copy of the APOE ε4 allele.

**Data analyses**

To compare baseline variables between the genotype nondisclosure group and the ε4-negative and ε4-positive subgroups, one-way Analysis of Variance (ANOVA) was used for contrasts of continuous variables and Chi-square test for categorical variables. Differences of risk communication dynamics between groups were analyzed using mixed effect models with a random

effect to account for clustering by genetic counselor. Covariates in all communication analysis included patient and companion gender, MMSE score, 3-year AD risk, patient-companion relationship and visit length. The primary analysis compared the two randomized groups (genotype disclosure and nondisclosure groups). A secondary analysis compared the subgroup of patients in the genotype disclosure group who were informed that they carried at least one ε4 allele (the ε4 positive subgroup), with a subgroup of patients who were informed that they did not carry an ε4 allele (the ε4 negative subgroup). MMSE score was coded to the sample mean for 3 patients with missing survey responses in this study. Missing values were excluded on a list-wise basis in all analyses. 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, Tex).

## RESULTS

### Sample characteristics

A full description of sample characteristics, stratified by genotype disclosure groups, is presented in Table 2.2. Three genetic counselors participated in this study representing three study sites (Ann Arbor, Boston and Philadelphia); all the counselors were female Caucasians with an average age of 36 years. The average number of patients seen by each genetic counselor was 26 (range: 4-40).

The 79 patients comprising our study sample averaged 76 years of age, with the majority of patients being male (56%) and Caucasian (96%). The mean level of education among patients was 16 years, and the average score on the numeracy scale was 6 out of 8 items answered correctly; 20

patients (25%) were classified as low numeracy, 37 patients (47%) were classified as average numeracy, and 22 (28%) were classified as high numeracy.

Patients had a mean MMSE score of 27 (range: 21–30). The majority of patients (86%) showed adequate cognitive function (MMSE >=24) and eleven were scored as having in the mild cognitive impairment (MMSE 20-23), nevertheless all patients entered the REVEAL IV study with a diagnosis of MCI. The average 3-year risk estimates of progressing to AD provided to all patients was 37% ranging from 8% to 57%.

Of the 54 patients in the genotype disclosure group, 57% (N=31) carried at least one ε4 allele; 10 had the ε4/ε4 genotype and 21 had the ε3/ε4 genotype. Among those did not have the ε4 allele (43%, N=23), 20 had the ε3/ε3 genotype and 3 had the ε2/ε3 genotype.

All patients were accompanied to the session by a family member. Visit companions (N=79) were on average 68 years of age and were predominantly female (70%), and spouses (65%), or adult children (24%); fewer companions were described as "other" (11%) and they were primarily relatives. Companions were well-educated with an average 16 years of education and the majority (89%) had average or high numeracy.

Patients who were ε4 positive had significantly higher 3-year AD risk ($p<0.001$) and were more likely to have a positive family history of AD or dementia ($p=0.02$) than those who were ε4 negative or those were assigned to receive risk assessment without ε4 disclosure. No other patient or companion baseline attributes differed significantly across the three study groups.

**AD risk disclosure communication**

*Verbal activity of genetic counselor, patient and companion*

The length of risk discussions ranged from 9.7 minutes to 63.5 minutes with a mean of 27.0 (SD=9.7). Genetic counselors clearly dominated the exchanges. The typical risk disclosure session averaged 556 statements; on average, the genetic counselor made 351 (63%) of these statements, while the patient and companion contributed similarly to the discussion (19% and 18%, respectively). The genetic counselor averaged 6 statements for each patient statement (range: 1–69) and 9 times more statements than visit companions (range: 2–97). The relationship between patient and companion statements was less extreme with an average of 2.5 patient statements for each companion statement (range: 0.2-17.3).

*Communication profile of genetic counselors, patients and companions*

Table 2.3 (second and third column) displays an overall communication profile of genetic counselors, patients and companions. Overall, the risk disclosure sessions were more patient-centered than biomedically-focused, demonstrated by the average ratio of patient-centered communication of 1.2 (SD=0.4).

Inspection of individual communication categories show that more than half of all genetic counselor statements (57%) were devoted to psychosocial and emotionally responsive dialogue; the most frequent communication categories were psychosocial and lifestyle information and counseling (20%), positive statements (13%), and partnership facilitation (12%). Genetic counselors responsivity to patient emotion (e.g., empathy, concern, reassurance) was less frequent (6%), and they asked few psychosocial questions (0.4%) to either patients or companions. Other categories of counselor exchange were primarily devoted to medical information (41%) and orientation statements (5%).

The most frequent category of interaction for both patients and companions was disclosure of psychosocial information (35% and 34%) followed by biomedical information (17% and 18%). Positive statements accounted for 21% and 18% of patients' and companions' total dialogue, reflecting high levels of expressed assent to what the genetic counselor had just said. Neither patients nor companions asked many questions (5.5% and 6.6%) or explicitly expressed emotion (9.7% and 7.8%).

*AD risk communication comparison between genotype disclosure and genotype nondisclosure groups*

As displayed in Table 2.3, there were no significant differences in the total number of statements by speakers between genotype disclosure (N=54) and nondisclosure groups (N=25). However, genotype nondisclosure relative to disclosure sessions were characterized by a more patient-centered communication pattern. More specifically, genetic counselors provided more psychosocial and lifestyle information, and used more partnering statements to clarify information or check for understanding, but gave less biomedical information when genotype was not discussed. No statistically significant differences were evident in the communication categories for patients or companions.

*AD risk communication comparison between ε4 positive and ε4 negative groups*

As shown in Table 2.4, contrasts between communication in the ε4 positive (N=31) and ε4 negative group (N=23) indicated that genetic counselors tended to ask more psychosocial and lifestyle questions in the ε4 positive group. Companions in the ε4 positive group were more verbally active, disclosed more medical information, and made more positive and orientation

statements. There were no significant differences between the ε4 positive and ε4 negative groups in patient communication categories.

In addition, patients tended to be more nonverbally negative (reflecting higher ratings of anxiety and distress) in the ε4 positive group compared to those in the ε4 negative group. Companions, on the other hand, were rated as more nonverbally positive (reflecting higher ratings of interest, warmth, engagement, empathy, respectfulness and interaction) in the ε4 positive group than those in the ε4 negative group.

## DISCUSSION

The primary study results were consistent with the study hypotheses; genotype disclosure discussions were less patient-centered than non-genotype AD risk discussions. We also found that a family companion was more verbally active in the communication processes of patients who receive ε4 positive rather than negative genetic test results.

Overall, the psychosocially oriented, patient-centered communication pattern identified in our study is consistent with Zaleta and Carpenter's (2010) findings of dementia diagnosis disclosure sessions (Zaleta and Carpenter 2010). Our findings show that the AD risk disclosure sessions (regardless of patient genotype status) are not as dense with biomedical information as genetic counseling communication in the context of BRCA or prenatal testing. These sessions reflect a psychosocially guiding process rather than a didactic teaching process. Genetic counselors incorporate more discussion about psychological issues, such as anticipatory coping strategies for MCI patients. Despite counselors devoting the major portion of the sessions to presenting information, they exhibit patient-centered communication behaviors such as emotional rapport

building, facilitation and patient activation. In these situations, genetic counselors are attempting to establish a shared understanding with the patient and actively facilitate the patient's perspective.

These findings differ from the general approach taken by genetic counselors in other contexts. As described in the analysis of APOE genotype disclosure to asymptomatic adult children of an AD parent (Ellington, Baty et al. 2006; Roter, Ellington et al. 2006; Meiser, Irle et al. 2008; Lerner, Roberts et al. 2014), genetic counseling sessions were largely didactic in nature with relatively little emphasis on psychosocial and emotional topics. Patient voice was largely absent for these sessions and most of their responses were indicative of passive listening and agreements and sharing relatively minimal information (Butow and Lobb 2004; Ellington, Baty et al. 2006). The patient-centered approach adapted by the genetic counselors in the current study may reflect counselors' attempts to elicit cognitive and emotional responses from patients and companions. This is evidenced by more than half of patient and companion statements were disclosing biomedical and psychosocial information, with relatively little passive agreement.

The differences in findings between our study and others may be attributed to the nature of AD genetic testing which requires less biomedical counseling than conditions such as hereditary breast cancer or prenatal diagnosis. In addition, MCI introduces unique complexities because of the impact of patient cognitive impairment on their engagement in session dialogue. Patients with MCI are likely experiencing challenges understanding the risk information provided, and genetic counselors may consequently spend additional time checking patient's understanding and making extra effort to facilitate the communication process. This interpretation is supported by findings in Zaleta and Carpenter's study on dementia diagnosis disclosure. The presence of a companion during risk feedback may also be related to the counselor's use of patient-centered communication, particularly facilitating behaviors.

As we hypothesized, APOE genotype inclusive discussions were less patient centered than those using only cognitive impairment and age to calculate the AD risk, because of the abstract and technical nature of the genetic information conveyed. This focus is likely to overwhelm the discussion as is evident in other genotype disclosure contexts (Ellington, Baty et al. 2006; Roter, Ellington et al. 2006; Meiser, Irle et al. 2008; Lerner, Roberts et al. 2014). Our results indicate that variation in session communication was primarily determined by the genetic counselors. Even within protocol-driven sessions where the counselors followed a standard research protocol, we found substantial variation in counselor's communication styles between the study groups.

An additional goal of the study was to explore companion's involvement in AD risk discussions. Companions are present in all of the study sessions, which is a common feature of medical care for older adults with memory complaints. We expected that family companion presence would influence the risk disclosure processes for patients and especially for those who are ε4 positive. However, given conflicted findings in the literature, we were unsure whether companion presence would help or hinder patient-centered communication and patient engagement in the discussions.

We found that the disclosure of ε4 positive test results was not associated with any specific patient communication behavior but it was related to companion talk. Companions appear to increase their participation when the AD risk information is complicated by the ε4 factor and when the need for more emotional support is greatest. The negative affect ratings for the patients indicate that they are experiencing and demonstrating overt distress and anxiety after receiving the ε4 positive test result. In this instance, the companion may take a more supportive and proactive role by providing or clarifying medical and family history, and directing the course of the session by prompting additional discussion or introducing a new agenda item. The higher positive affect

ratings for companions in the ε4 positive group relative to the ε4 negative group may also demonstrates positive emotional support for patients.

Additionally, nearly a third of companions in this study are blood related family members of the patients and a positive test result has implications for an increased risk for them to develop late-onset AD. The content of the risk discussion is likely to be more directly and personally engaging for companions as it relates to their own concerns about personal risk and risks for their children. Interestingly, counselor's and companion's communication behaviors did not have an impact on patient engagement in the dialogue. While it may be possible for a skilled counselor to facilitate emotional expression and cognitive processing of patients with MCI, this does not appear to be the case in the study sessions. A challenge in this regard, evident in the AD literature broadly is training of clinicians and caregivers in facilitative and non-oppositional communication strategies.

**Limitations**

The study has several notable limitations. The risk estimates do not consider other potential risk factors for the disease, including other genes, environmental exposures and gene–gene or gene–environment interactions. Several predictors of interest that may be relevant to the communication process cannot be evaluated in this study due to little variance, including patient and genetic counselor race. Furthermore, the patients enrolled in the REVEAL IV were largely self-referred and well-educated and may have had different motivations and levels of concern than a typical at-risk individual. Our findings may not apply to other AD risk disclosure sessions, due to the constraints of REVEAL IV as a controlled trial and that only three genetic counselors took part in the study. It is possible that these counselors are not representative of others and their practices do not reflect

common practice but rather idiosyncratic approaches to communication driven by a research protocol.

**Conclusions**

Despite these limitations, our findings suggest that AD risk discussion sessions are primarily counselor driven with a psychosocial focus. Our findings also indicate that the largely unacknowledged role of the visit companion may have important implications for the comprehensiveness of the information a counselor collects and may influence how the patient understands risks. Even with the apparent restriction of a research protocol, we found that the manner in which this was accomplished differed across the study groups. We believe that this study furthers our understanding of how cognitively impaired patients and family members communicate in AD risk delivery processes, and contributes to an evidence base to guide communication training and service for the benefit of patients and their families. More research is needed to understand the predictors of individual counselor communication style, the effects of using patient-centered communication on outcomes important to patients and companions, along with the impact of clinical training on counselor communication behaviors.

## TABLES

### Table 2. 1. RIAS composite codes and coding examples

| RIAS Code | Definition | Coding Examples: Genetic Counselor | Coding Examples: Patient & Companion |
|---|---|---|---|
| Information giving (Biomedical) | Information regarding medical condition, symptoms, diagnosis, prognosis, test results, personal and family medical histories, future treatments or tests to be performed. | -Based on these factors, we would say your risk to develop dementia, the AD type, is estimated to be 8% in the next three years. | -That must mean that my parents somewhere along the line were carrying that, but I know of no Alzheimer's on either side of the family. |
| Information giving (Psychosocial/Lifestyle) | Discussion of emotional reactions, and the impact on family and social relationships relevant to genetic test result and decision making, information on self-care and preventive health habits, implication for work, insurance and finances. | -Other things you can do is maintaining physical, social and mental activity, and limiting alcohol use. | -I tend to be a dark side person.<br>-Maybe that little Lord is telling me "I want to test how strong you are". |
| Question asking (Biomedical) | Questions related to medical condition, symptoms, diagnosis, prognosis, test results, personal and family medical histories, future treatments or tests to be performed. | -What do you recall in terms of being told about MCI?<br>-So what can you do to cope with MCI? | -What does APOE stand for?<br>-Whether it's paired with two or three, doesn't seem to make any difference?<br>-Is there medication for people who cannot function? |
| Question asking (Psychosocial/Lifestyle) | Questions regarding feelings, general state of mind, values and beliefs, lifestyle, family and home situations, work or employment, health habits and self-care issues. | -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? | -Wouldn't you want to know whether you've got it or not?<br>-Do I have to tell my insurance company about all this? |
| Partnering statements | Asking for opinion, permission and reassurance, checking for understanding, cueing interest for further elaboration, and paraphrasing. | -Does that definition help at all?<br>-Does that make sense?<br>-Were you expecting that?<br>-So when you say that, you mean if you're taking life insurance, there's a two-year suicide clause? | -When you say your doctor, you are talking about family doctor at home? |

| | | | |
|---|---|---|---|
| Positive statements | Laughs, compliments, agreements and approval. | -Sounds like you're in good shape on that one. | -You explained it very well. |
| Negitive statements | Criticism and disapproval. | -That's not what I meant. | -I hoped you can come up some ideas I don't know. |
| Emotion Statements | Statements of partnership or alliance, expressions of reassurance, concern, empathy and legitimization. | -It's hard to lose people you care about. -I'm not quite sure about the exact number.<br>-What you're talking about is very common in people who are in a similar situation.<br>-If you think of any questions, feel free to ask. | -This makes me happy not only for myself, probably more for my family.<br>-I get frustrate when I can't remember something that I know I should.<br>-Not to be able to live with XXX as a phenomenal relationship, it's a very depressing thought. |
| Orientation Statements | Gives orientation, instructions, setting visit goals and agenda. | -The purpose of today's visit is to talk about your estimated risk of progressing to Alzheimer's disease in the next three years.<br>-Tell me more what you want to know more about. | -Let me ask you a question.<br>-Go back to that slide. |

**Table 2. 2. Sample characteristics of patients and companions**

| | All | Genotype nondisclosure | Genotype disclosure | |
|---|---|---|---|---|
| | | | ε4 negative | ε4 positive |
| Sample, N | 79 | 25 | 23 | 31 |
| **Patient** | | | | |
| Age, mean (SD) | 75.7 (7.4) | 77.7 (8.0) | 75.7 (6.5) | 74.0 (7.5) |
| Female, % | 35 (44.3) | 9 (36.0) | 13 (56.5) | 13 (42.0) |
| Race, % | | | | |
| African American | 3 (3.8) | 2 (8.0) | 1 (4.3) | 0 |
| White | 76 (96.2) | 23 (92.0) | 22 (95.7) | 31 (100) |
| Education years, mean (SD) | 16.2 (2.9) | 16.0 (2.9) | 16.1 (2.9) | 16.5 (2.9) |
| Numeracy, mean (SD) | 5.9 (2.1) | 5.7 (2.1) | 5.8 (2.2) | 6.1 (2.1) |
| MMSE, mean (SD) | 26.9 (2.1) | 26.5 (2.6) | 27.0 (1.9) | 27.1 (1.8) |
| Family history of AD/dementia, % | 49 (62.0) | 13 (52.0) | 11 (47.8) | 25 (80.6)* |
| 3-year risk, mean (95%CI) | 37.3 (13.7) | 37.0 (8.0) | 23.0 (9.2) | 48.1 (9.8)** |
| **Family Companion** | | | | |
| Age, mean (SD) | 68.0 (13.3) | 64.7 (12.9) | 69.0 (13.9) | 70.0 (13.2) |
| Female, % | 56 (70.5) | 20 (78.6) | 16 (65.3) | 20 (67.6) |
| Race, % | | | | |
| African American | 3 (3.8) | 2 (8.0) | 1 (4.3) | 0 |
| White | 76 (96.2) | 23 (92.0) | 22 (95.7) | 31 (100) |
| Education years, mean (SD) | 16.2 (2.6) | 15.3 (2.3) | 16.7 (2.8) | 16.5 (2.6) |
| Numeracy, mean (SD) | 6.8 (1.8) | 6.8 (1.8) | 6.5 (2.0) | 6.9 (1.5) |
| Relationship to participant, % | | | | |
| Spouse | 51 (64.6) | 12 (48.0) | 14 (60.9) | 25 (80.6) |
| Child | 19 (24.1) | 10 (40.0) | 6 (26.1) | 3 (9.7) |
| Other (other relative or friend) | 9 (11.3) | 3 (2.0) | 3 (13.0) | 3 (9.7) |

*p<0.05; **p<0.01

**Table 2. 3. AD risk communication comparison between disclosure and nondisclosure groups**

| Communication Profile | All (N=79) | | | Genotype Nondisclosure (N=25) | | Genotype Disclosure (N=54) | | |
|---|---|---|---|---|---|---|---|---|
| | mean | % | (95%CI) | adjusted mean | (95%CI) | adjusted mean | (95%CI) | P-value |
| Ratio of patient-centered communication | 1.1 | NA | (1.1, 1.2) | 1.4 | (1.2, 1.5) | 1.0 | (1.0, 1.1) | **<0.001** |
| **Genetic Counselor** | | | | | | | | |
| All statements | 351.1 | 100 | (329.4, 372.8) | 343.0 | (325.1, 360.7) | 352.9 | (337.7, 368.1) | 0.17 |
| Biomedical information | 143.2 | 40.8 | (134.9, 151.6) | 127.0 | (114.4, 139.6) | 152.3 | (141.7, 162.9) | **<0.001** |
| Psychosocial/Lifestyle information | 71.1 | 20.3 | (67.9, 74.3) | 74.1 | (64.6, 83.6) | 65.3 | (56.7, 74.0) | **0.003** |
| Questions (Biomedical) | 5.9 | 1.7 | (5.1, 6.7) | 5.9 | (3.3, 8.4) | 5.3 | (2.8, 7.7) | 0.26 |
| Questions (Psychosocial/Lifestyle) | 1.5 | 0.4 | (1.1, 1.8) | 1.4 | (0.7, 2.0) | 1.5 | (1.0, 1.9) | 0.79 |
| Partnering statements | 41.8 | 11.9 | (35.2, 48.4) | 46.5 | (41.7, 51.4) | 39.6 | (36.4, 42.8) | **0.02** |
| Positive statements | 47.0 | 13.4 | (41.4, 52.6) | 47.8 | (41.9, 53.7) | 46.6 | (42.7, 50.5) | 0.74 |
| Negitive statements | 0.7 | 0.2 | (0.5, 0.9) | 0.6 | (0.3, 0.9) | 0.7 | (0.5, 0.9) | 0.82 |
| Emotion Statements | 22.2 | 6.3 | (20.1, 24.2) | 22.4 | (20.0, 24.8) | 22.0 | (20.4, 23.7) | 0.81 |
| Orientation Statements | 17.7 | 5.0 | (16.2, 19.2) | 17.5 | (13.2, 21.8) | 19.8 | (16.0, 23.6) | 0.13 |
| Positive affect (nonverbal) | 4.1 | NA | (4.0, 4.2) | 4.1 | (4.0, 4.3) | 4.1 | (4.0, 4.2) | 0.95 |
| Negative affect (nonverbal) | 3.7 | NA | (3.6, 3.9) | 3.7 | (3.5, 3.9) | 3.7 | (3.6, 3.9) | 0.81 |
| **Patient** | | | | | | | | |
| All statements | 108.1 | 100 | (84.5, 131.7) | 110.4 | (83.5, 137.2) | 107.1 | (89.3, 124.9) | 0.85 |
| Biomedical information | 18.0 | 16.7 | (13.4, 22.6) | 19.2 | (13.5, 24.9) | 17.4 | (13.7, 21.2) | 0.62 |
| Psychosocial/Lifestyle information | 38.1 | 35.2 | (27.1, 49.2) | 37.7 | (23.3, 52.1) | 38.3 | (28.8, 47.9) | 0.95 |
| Questions (Biomedical) | 4.4 | 4.1 | (3.4, 5.4) | 4.3 | (3.1, 5.5) | 4.4 | (3.6, 5.2) | 0.90 |
| Questions (Psychosocial/Lifestyle) | 1.5 | 1.4 | (1.0, 2.1) | 2.1 | (1.3, 2.9) | 1.3 | (0.7, 1.8) | 0.12 |
| Partnering statements | 8.5 | 7.9 | (6.0, 11.1) | 9.5 | (6.0, 13.0) | 8.1 | (5.7, 10.4) | 0.53 |
| Positive statements | 22.9 | 21.2 | (18.6, 27.1) | 23.1 | (17.9, 28.3) | 22.8 | (19.3, 26.2) | 0.92 |
| Negitive statements | 1.3 | 1.2 | (0.8, 1.8) | 1.2 | (0.5, 2.0) | 1.4 | (0.8, 1.9) | 0.80 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Emotion Statements | 10.5 | 9.7 | (8.3, 12.6) | 10.7 | (7.8, 13.6) | 10.4 | (8.4, 12.3) | 0.87 |
| Orientation Statements | 2.4 | 2.2 | (1.8, 2.9) | 2.2 | (1.1, 3.3) | 2.5 | (1.6, 3.4) | 0.57 |
| Positive affect (nonverbal) | 4.0 | NA | (3.8, 4.1) | 3.9 | (3.7, 4.2) | 4.0 | (3.8, 4.1) | 0.70 |
| Negative affect (nonverbal) | 1.5 | NA | (1.4, 1.7) | 1.8 | (1.3, 2.3) | 1.7 | (1.2, 2.1) | 0.42 |
| **Family Companion** | | | | | | | | |
| All statements | 75.5 | 100 | (64.3, 86.8) | 76.6 | (59.3, 93.8) | 75.1 | (63.6, 86.5) | 0.89 |
| Biomedical information | 13.4 | 17.7 | (10.3, 16.6) | 10.8 | (5.8, 15.9) | 14.6 | (11.2, 18.0) | 0.23 |
| Psychosocial/Lifestyle information | 25.5 | 33.8 | (20.1, 30.8) | 29.4 | (20.8, 38.0) | 23.7 | (18.0, 29.4) | 0.29 |
| Questions (Biomedical) | 3.8 | 5.0 | (2.8, 4.9) | 2.9 | (1.3, 4.6) | 4.3 | (3.2, 5.4) | 0.20 |
| Questions (Psychosocial/Lifestyle) | 1.2 | 1.6 | (0.8, 1.5) | 1.5 | (0.9, 2.1) | 1.0 | (0.7, 1.4) | 0.20 |
| Partnering statements | 8.1 | 10.7 | (5.8, 10.4) | 6.9 | (2.9, 10.9) | 8.7 | (6.0, 11.3) | 0.49 |
| Positive statements | 13.3 | 17.6 | (11.2, 15.4) | 13.9 | (10.5, 17.2) | 13.1 | (10.8, 15.3) | 0.70 |
| Negitive statements | 1.6 | 2.1 | (1.1, 2.1) | 2.2 | (1.4, 3.1) | 1.3 | (0.7, 1.9) | 0.10 |
| Emotion Statements | 5.9 | 7.8 | (4.7, 7.1) | 6.1 | (3.9, 8.3) | 5.8 | (4.4, 7.3) | 0.84 |
| Orientation Statements | 2.1 | 2.8 | (1.4, 2.7) | 2.1 | (0.7, 3.5) | 2.0 | (0.9, 3.2) | 0.92 |
| Positive affect (nonverbal) | 4.0 | NA | (3.8, 4.1) | 3.9 | (3.6, 4.1) | 4.0 | (3.8, 4.2) | 0.24 |
| Negative affect (nonverbal) | 1.3 | NA | (1.2, 1.4) | 1.4 | (1.1, 1.7) | 1.4 | (1.1, 1.6) | 0.83 |

Adjusted means derived from models that controlled for patient and companion gender, patient-companion relationship, patient MMSE score, 3-year AD risk and visit length.

**Table 2. 4. AD risk communication comparison between ε4 positive and ε4 negative groups**

| Communication Profile | ε4 negative (N=23) | | ε4 positive (N=31) | | P-value |
|---|---|---|---|---|---|
| | adjusted mean | (95%CI) | adjusted mean | (95%CI) | |
| **Ratio of patient-centered communication** | 1.1 | (0.9, 1.3) | 1.0 | (0.9, 1.2) | 0.69 |
| **Genetic Counselor** | | | | | |
| All statements | 378.3 | (356.5, 400.0) | 356.0 | (336.1, 375.9) | 0.13 |
| Biomedical information | 163.6 | (144.2, 182.9) | 152.6 | (133.9, 171.3) | 0.30 |
| Psychosocial/Lifestyle information | 66.8 | (60.5, 73.0) | 72.3 | (67.3, 77.3) | 0.27 |
| Questions (Biomedical) | 6 | (3.3, 8.7) | 5 | (2.3, 7.7) | 0.39 |
| Questions (Psychosocial/Lifestyle) | 0.8 | (0.1, 1.6) | 2.0 | (1.4, 2.5) | **0.06** |
| Partnering statements | 45.6 | (38.7, 52.6) | 40.3 | (34.7, 45.8) | 0.34 |
| Positive statements | 56.3 | (47.0, 65.6) | 44.4 | (37.0, 51.8) | 0.11 |
| Negitive statements | 1.0 | (0.5, 1.6) | 0.6 | (0.2, 1.0) | 0.28 |
| Emotion Statements | 22.3 | (18.9, 25.6) | 23.5 | (20.9, 26.3) | 0.62 |
| Orientation Statements | 19.9 | (15.1, 24.6) | 20.6 | (16.1, 25.1) | 0.81 |
| Positive affect (nonverbal) | 4.0 | (3.8, 4.2) | 4.3 | (4.1, 4.4) | 0.15 |
| Negative affect (nonverbal) | 3.6 | (3.3, 4.0) | 3.7 | (3.5, 3.9) | 0.84 |
| **Patient** | | | | | |
| All statements | 129.5 | (86.6, 172.4) | 103.6 | (69.4, 137.8) | 0.45 |
| Biomedical information | 19.1 | (10.8, 27.4) | 18.2 | (11.6, 24.8) | 0.90 |
| Psychosocial/Lifestyle information | 55.2 | (31.3, 79.0) | 31.0 | (12.0, 50.0) | 0.21 |
| Questions (Biomedical) | 4.6 | (2.7, 6.6) | 4.8 | (3.2, 6.3) | 0.93 |
| Questions (Psychosocial/Lifestyle) | 1.4 | (0.3, 2.5) | 1.5 | (0.7, 2.4) | 0.85 |
| Partnering statements | 7.8 | (2.9, 12.6) | 9.6 | (5.7, 13.4) | 0.65 |
| Positive statements | 24.4 | (16.1, 32.8) | 23.7 | (17.1, 30.4) | 0.92 |
| Negitive statements | 1.5 | (0.3, 2.8) | 1.4 | (0.4, 2.4) | 0.88 |
| Emotion Statements | 13 | (8.7, 17.4) | 9.6 | (6.1, 13.0) | 0.32 |
| Orientation Statements | 2.2 | (0.7, 3.7) | 2.8 | (1.5, 4.2) | 0.53 |

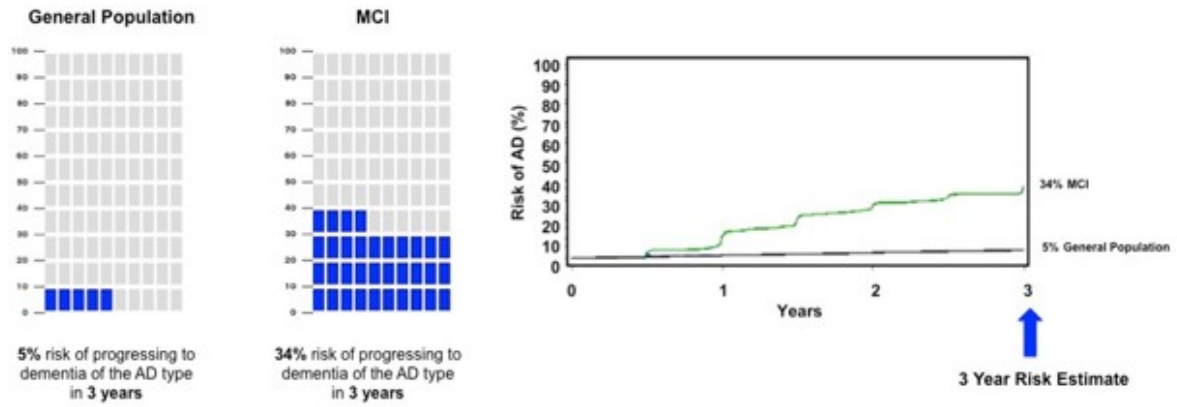
| | | | | | |
|---|---|---|---|---|---|
| Positive affect (nonverbal) | 4.1 | (3.7, 4.5) | 3.9 | (3.6, 4.2) | 0.51 |
| Negative affect (nonverbal) | 1.5 | (0.8, 2.1) | 2.0 | (1.3, 2.6) | **0.07** |
| **Family Companion** | | | | | |
| All statements | 54.1 | (27.7, 80.6) | 98.6 | (77.6, 119.7) | **0.04** |
| Biomedical information | 7.7 | (-0.5, 15.8) | 20.6 | (14.1, 27.1) | **0.049** |
| Psychosocial/Lifestyle information | 16.4 | (2.9, 30.0) | 32.9 | (22.1, 43.7) | 0.13 |
| Questions (Biomedical) | 2.5 | (-0.1, 5.1) | 5.9 | (3.8, 7.9) | 0.10 |
| Questions (Psychosocial/Lifestyle) | 1.0 | (0, 1.8) | 1.3 | (0.6, 2.0) | 0.60 |
| Partnering statements | 8.0 | (1.2, 14.9) | 10.2 | (4.7, 15.7) | 0.70 |
| Positive statements | 9.7 | (5.7, 13.8) | 16.1 | (12.9, 19.3) | **0.048** |
| Negitive statements | 1.7 | (0.4, 3.1) | 1.2 | (0.1, 2.3) | 0.63 |
| Emotion Statements | 5.9 | (2.7, 9.2) | 6.3 | (3.7, 8.9) | 0.88 |
| Orientation Statements | 0.8 | (-1.0, 2.5) | 3.5 | (1.9, 5.0) | **0.04** |
| Positive affect (nonverbal) | 3.7 | (3.5, 4.0) | 4.3 | (4.1, 4.6) | **0.006** |
| Negative affect (nonverbal) | 1.4 | (1.0, 1.8) | 1.3 | (1.0, 1.7) | 0.72 |

Adjusted means derived from models that controlled for patient and companion gender, patient-companion relationship, patient MMSE score, 3-year AD risk and visit length.

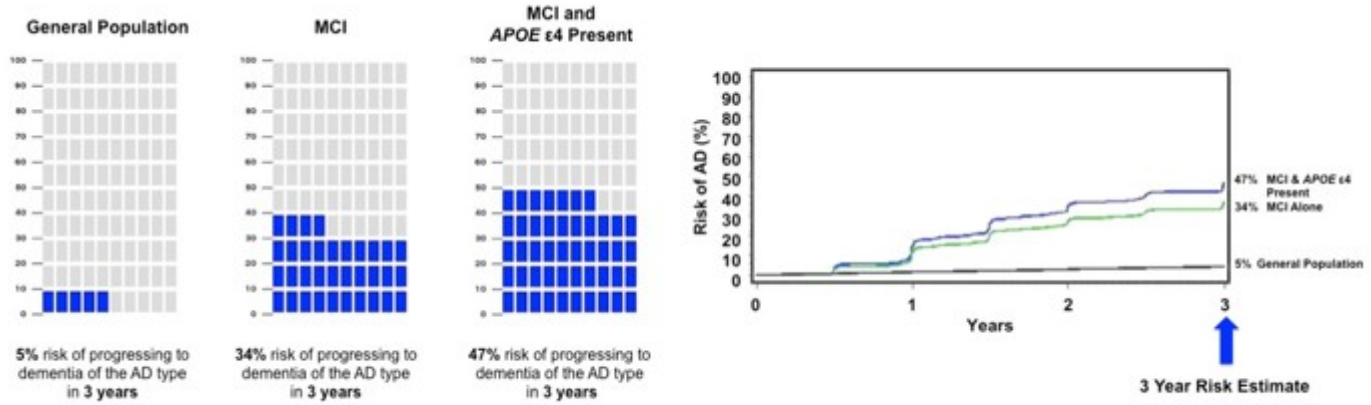
## FIGURES

### Figure 2. 1. Risk of progressing to dementia of the Alzheimer's disease type

A. Genotype nondisclosure group example: Age (71-77)




B. Genotype disclosure group example: Age (71-77), APOE ε4 positive



# CHAPTER 3: MANUSCRIPT TWO

**Cognitive and emotional processing of Alzheimer's disease risk: Impacts of genetic counselor facilitative communication**


## ABSTRACT

**Objectives:** To explore the relationship between genetic counselors' use of facilitative communication strategies on verbal indicators of cognitive and emotional processing by patients and an accompanying family member in the context of an Alzheimer's disease risk disclosure session.

**Methods:** Seventy nine audio recordings and transcripts of AD risk disclosure sessions collected as part of a randomized clinical trial, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL IV), were analyzed for this study. The Roter Interaction Analysis System (RIAS) was used to identify genetic counselor cognitive and affective facilitating communication strategies. Linguistic Inquiry Word Count (LIWC) was used to identify linguistic indicators of cognitive and emotional processing by patients and family companions. Multilevel mixed-effect linear regression models were used to determine the association between facilitative communication strategies and indicators of cognitive and emotional processing, accounting for patient and companion gender, patient Mini-Mental State Examination score, the inclusion or not of genotype in AD disclosure, and total session words.

**Results:** Genetic counselors' use of facilitative strategies were positively associated with patient and companion word use indicative of cognitive and emotional processing of the AD risk information in both unadjusted and adjusted models.

**Conclusions:** Consistent with the Social Cognitive Processing Model, the study results highlight specific counselor's communication strategies that facilitate cognitive and emotional processing of patients and companions in a way that may be linked to of therapeutic benefit. These findings add to a small theoretical literature that examines mechanism through which both emotional and cognitive counseling goals may be achieved.

## INTRODUCTION

Alzheimer's disease (AD) is a prevalent, severe and currently incurable neurological condition characterized by progressive declining levels of cognitive function, leading ultimately to disability and death (Green 2005). There is a growing consensus that interventions may be more effective before rather than after the degenerative process of AD has progressed (Albert, DeKosky et al. 2011; Sperling, Jack et al. 2011). Consequently, genetic testing and other forms of predictive testing have been increasingly used in research studies to identify at risk individuals. While several studies suggest that people seeking risk information for AD through genetic counseling generally find it useful and do not experience adverse effects (Romero, Garry et al. 2005; Cassidy, Roberts et al. 2008), few studies have explored how patients process the risk information that is conveyed. The role of the genetic counselor in facilitating cognitive and emotional processing of AD risks is especially critical when counseling patients with mild cognitive impairment (MCI) and the family members who accompany them to risk disclosure sessions.

Individuals process threatening health information at both an emotional and cognitive level (Leventhal 1997; Miller SM 2000). The abstract and complex nature of genetic information conveyed during AD risk disclosure can be cognitively and emotionally overwhelming for anyone, and patients with MCI are likely to struggle even more than others to understand this information (Heshka, Palleschi et al. 2008; Roberts, Christensen et al. 2011). The social cognitive processing model (SCPM), proposed by Lepore and colleagues, suggests that the act of 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 (Lepore, Ragan et al. 2000; Lepore 2001). Consequently, individuals who disclose their thoughts and feelings are more likely to make sense of their situation, thereby reducing distress,

facilitating informed actions, and even achieving physical benefit (Lepore, Ragan et al. 2000; Kennedy-Moore 2001; Austenfeld and Stanton 2004; Lepore SJ, Kernan WD et al. 2009). For instance, supportive social responses to the disclosures of prostate cancer patients (Lepore 1998) and bereaved mothers (Lepore 1996) have been found to facilitate disclosure and reduce avoidant thinking and behaviors.

Despite the growing evidence linking supportive social interactions to cognitive processing and emotional adjustment, we know little about the mechanisms that underlie this phenomenon in health care contexts. A pioneering study in this area by Ellington and colleagues explored the application of the SCPM principals to simulated prenatal and cancer pretest genetic counseling sessions. Genetic counselors' contribution to the session dialogue were coded with the Roter Interaction Analysis System (RIAS) to identify communication strategies used to elicit indicators of cognitive and emotional processing based on analysis of simulated clients' contribution to the session dialogue using the Linguistic Inquiry Word Count (LIWC) (Ellington, Kelly et al. 2011). The study found that genetic counselors' use of facilitative communication was associated with indicators of simulated clients' cognitive and emotional processing, consistent with the SCPM.

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 an accompanying family member. Consistent with tenets of the SCPM, we hypothesize that greater use of emotional and cognitive facilitation strategies by genetic counselors will be positively associated with patient and family member word usage indicative of emotional and cognitive processing.

## METHODS

**Study design and data collection**

This study uses a sample of audio-recorded AD risk disclosure sessions collected as part of the REVEAL IV randomized clinical trial. Patients and accompanying family members (referred to as visit companions) were recruited at four REVEAL study sites (Ann Arbor, Boston, Philadelphia and Washington, D.C.). Eligible patients were older adults (age range: 55-90 years) who did not have dementia, had received a diagnosis of MCI from a specialist through the REVEAL site's research registry or through clinical referrals or community screening, and had a memory complaint either reported by the patient or an informant.

Patients were randomly assigned in a 2:1 ratio to either APOE genotyping disclosure group (N=75) or APOE genotyping nondisclosure group (N=39). Patients assigned to the nondisclosure group received 3-year risk estimates that were specific for age and the diagnosis of MCI. Patients in the disclosure group were given the same risk estimates with additional information for their genotype-specific risk (Figure 1 displays sample risk presentations).

The 3-year risk estimates provided to patients was defined as the cumulative risk of developing AD from the age at disclosure over the next three years. These risk estimates were calculated from the Memory Impairment Study, a clinical trial involving 769 amnestic-MCI patients, which provided three-year risk data stratified by APOE genotype (Petersen, Thomas et al. 2005). Patients with one or two ε4 alleles are at increased risk of developing Alzheimer's disease. Although patients were given additional information that the risk for ε4/ε4 may be higher than a single copy of the gene, they were not provided with a specific risk number stratified by APOE genotype. Individuals with the ε2/ε4, ε3/ε4 and ε4/ε4 genotypes were given the same positive genotype risk estimates.

The risk disclosure session was led by a study clinician who specialized in genetic counseling, clinical psychology, general practice or neurology. Although study clinicians were instructed to follow a prescribed topic protocol, they were given latitude to incorporate their style of communication and address the specific needs of individual patients.

Of the 114 patients who received AD risk assessment, 79 (69.3%) agreed to have their risk disclosure session audio-recorded and received the disclosure session from a board certified genetic counselor. This comprises the sample for the current study. The current study was reviewed by the Johns Hopkins University Bloomberg School of Public Health Institutional Review Board.

**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 (Roter and Larson 2002). The unit of analysis is a complete thought communicated as a single word, simple sentence, or a clause in complex sentence. Statements are coded directly from recordings and assigned to one of thirty-seven mutually exclusive and exhaustive code categories. The code categories address task-focused categories such as questions and information and counseling statements in topical areas related to medical condition, therapeutic regimen, lifestyle and psychosocial information, as well as socio-emotional categories that capture positive or negative exchange through approvals, compliments, disagreements and criticisms, as well as socioemotional responses like empathy, concern, reassurance and legitimation.

For purposes of the current study, genetic counselor's facilitation of cognitive and emotional processing was operationalized as illustrated in Table 3.1. Cognitive facilitation includes question asking in the biomedical realm, checks and paraphrasing, cueing interest for further elaboration, as

well as asking for opinions, reassurance and understanding. Emotional facilitation consists of both psychosocial and lifestyle questions, statements of approval and compliment, and emotional talk (statements of partnership or alliance, expressions of reassurance, concern, empathy and legitimization).

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 .83 across clinician categories and .93 for patient categories.

**Linguistic inquiry word count (LIWC)**

LIWC was used to identify patient and companion expressions of emotion and markers of cognitive processing of genetic counselor conveyed information. LIWC is a valid and reliable method for identifying key words indicative of emotional and cognitive expressions (Kahn, Tobin et al. 2007). The word categories of the LIWC are theoretically derived and consistent with the tenets of the SCPM. As shown in Table 3.1, the LIWC category of cognitive mechanisms includes words that indicate causal linkages such as "because" or "effect" and words that relay more tentative associations such as "think" or "realize". The emotion categories include negative emotion (e.g., guilty, angry, worry) and positive emotion (e.g., happy, love). Audio recordings of the AD risk disclosure session were transcribed and the transcripts were prepared in accordance with recommendations from the manual accompanying LIWC software. The frequency of words designated to different word categories is generated by LIWC.

**Data analyses**

Descriptive statistics were used to present an overall picture of facilitation communication and key word counts for the session dialogue. To determine how genetic counselors' facilitative communication behaviors predicted patient and companion word use in cognitive mechanisms and emotional word categories, we ran separate regressions with each word category as the dependent variable and genetic counselor communication behaviors as the independent variable, using multilevel mixed-effect linear regression models with a random effect to account for clustering at the genetic counselor. In the adjusted models, we included patient and companion gender, patient-companion relationship, patient Mini-Mental State Examination (MMSE) score, group assignment (genotype nondisclosure, ε4 negative and ε4 positive groups), and total word count of the three speakers as control variables. Missing values were excluded on a list-wise basis in all analyses. 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, Tex).

## RESULTS

### Sample characteristics

A full description of sample characteristics is presented in Table 3.2. Three genetic counselors participated in this study representing three REVEAL IV study sites (Ann Arbor, Boston and Philadelphia); all were female Caucasians averaging 36 years of age. The average number of patients seen by each genetic counselor was 26 (range: 4-40).

The 79 patients comprising our study sample were on average 76 years of age (range: 57-89), with the majority of being male (56%) and Caucasian (96%). The mean level of education was 16 years, and the average score on the numeracy scale was 6 items out of 8 answered correctly; 20

patients (25%) were classified as low numeracy, 37 (47%) were classified as average numeracy, and 22 (28%) were classified as high numeracy.

Patients had a mean MMSE score of 27 (range: 21–30). The majority of patients (86%) showed adequate cognitive function (MMSE >24) and eleven were scored as having in the mild cognitive impairment (MMSE 20-24) (Folstein, Folstein et al. 1975), nevertheless all patients entered the REVEAL IV study with a diagnosis of MCI. The average 3-year risk estimates of progressing to AD for all patients was 37% ranging from 8% to 57%.

Of the 54 patients in the genotype disclosure group, 57% (N=31) carried at least one ε4 allele; 10 had the ε4/ε4 genotype and 21 had the ε3/ε4 genotype. Among those without the ε4 allele (43%, N=23), 20 had the ε3/ε3 genotype and 3 had the ε2/ε3 genotype. None of the patients had the ε2/ε2 or ε2/ε4 genotype.

All patients were accompanied to the session by a family member. Visit companions (N=79) were on average 68 years of age and were predominantly female (70%), and spouses (65%), or adult children (24%); fewer companions were described as "other" (11%) and they were primarily relatives. Companions were well-educated with an average 16 years of education. The majority (89%) scored average or high on the numeracy screen.

**RIAS analysis of genetic counselor talk**

The length of risk discussions ranged from 9.7 minutes to 63.5 minutes with a mean of 27.0 (SD=9.7). Genetic counselor clearly dominated the sessions; typically, the risk disclosure sessions averaged 556 statements with the genetic counselor contributing 351 (63%) of these statements. As displayed in Table 3.3, the majority (82%) of counselor talk was directed to the patient while 18% was directed to the companion.

Counselor use of facilitation strategies were relatively infrequent during the AD risk disclosure session; cognitive and emotional facilitation strategies comprised a total of 14% and 10% of all genetic counselor talk, respectively. As is evident in Table 3.3, these strategies were more commonly directed toward patients than companions.

**LIWC analysis of patient and companion word use**

As shown in Table 3.4, patients and companions contributed to the discussion similarly in terms of word count and its distribution across cognitive and emotional domains. Approximately 18% of patient word use and 17% of companion words are indicative of cognitive processing, while 6% of patient words and 5% of companion word use reflects emotional processing. Also evident in Table 3.4, is a tendency for far greater use of positive rather than negative emotion words by both patients and companions.

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

Table 3.5 illustrates the regression coefficients from the linear mixed effects models (both adjusted and unadjusted for covariates) for each word category regressed on genetic counselors' use of facilitation strategies. In all unadjusted models (column 2 and 4), facilitation of emotional and cognitive processing is positively correlated with both patient and companion word use indicative of cognitive and emotional processing session information ($p<0.001$).

To adjust for potential confounders, additional regression models were created to include patient and companion gender, patient-companion relationship, patient MMSE score, group assignment (genotype nondisclosure, ε4 negative and ε4 positive groups), and total word count of

the three speakers (see Table 3.5 column 3 and 5). After controlling for these variables, genetic counselors' use of cognitive and emotional facilitation continues to have significant positive effects on patient and companion use of positive emotional words, companion use of negative words, and cognitive processing word use by both patients and companions. ($p<0.01$). Emotional facilitation shows a non-significant trend for patient use of negative words ($p=0.06$). In this case, patients in the genotype nondisclosure group were significantly more negative in their emotional expression relative to patients who were informed that they carried at least one ε4 allele ($\beta=4.4$, $p=0.02$). Total word count was the only other significant predictor ($p<0.001$), but the regression coefficient was small in magnitude ($\beta<0.001$).

**DISCUSSION**

This study provides an exploratory analysis of how patients with mild cognitive impairment and their family companions process cognitive and emotional information conveyed during an AD risk disclosure session. As we hypothesized, genetic counselors' use of facilitative communication strategies was positively associated with linguistic indicators of affective and cognitive processing by patients and family 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 session companions use more cognitive and emotional words indicative of processing. This effect is evident even after controlling for factors that have been shown to influence clinician-patient interactions (e.g. gender, cognitive function and APOE genotype) (Roter DL 2006). The disclosure of thoughts and feelings have been shown to have therapeutic benefits through the conversion of a stressful event (e.g. AD risk) into a linguistic

structure which in itself may promote understanding of a stress and a reduction of associated negative emotion (Pennebaker 1993; Pennebaker, Mayne et al. 1997). This interpretation is supported by studies linking emotional disclosure to positive patient outcomes, including improved reported physical health and psychological well-being (Murray and Segal 1994; Lepore, Ragan et al. 2000; Kennedy-Moore 2001; Austenfeld and Stanton 2004; Lepore SJ, Kernan WD et al. 2009; Kelly, Ellington et al. 2014). 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 emotion expression was positively related to several indicators of knowledge gain following BRCA1 genetic counseling sessions (Kelly, Ellington et al. 2014). Based upon these findings and others, our results suggest that counselor's 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 extends the current literature by demonstrating the effects of counselor communication strategies on the way family companions express cognitive and emotional processing, which has important implications in the context 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 family member, usually the spouse or adult children (Wolff and Roter 2008; Wolff, Boyd et al. 2012). 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 session companions is of particular importance in AD risk disclosure, given the sensitive and life-changing nature of the

AD risk being disclosed, as well as the implications these disclosures have for both patient and family member risks and future caregiver responsibility.

Taken together, the study findings point to the importance of structuring counselor communication behaviors to better achieve patient and family companion processing on both a cognitive and emotional level. Counselors in our study engaged in more facilitation of cognitive than emotional processing, and patient and companion talk during the sessions indicated more words indicative of cognitive than emotional processing. These findings are consistent with Ellington's findings based on simulated prenatal and cancer genetic counseling sessions (Ellington, Kelly et al. 2011). Patient and companion word use in the current study demonstrates the active engagement of both in cognitive processing (17%). However, the relatively lower levels of emotional processing (5%) by patients and companions suggests that they are not responding to the information at emotional level. Based upon our findings, higher levels of emotional facilitation by the counselor are needed to achieve more of patient and companion emotional engagement.

The genetic counselors in the current study face 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. Further, activating the cognitive processes is especially challenging for those who have cognitive deficits and patients may have difficulty comprehending implications of the AD risks conveyed. As a result, genetic counselors may spend more time checking for patient understanding than engaging in emotional communication. It is also worth noting that the counselors in this study were instructed to follow the risk disclosure protocol, they might feel pressured to cover the medical information (e.g., review of APOE genotype, AD risk estimates presentation) and devoted less time to facilitating participant and companion psychosocial responses.

**Limitations**

The 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 expressed more negative emotion in the genotype nondisclosure group than those received ε4 positive result, regardless of counselor's emotional facilitation efforts and other factors that might influence emotional expression. 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 unhappy at having their genotype information withheld. One patient expressed her feelings about being assigned to the genotype nondisclosure group: "This feels as if this is providing you folks with a good kind of information, but it doesn't provide us with the help to deal with whatever the information is, which could be more disturbing, and therefor disorienting". This is a common problem faced by researchers undertaking an RCT. However, we could not disentangle our findings related to the expression of negative emotions from that associated with AD risk.

In addition, our analyses cannot determine the causal pathways that precipitated patient and companion expression 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, including patient and genetic counselor race. Furthermore, the patients enrolled in the REVEAL IV were largely self-referred and well-educated and may have had different motivations and levels of concern than a typical at-risk individual. Our findings may not apply to other AD risk disclosure sessions, due to the constraints of REVEAL IV as a controlled trial and only three genetic counselors took part in the study. It is possible that these

counselors are not representative of the field at large and that their disclosure style may more accurately reflect communication characteristic of research protocol-driven sessions than common practice.

## Conclusions

The results of this study provides evidence supporting the role of genetic counselors' facilitative talk in eliciting cognitive and emotional processing. We identified specific counselor's communication strategies that facilitate both cognitive and emotional processing of complex AD risk information by patients and visit companions. 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. While the current study contributes to a small but important literature, and suggests directions for future theoretically supported communication interventions and education efforts for genetic counselors and other health care providers, more research, both quantitative and qualitative, is needed. Further, given the frequent engagement of family companions in the communication processes health care, there is a need for more explicit address of ways in which they may be more fully and productively included in session dialogue.

## TABLES

### Table 3. 1. Application of the SCPM to the AD risk disclosure session

| SCP constructs | Coding categories | Examples |
|---|---|---|
| Genetic counselor communication indicators operationalized with composite 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?<br>-Does that make sense?<br>-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?<br>-It's hard to lose people you care about.<br>-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.<br>-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.<br>-This makes me *happy* not only for myself, probably more for my family.<br>-It's a very *depressing* thought.<br>-She was very *sad* for her. |

**Table 3. 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) |
| Numeracy, mean (SD) | 5.9 (2.1) | 6.8 (1.8) |
| 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) |

**Table 3. 3. RIAS codes for genetic counselor (GC): Descriptive analysis**

| RIAS Codes | Mean (SD) | Range | % of Total GC Talk |
|---|---|---|---|
| All GC talk | 351.1 (96.9) | 138-729 | NA |
| GC talk to patient | 288.6 (81.3) | 126-602 | 82.2 |
| Cognitive facilitation | 36.1 (28.6) | 3-152 | 10.3 |
| Emotional facilitation | 27.6 (13.4) | 7-80 | 7.9 |
| GC talk to companion | 55.3 (43.4) | 6-215 | 15.8 |
| Cognitive facilitation | 12.9 (10.1) | 0-45 | 3.7 |
| Emotional facilitation | 7.8 (6.8) | 0-32 | 2.2 |

**Table 3. 4. LIWC output for patients and companions: Descriptive analysis**

| LIWC word category | Mean frequency (SD) | Median | Range | |
|---|---|---|---|---|
| Total patient word count | 699.8 (788.6) | 427 | (5-4451) | % of total patient talk |
| Emotional expression | 39.9 (41.6) | 28 | (1-264) | 5.7 |
| Positive emotion | 30.8 (32.3) | 23 | (1-199) | 4.4 |
| Negative emotion | 9.0 (11.0) | 6 | (0-65) | 1.3 |
| Cognitive expression | 122.6 (146.8) | 70 | (0-818) | 17.5 |
| Total companion word count | 501.1 (395.8) | 383 | (3-1792) | % of total companion talk |
| Emotional expression | 26.7 (17.8) | 24 | (0-73) | 5.3 |
| Positive emotion | 20.6 (13.9) | 18 | (0-66) | 4.1 |
| Negative emotion | 6.0 (5.9) | 4 | (0-28) | 1.2 |
| Cognitive expression | 86.2 (71.9) | 62 | (0-334) | 17.2 |

**Table 3. 5. Impacts of genetic counselor facilitative communication on cognitive and emotional expression of patient and companion**

| LIWC word categories | GC Cognitive Facilitation | | GC Emotional Facilitation | |
|---|---|---|---|---|
| | unadjusted coefficient (SE) | adjusted coefficient (SE) | unadjusted coefficient (SE) | adjusted coefficient (SE) |
| **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)* |
| Positive emotion | 1.0 (0.1)** | 0.9 (0.1)** | 1.7 (0.2)** | 0.7 (0.1)* |
| Negative emotion | 0.4 (0.03)** | 0.2 (0.1)** | 0.5 (0.1)** | 0.2 (0.1) |
| **Family 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)** |
| Positive emotion | 0.8 (0.1)** | 0.6 (0.1)** | 1.3 (0.2)** | 1.1 (0.2)** |
| Negative emotion | 0.4 (0.1)** | 0.4 (0.1)** | 0.4 (0.1)** | 0.4 (0.1)** |

*P<0.01;**P<0.001

Adjusted coefficient derived from models that controlled for patient and companion gender, patient-companion relationship, patient MMSE score, group assignment (genotype nondisclosure, ε4 negative and ε4 positive groups), and total word count of the three speakers.

# CHAPTER 4: MANUSCRIPT THREE

**Communication predictors of patient and companion satisfaction with Alzheimer's disease risk disclosure sessions**


## ABSTRACT

**Objectives:** To identify features of the Alzheimer's disease risk disclosure encounter that predict patient and family companion satisfaction.

**Methods:** Seventy nine audio recordings of AD risk disclosure sessions collected as part of an earlier randomized clinical trial, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL IV), were analyzed for this study. The Roter Interaction Analysis System (RIAS) was used to quantitatively describing AD risk disclosure interpersonal communication among the genetic counselor, patient and family companion. Patient and companion satisfaction was measured by a 10-item satisfaction survey after the disclosure session. Simple and multivariate logistic regression models were used to determine the association between communication behaviors and satisfaction outcomes, accounting for patient and companion gender, educational level, and patient 3-year AD risk.

**Results:** Patients and companions were generally highly satisfied with the communication of the AD risk disclosure, but agreement between patients' and companions' ratings of complete satisfaction was low (kappa=0.04). Patient satisfaction was positively associated with patients' own expression of emotions (OR=1.06) and companion's psychosocial question asking (OR=1.75) during the session. Companion-rated satisfaction was positively related to the overall patient-centeredness of the disclosure session (OR=3.97).

**Conclusions:** The positive satisfaction outcomes associated with patient-centered communication support the growing literature on patient-centered care. Findings from this study also suggest a significant positive role of family companions in facilitating patient satisfaction. The study results highlight opportunities for healthcare providers, patients and family companions to increase effective interactions in AD risk disclosure settings.

## INTRODUCTION

More than five million Americans are currently affected by Alzheimer's disease (AD), and that number is expected to triple by 2050 (Alzheimer'sAssociation 2014). These staggering figures evoke dread; people fear developing the disease as well as the prospect of assuming the physical and emotional burden of caregiving for an affected family member (Georges 2011; HarrisInteractive 2011). Therapeutic approaches to AD care are increasingly focused on early detection and often involve identification of individuals at heightened risk for the disease. Family history, early evidence of cognitive impairment and other biomarkers are increasingly used to refine risk profiles for at risk individuals (Sperling, Aisen et al. 2011; Sperling, Jack et al. 2011). For many older adults, particularly those with memory complaints, assessment of AD risk is anticipated to occur more frequently in both clinical and research settings. However, the abstract and complex nature of probabilistic information conveyed during AD risk disclosure discussions can be cognitively and emotionally overwhelming for anyone, and patients with impaired cognitive function are likely to struggle even more than others to understand this information (Heshka, Palleschi et al. 2008; Roberts, Christensen et al. 2011). Consequently, patients with cognitive deficits often rely on assistance from family or friends in communicating with their health care providers (Wolff and Roter 2011; Wolff and Boyd 2015).

Family members who accompany older patients to medical visits are most often spouse or adult children and these visit companions play an important and largely positive role in facilitating physician-patient communication. Estimates from the Medicare Current Beneficiary Survey and meta-analysis of family involvement in patients' general medical visits shows that some 40% of older adults are routinely accompanied to their medical visits and that they report higher satisfaction with physician informativeness and rapport building skills than those who are unaccompanied or

accompanied by less active family members (Street and Gordon 2008; Wolff and Roter 2008; Wolff and Roter 2011).

While several studies have examined the impact of family member presence on patient satisfaction with visit communication, there has been less attention paid to companions' perspective on the communication process. One study by Schmidt and colleagues analyzed 23 routine AD primary care visit found that the more an accompanying family member contributed to visit interaction, the more satisfied they were with the visit (Schmidt, Lingler et al. 2009). In the context of AD risk disclosure, when patients are likely to have mild cognitive impairment, companions can offer a unique and perhaps more accurate perspective on care quality to complement the patient's assessment (Lynn Snow, Cook et al. 2005; Pickard and Knight 2005).

The current study extends previous work by analyzing audio recordings and survey data of 79 AD risk disclosure sessions with patients who have mild cognitive impairment (MCI) and an accompanying family member collected as part of the Risk Evaluation and Education for Alzheimer's Disease (REVEAL IV) study. Earlier analysis of this data found that the AD risk disclosure sessions, with and without genetic risk discussion, were generally more patient-centered than biomedically-focused (manuscript one). This communication pattern is consistent with findings of dementia diagnosis disclosure sessions (Zaleta and Carpenter 2010), but is different from the general didactic biomedically-focused approach described in the genetic counseling literature (Ellington, Baty et al. 2006; Lerner, Roberts et al. 2014). It was also found that genetic counselors' use of patient-centered facilitative communication strategies, such as question asking, checks, paraphrasing and emotional talk, were positively associated with linguistic indicators of patients' and companions' cognitive and emotional processing of the AD risk information in a way that may be linked to of therapeutic benefit (manuscript two).

In the current analysis, disclosure session communication, including dialogue contributions from the genetic counselor, patient and accompanying family member, will be explored in relation to post-session patient and family companion satisfaction. Based on the previous research on physician-patient communication broadly and specifically in regard to older adults, we expect that genetic counselors who demonstrate a more patient-centered communication style will receive higher satisfaction ratings from both patients and companions. We also hypothesize that companions will play a significant role in bridging patient-genetic counselor communication and that their communication will be associated with patient satisfaction.

## METHODS

### Study design and data collection

This study uses a sample of audio-recorded AD risk disclosure sessions collected as part of the REVEAL IV randomized clinical trial. Patients and accompanying family members (referred to as visit companions) were recruited at four REVEAL study sites (Ann Arbor, Boston, Philadelphia and Washington, D.C.). Eligible patients were older adults (age range: 55-90 years) who did not have dementia, had received a diagnosis of MCI from a specialist through the REVEAL site's research registry or through clinical referrals or community screening, and had a memory complaint either reported by the patient or an informant. Patients were excluded if they scored in clinically significant ranges on validated measures of cognitive functioning (Mini-Mental State Examination score<=20), depression (The Geriatric Depression Rating Scale score>=12), or anxiety (The State-Trait Anxiety Inventory score>=19).

Patients were randomly assigned in a 2:1 ratio to either APOE genotyping disclosure group (N=75) or APOE genotyping nondisclosure group (N=39). Patients assigned to the nondisclosure

group received 3-year risk estimates that were specific for age and the diagnosis of MCI. Patients in the disclosure group were given the same risk estimates with additional information about their genotype-specific risk.

The 3-year risk estimates provided to patients was defined as the cumulative risk of developing AD from the age at disclosure over the next three years. These risk estimates were calculated from the Memory Impairment Study, a clinical trial involving 769 amnestic-MCI patients, which provided three-year risk data stratified by APOE genotype (Petersen, Thomas et al. 2005). Patients with one or two ε4 alleles are at increased risk of developing Alzheimer's disease. Although patients were given additional information that the risk for ε4/ε4 may be higher than a single copy of the gene, they were not provided with a specific risk number stratified by APOE genotype. Individuals with the ε2/ε4, ε3/ε4 and ε4/ε4 genotypes were given the same positive genotype risk estimates.

Study clinicians were instructed to follow a prescribed topic protocol, but they were given latitude to address the specific needs of individual patients. After the risk disclosure session, patients and family companions independently completed study questionnaires and rated their satisfaction with the session.

Of the 114 patients who received AD risk assessment, 79 (69.3%) agreed to have their risk disclosure session audio-recorded and received the disclosure session from a board certified genetic counselor. This group comprises the sample for the current study. The study was reviewed by the Johns Hopkins University Bloomberg School of Public Health Institutional Review Board.

**Patient and companion satisfaction with provider communication**

The primary study outcomes are patient and family companion satisfaction with the AD risk disclosure session. The 10-item satisfaction measure was developed and used by Roter and colleagues in previous genetic counseling studies (Roter, Ellington et al. 2006) and include items such as: "your clinician was able to explain the Alzheimer's disease risk estimate and its meaning in a way that you could understand" (Appendix 4.1). Patients and companions were asked to rate their satisfaction on the communication process using a 5-point scale ranging from "strongly disagree=1" to "strongly agree=5". The results of principal-components analysis and parallel analysis on the 10 survey items for both patient and companion satisfaction scales support extraction of one factor. Scores were then summed with a possible range from 0 to 50, with higher scores indicating greater satisfaction. The scales demonstrated strong internal consistency (Cronbach's Alpha=0.88 and 0.90 for patient and companion satisfaction scales, respectively).

**Roter Interaction Analysis System (RIAS)**

Audio recordings of risk disclosure dialogue were coded using RIAS, a widely used quantitative coding system for medical dialogue that has demonstrated high reliability and predictive validity to patient satisfaction, utilization and adherence (Roter and Larson 2002). The unit of analysis is a complete thought communicated as a single word, simple sentence, or a clause in complex sentence. Statements are coded directly from recordings and assigned to one of thirty-seven mutually exclusive and exhaustive code categories. The code categories address task-focused categories such as questions and information and counseling statements in topical areas related to medical condition, therapeutic regimen, lifestyle and psychosocial information, as well as socio-emotional categories that capture positive or negative exchange through approvals, compliments,

disagreements and criticisms, as well as socioemotional responses like empathy, concern, reassurance and legitimation. Examples of the RIAS composite codes are presented in Table 4.1. In addition, a measure of patient-centered communication was calculated to reflect the ratio of psychosocial and socioemotional exchange relative to biomedical exchange. The numerator of the measure consists of patient and companion psychosocial and lifestyle disclosure, all patient and companion questions and emotional statements plus genetic counselor psychosocial and lifestyle questions, information and counseling and activation/facilitation statements. The denominator consists of the sum of genetic counselors' medical questions and orientations, as well as patient, companion and genetic counselors' statements relating medical information. The measure has been used in a number of studies and it shows predictive and concurrent validity to a variety of patient and physician outcomes (Mead and Bower 2000; Roter and Hall 2004).

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 .83 across clinician categories and .93 for patient categories.

**Baseline measures**

Patient and companion characteristics, including age, gender, race, level of education and dyad relationship were assessed by self-report. General cognitive function of the patient was assessed by the Mini-Mental State Examination (MMSE) (Folstein, Folstein et al. 1975). A score greater than or equal to 24 indicates adequate general cognitive function, 20 to 24 suggests mild cognitive impairment, 13 to 20 suggests moderate cognitive impairment, and less than 12 indicates severe cognitive impairment. APOE genotype was dichotomized depending on carrier status of one copy of the APOE ε4 allele or not.

**Data analyses**

The primary outcomes are patient and companion satisfaction. Because satisfaction scores are negatively skewed, we dichotomized scale scores to compare the highest ranking category (highly satisfied; total satisfaction score=50) with all other responses for both patients and companions. MMSE score was coded to the sample mean for three patients with missing survey responses in this study.

To assess patient and companion agreement on satisfaction with session communication, Cohen's unweighted kappa was calculated. Because the likelihood-ratio tests were not significant when mixed effect models accounting for clustering at the genetic counselor were compared to ordinary logistic regressions, logistic regressions were used to determine the contribution of each speaker's communication to patient and companion satisfaction (in separate models). To identify potential confounders, adjusted multivariate regression models were generated including patient and companion factors thought to act as confounders in the relations between communication style and satisfaction (i.e., patient age, gender, educational level, numeracy, patient-companion relationship, visit length, MMSE score, 3-year AD risk and APOE genotype). Patient and companion characteristics found to be statistically significantly ($P<0.05$) related to either communication behaviors or satisfaction included patient and companion gender, years of education and patient 3-year AD risk. These variables were included as control variables in the final multivariate logistic regression models.

Missing values were excluded on a list-wise basis in all analyses. 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, Tex).

## RESULTS

### Sample characteristics

A full description of sample characteristics is presented in Table 4.2. Three genetic counselors participated in this study representing three REVEAL IV study sites (Ann Arbor, Boston and Philadelphia); all were female Caucasians averaging 36 years of age. The average number of patients seen by each genetic counselor was 26 (range: 4-40).

The 79 patients comprising our study sample were on average 76 years of age (range: 57-89), with the majority of being male (56%) and Caucasian (96%). The mean level of education was 16 years. Patients had a mean MMSE score of 27 (range: 21–30). The majority of patients (86%) showed adequate cognitive function (MMSE >24) and eleven were scored as having in the mild cognitive impairment (MMSE 20-24), nevertheless all patients entered the REVEAL IV study with a diagnosis of MCI. The average 3-year risk estimates of progressing to AD for all patients was 37% ranging from 8% to 57%.

Of the 54 patients in the genotype disclosure group, 57% (N=31) carried at least one ε4 allele; 10 had the ε4/ε4 genotype and 21 had the ε3/ε4 genotype. Among those without the ε4 allele (43%, N=23), 20 had the ε3/ε3 genotype and 3 had the ε2/ε3 genotype.

All patients were accompanied to the session by a family member. Companions (N=79) were on average 68 years of age and were predominantly female (70%). Companions most often self-identified as a spouse (65%), adult child (24%) or other relative (11%). Companions, like patients, were well-educated with an average 16 years of education.

### Patient and companion satisfaction on interpersonal communication

Patients and companions in this study were generally highly satisfied with the communication of the AD risk disclosure. The average satisfaction scores were 46 (SD=4) and 47 (SD=4) for patients and companions, respectively. Overall, 24% of patients (N=19) and 48% of companions (N=38) reported being completely satisfied with the communication process. The simple observed agreement between patient and companion on highly satisfying sessions was 53%; however, the kappa (0.04, SE=0.10) indicated only poor to slight agreement when accounting for chance (Landis and Koch 1977).

**Communication predictors of patient and companion satisfaction**

Table 4.3 illustrates the odds ratios from logistic regression models (both unadjusted and adjusted for covariates) to identify communication behaviors that are predictive of patient and family companion satisfaction. The adjusted multivariate logistic regression models include patient and companion gender, years of education and patient 3-year AD risk.

In unadjusted models, patients were more satisfied with the AD risk communication when genetic counselors made more positive statements (OR=1.02) and when family companions asked more psychosocial questions (OR=1.60). After adjusting for the covariates, companion's psychosocial question asking continued to have significant positive effects on patient satisfaction (OR=1.75). Patients' own expression of emotions emerged as a significant positive predictor for their satisfaction (OR=1.06). A trend in both unadjusted and adjusted models suggested that patients were more satisfied with the communication process when they were more actively engaged in the session by talking more, disclosing more psychosocial information, making more facilitating statements that clarified or checked information and when they engaged in more positive

talk. Additionally, patients tended to be more satisfied when their companions engaged in more positive talk and less negative talk.

Companion-rated satisfaction was negatively related to their own facilitation statements (OR=0.92) in unadjusted but not adjusted models. In the final adjusted models, companions who experienced a more patient-centered session had almost four times the odds of being very satisfied with the AD risk communication process (OR=3.97). Also, companions who reported higher levels of satisfaction tended to disclose more psychosocial information and made more emotional statements during the session.

## DISCUSSION

In general, our findings demonstrate that patient-centered and psychosocially focused session communication was associated with greater patient and family member satisfaction with AD risk disclosure sessions. Moreover, companion communication, appeared to play a significant role in enhancing patient satisfaction.

We found that patients' active engagement in the AD risk communication process positively influenced their satisfaction; when patients expressed emotion, either positive or negative, they were more likely to be highly satisfied. Prior research has shown that active patient involvement in medical encounters has been associated with greater satisfaction as well as other desirable outcomes including increased adherence and positive treatment outcomes (Tennstedt 2000). The interactions that occur when emotional disclosures are made can enhance social relationships and increase bonding between patients and health care providers (Kennedy-Moore 2001; Smith, Soubhi et al. 2012).

We confirmed the important role of companion's psychosocial question asking in enhancing patient satisfaction. This finding builds upon prior research linking the involvement of visit companions to older patients' reports of satisfaction with care (Wolff and Roter 2008). Observational studies and meta-analyses have provided compelling evidence that the presence of a companion is beneficial to the care process: physicians give more information when family members are present than when patients are unaccompanied (Labrecque, Blanchard et al. 1991; Prohaska 1996) and the presence of a companion increases patient information recall (Jansen, van Weert et al. 2010), engagement in medical decision-making (Clayman, Roter et al. 2005), adherence to medical treatments (DiMatteo 2004), as well as both patient and physician understanding of one another (Schilling, Scatena et al. 2002).

In contrast to companion communication predictors of patient satisfaction, we found few genetic counselor communication correlates patient satisfaction. This may suggest that study patients relied on their companions to translate and bridge communication between themselves and the genetic counselor, perhaps as a function of mild cognitive deficits that characterize the study patient population. This finding may also reflect low counselor use of facilitation strategies during the risk disclosure session. Less than a quarter of genetic counselor's talk was devoted to cognitive and emotional facilitation, such as question asking, checking for understanding, empathy, concern and reassurance statements (manuscript two), and this may have increased patients reliance on their family companions. The non-significant results could also due to a Type II error because of the small sample size. Given the significant impact of patient-centered communication, enhancing genetic counselors' facilitation efforts is vital in reaching all patients, but especially those with cognitive deficits.

We found that the more patient-centered the session was, the greater the likelihood that the companion would be very satisfied with session communication. This result is consistent with previous findings that that a higher frequency of patient centered behaviors is associated with greater patient satisfaction (Ong, de Haes et al. 1995; Stewart 1995; Aruguete and Roberts 2002; Beck, Daughtridge et al. 2002; Zachariae, Pedersen et al. 2003; Roter DL 2006).

It is important to note that session interaction influenced patient and companion satisfaction in a mostly similar way. However, there were substantial discrepancies between patient's and companion's ratings of complete satisfaction, which is consistent with prior research on patient-companion agreement (Neumann, Araki et al. 2000). There are many factors affecting this discrepancy, including the unmeasured characteristics of the patient, the companion, and of the AD risk communication process. One contributing factor to the discrepancy may be due to our study design. Companions were asked not only to evaluate the communication between the genetic counselor and themselves, but also the interaction between the genetic counselor and the patient. Patients focused solely on their interactions with the genetic counselor. It is also possible that companions and patients have different expectations for the session. Several studies have shown that patients and companions almost never show perfect agreement and they are less likely to agree about subjective issues, such as satisfaction with care (Epstein, Hall et al. 1989; Castle 2005; Eggenberger, Heimerl et al. 2013). The disagreement between patients and companion could also due to the effects of MCI; the patient may be less accurate or less critical of communication process.

A growing literature has shown that physicians can be taught to understand and implement a variety of patient-centered techniques, including demonstrating empathy, asking for patient understanding, and conveying reassurance (Roter, Hall et al. 1995; Cooper, Roter et al. 2011; Helitzer, Lanoue et al. 2011; Steinwachs, Roter et al. 2011). When working with patients with

dementia, communication skills training is particularly important for health professionals and family caregivers (Doyle 2009). Systematic reviews in dementia care have demonstrated significant positive impacts of communication skills training on professional and family caregivers' communication skills, competencies, and knowledge (Haberstroh, Neumeyer et al. 2011; Eggenberger, Heimerl et al. 2013; Wolff, Roter et al. 2014). There is far less literature describing effective strategies for patients with MCI. Our findings provide additional direction and rationale to develop tailored health communication programs for not only physicians and family caregivers, but for patients with mild cognitive deficits, as well.

**Limitations**

Some caution is necessary in interpreting our results given the exploratory nature of this study and the associations found in this descriptive study do not necessarily indicate a causal relation. In addition, satisfaction is a complex construct that may be influenced by unmeasured factors external to the disclosure session communication. Furthermore, patients enrolled in the REVEAL trial may differ from a broader population of older adults who are at risk for AD considering their high levels of education and motivations to seek genetic testing. Our findings may not apply to other AD risk disclosure sessions, due to the nature of the REVEAL protocol and the limited number of genetic counselors that took part in the study.

**Conclusions**

The positive satisfaction outcomes associated with patient-centered communication support the growing literature on patient-centered care. We also acknowledge the significant positive influence of family companions in achieving greater patient satisfaction. With the presence of

cognitive deficits, the active involvement of companions is critical to facilitate older adults to function successfully in complex healthcare environment. Additional research in this area may evaluate the significant effects of the triadic communication on psychological outcomes, such as distress and anxiety. Findings of this study also highlight opportunities for healthcare providers, patients and family companions to increase effective interactions in AD risk disclosure settings, which may ultimately lead to improved medical care quality and better patient outcomes.

## TABLES

### Table 4. 1. RIAS composite codes and coding examples

| RIAS Code | Definition | Coding Examples: Genetic Counselor | Coding Examples: Participant & Companion |
|---|---|---|---|
| Information giving (Biomedical) | Information regarding medical condition, symptoms, diagnosis, prognosis, test results, personal and family medical histories, future treatments or tests to be performed. | -Based on these factors, we would say your risk to develop dementia, the AD type, is estimated to be 8% in the next three years. | -That must mean that my parents somewhere along the line were carrying that, but I know of no Alzheimer's on either side of the family. |
| Information giving (Psychosocial/Lifestyle) | Discussion of emotional reactions, and the impact on family and social relationships relevant to genetic test result and decision making, information on self-care and preventive health habits, implication for work, insurance and finances. | -Other things you can do is maintaining physical, social and mental activity, and limiting alcohol use. | -I tend to be a dark side person.<br>-Maybe that little Lord is telling me "I want to test how strong you are". |
| Question asking (Biomedical) | Questions related to medical condition, symptoms, diagnosis, prognosis, test results, personal and family medical histories, future treatments or tests to be performed. | -What do you recall in terms of being told about MCI?<br>-So what can you do to cope with MCI? | -What does APOE stand for?<br>-Whether it's paired with two or three, doesn't seem to make any difference?<br>-Is there medication for people who cannot function? |
| Question asking (Psychosocial/Lifestyle) | Questions regarding feelings, general state of mind, values and beliefs, lifestyle, family and home situations, work or employment, health habits and self-care issues. | -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? | -Wouldn't you want to know whether you've got it or not?<br>-Do I have to tell my insurance company about all this? |
| Partnering statements | Asking for opinion, permission and reassurance, checking for understanding, cueing interest for further elaboration, and paraphrasing. | -Does that definition help at all?<br>-Does that make sense?<br>-Were you expecting that?<br>-So when you say that, you mean if you're taking life insurance, there's a two-year suicide clause? | -When you say your doctor, you are talking about family doctor at home? |

| | | | |
|---|---|---|---|
| Positive statements | Laughs, compliments, agreements and approval. | -Sounds like you're in good shape on that one. | -You explained it very well. |
| Negitive statements | Criticism and disapproval. | -That's not what I meant. | -I hoped you can come up some ideas I don't know. |
| Emotion Statements | Statements of partnership or alliance, expressions of reassurance, concern, empathy and legitimization. | -It's hard to lose people you care about. -I'm not quite sure about the exact number.<br>-What you're talking about is very common in people who are in a similar situation.<br>-If you think of any questions, feel free to ask. | -This makes me happy not only for myself, probably more for my family.<br>-I get frustrate when I can't remember something that I know I should.<br>-Not to be able to live with XXX as a phenomenal relationship, it's a very depressing thought. |
| Orientation Statements | Gives orientation, instructions, setting visit goals and agenda. | -The purpose of today's visit is to talk about your estimated risk of progressing to Alzheimer's disease in the next three years.<br>-Tell me more what you want to know more about. | -Let me ask you a question.<br>-Go back to that slide. |

**Table 4. 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) |

**Table 4. 3. Patient and family companion satisfaction with AD risk disclosure**

| Communication Profile | Patient Satisfaction (N=79) | | Family Companion Satisfaction (N=79) | |
|---|---|---|---|---|
| | unadjusted OR (SE) | adjusted OR (SE) | unadjusted OR (SE) | adjusted OR (SE) |
| Patient centeredness ratio | 1.38 (0.96) | 1.24 (0.92) | 2.51 (1.58) | **3.97 (2.78)*** |
| **Genetic counselor communication** | | | | |
| All statements | 1.00 (0) | 1.00 (0) | 1.00 (0) | 1.00 (0) |
| Biomedical information | 1.01 (0.01) | **1.01 (0.01)†** | 0.99 (0.01) | 0.99 (0.01) |
| Psychosocial/Lifestyle information | 1.00 (0.02) | 0.99 (0.02) | 0.99 (0.02) | 1.01 (0.02) |
| Questions (Biomedical) | 1.12 (0.08) | 1.12 (0.09) | 1.05 (0.07) | 1.05 (0.07) |
| Questions (Psychosocial/Lifestyle) | 1.09 (0.20) | 1.18 (0.23) | 0.94 (0.15) | 0.90 (0.16) |
| Partnering statements | 1.01 (0.01) | 1.01 (0.01) | 1.00 (0.01) | 1.00 (0.01) |
| Positive statements | **1.02 (0.01)*** | **1.02 (0.01)†** | 1.01 (0.01) | 1.01 (0.01) |
| Negative statements | 0.92 (0.27) | 0.83 (0.27) | 0.84 (0.21) | 0.88 (0.23) |
| Emotion Statements | 1.02 (0.03) | 1.03 (0.03) | 1.02 (0.03) | 1.02 (0.03) |
| Orientation Statements | 1.01 (0.04) | 1.01 (0.04) | 1.03 (0.04) | 1.05 (0.04) |
| **Patient communication** | | | | |
| All statements | **1.01 (0)†** | **1.01 (0)†** | 1.00 (0) | 1.00 (0) |
| Biomedical information | 1.02 (0.01) | 1.02 (0.01) | 1.00 (0.01) | 1.00 (0.01) |
| Psychosocial/Lifestyle information | **1.01 (0.01)†** | **1.01 (0.01)†** | 1.00 (0.01) | 1.00 (0.01) |
| Questions (Biomedical) | 1.05 (0.06) | 1.04 (0.06) | 0.96 (0.05) | 0.96 (0.05) |
| Questions (Psychosocial/Lifestyle) | 1.11 (0.19) | 1.09 (0.20) | 1.20 (0.19) | 1.29 (0.23) |
| Partnering statements | **1.05 (0.03)†** | **1.05 (0.03)†** | 1.02 (0.02) | 1.03 (0.03) |
| Positive statements | **1.03 (0.02)†** | **1.03 (0.02)†** | 1.01 (0.01) | 1.02 (0.02) |
| Negative statements | 0.93 (0.16) | 0.95 (0.17) | 0.94 (0.12) | 0.92 (0.12) |
| Emotion Statements | **1.05 (0.03)†** | **1.06 (0.03)*** | 1.03 (0.03) | 1.05 (0.03) |
| Orientation Statements | 1.08 (0.12) | 1.08 (0.13) | 0.90 (0.09) | 0.93 (0.10) |
| **Family companion communication** | | | | |
| All statements | 1.00 (0.01) | 1.01 (0.01) | 1.00 (0.01) | 1.01 (0.01) |
| Biomedical information | 1.01 (0.03) | 1.00 (0.03) | 1.00 (0.02) | 1.01 (0.02) |
| Psychosocial/Lifestyle information | 1.01 (0.01) | 1.01 (0.01) | 1.02 (0.01) | **1.02 (0.01)†** |
| Questions (Biomedical) | 0.99 (0.06) | 0.99 (0.06) | 0.91 (0.06) | 0.92 (0.06) |
| Questions (Psychosocial/Lifestyle) | **1.60 (0.34)*** | **1.75 (0.41)*** | 0.87 (0.17) | 1.00 (0.21) |
| Partnering statements | 1.01 (0.03) | 1.01 (0.03) | **0.92 (0.04)*** | 0.94 (0.04) |
| Positive statements | **1.05 (0.03)†** | **1.07 (0.04)†** | 1.01 (0.03) | 1.02 (0.03) |
| Negative statements | **0.62 (0.18)†** | **0.53 (0.18)†** | 0.87 (0.12) | 0.95 (0.14) |

| | | | | |
|---|---|---|---|---|
| Emotion Statements | 1.00 (0.05) | 1.02 (0.05) | 1.08 (0.05) | **1.10 (0.06)†** |
| Orientation Statements | 1.02 (0.10) | 1.05 (0.11) | 0.90 (0.09) | 0.95 (0.09) |

†P<0.1; *P<0.05.

Adjusted odds ratios control for patient and companion gender, years of education and patient 3-year AD risk.

# CHAPTER 5: DISCUSSION

## SUMMARY OF FINDINGS

This dissertation addresses a significant need for observational studies of how genetic counselors communicate AD risk to patients with mild cognitive deficits and their accompanying family members; as evident in the review of this literature, these descriptions are rare. By using a novel combination of coding approaches designed to address different but complementary elements of the communication process, our results produced a comprehensive description that will be useful to researchers interacting with this vulnerable population as well as clinicians in the delivery of care.

We found that the AD risk disclosure sessions, with and without genetic risk discussion, were generally more patient-centered than biomedically-focused. This communication pattern is consistent with findings of dementia diagnosis disclosure sessions (Zaleta and Carpenter 2010), but is different from the general didactic biomedically-focused approach described in the genetic counseling literature (Ellington, Baty et al. 2006; Lerner, Roberts et al. 2014). For the APOE genotype inclusive discussions, they were less patient centered than those using only cognitive impairment and age to calculate the AD risk, because of the abstract and technical nature of the genetic information conveyed. The focus on genotype is likely to overwhelm the discussion as is evident in other genetic counseling contexts (Ellington, Baty et al. 2006; Roter, Ellington et al. 2006; Meiser, Irle et al. 2008; Lerner, Roberts et al. 2014).

The results of this dissertation provide evidence supporting the role of genetic counselors' facilitative talk in eliciting cognitive and emotional processing of complex AD risk information by patients and visit companions. It is significant that the broader literature on cognitive and emotional processing suggests therapeutic benefit (Lepore, Ragan et al. 2000; Kennedy-Moore 2001; Austenfeld and Stanton 2004; Lepore SJ, Kernan WD et al. 2009), and although not measured, it may be the case in the current study.

The immediate outcomes measured in this dissertation were patient and companion satisfaction with the AD risk communication processes. The positive satisfaction outcomes associated with patient-centered communication support the growing literature on patient-centered care. However, specific counselor's communication behaviors did not have a significant impact on patient satisfaction with the interaction. It appeared that patients with MCI relied on their visit companions to compensate for this by taking a more active and facilitative role in the visit dialogue.

In particular, we found that family companions increased their verbal participation in the APOE ε4 positive subgroup when the AD risk information is complicated by the ε4 factor and when the need for more emotional support is greatest. They also took a more facilitative role by being nonverbally positive, providing or clarifying medical and family history, and directing the course of the session by prompting additional discussion or introducing a new agenda item in the ε4 positive group relative to the ε4 negative group. Furthermore, family companion's psychosocial question asking showed to have a positive impact on patient satisfaction with the risk disclosure session. These findings build upon prior research linking the involvement of visit companions to older patients' reports of satisfaction with care and these relationships were strongest among patients who were older or who had poorer health (Wolff and Roter 2008; Wolff, Boyd et al. 2012).

Overall, the findings of this dissertation advance our understanding of the nature and consequences of complex AD risk information communication to patients with cognitive impairment and an accompanying family member in a research context, as well as contribute to an evidence base to guide communication training and service for the benefit of patients and their families.

**STRENGTHS**

The strengths of this dissertation are reflected in several areas. To our knowledge, this is the first investigation of how genetic counselors communicate AD risk (with or without genotype

information) to patients with MCI. It also provides new insights into family member's roles in these visits, an area largely unexamined to date. The inclusion of a family companion is especially relevant to the field of geriatric care, because it is reflective of the clinical reality of some 40% of patients over 65 years of age are routinely accompanied to their medical visits by a family member (Wolff and Roter 2008).

Another strength in this work is the pioneering application of the social cognitive processing (SCP) model to AD risk disclosure visits. Ellington's and colleagues' preliminary work in cancer genetic counseling suggests the complementary contributions of both RIAS and LIWC coding and informs the approach taken in this dissertation. Moving beyond Ellington's earlier work, the design of our studies expended the model to the triadic genetic counselor-patient-companion interaction. We captured genetic counselor's facilitation of emotional and cognitive processing of complex AD risk information not only to patients with MCI, but also to family companions. Furthermore, we applied the SCP model to actual medical discourse of any kind rather than using simulated patients.

A related strength of this dissertation is the use of RIAS and LIWC as standardized quantitative coding systems. Most research on clinician-patient communication in dementia care has used qualitative interviews and post-visit questionnaires to obtain retrospective accounts from patients, caregivers, and physicians to characterize diagnostic conversations (Smith and Beattie 2001; Bamford, Lamont et al. 2004; Aminzadeh, Byszewski et al. 2007). Application of the combination of these two coding approaches has the potential to create a comprehensive description of the AD risk disclosure discussions without reporter bias or recall bias. Additionally, comparison across projects and research settings is possible.

The design of RCT is an important strength to address Aim 2 to contrast communication style of risk disclosure discussions in which genotype results are disclosed (or not) to family-accompanied patients with MCI. Selection bias is unlikely because of the generation of the randomization sequence

and comparable baseline characteristics of patients and visit companions. Such information is critical in order to examine whether differences in communication dynamics across the three study groups are due to patients' genotype status (unknown, ε4 positive and ε4 negative).

## LIMITATIONS

This dissertation has several limitations. The risk estimates do not consider other potential risk factors for the disease, including other genes, environmental exposures and gene-gene or gene-environment interactions. Several predictors of interest that may be relevant to the communication process cannot be evaluated in this study due to little variance, such as race. In addition, satisfaction is a complex construct with many determinants and individuals' perceptions may be influenced by unmeasured factors external to the disclosure session communication, including patients' and companions' health status and state of mind.

LIWC is limited in the extent to which it can depict the context of interaction since it relies only on counts of word frequency. For example, we found that patients expressed more negative emotion in the genotype nondisclosure group than those received ε4 positive result, regardless of counselor's emotional facilitation efforts and other factors that might influence emotional expression. We could not differentiate the expression of negative emotions associated with AD risk from that related to study randomization, but have observed that patients in the genotype nondisclosure group were unhappy at having their genotype information withheld.

Caution is necessary in interpreting our results given the exploratory nature of this study and the associations found in this descriptive study do not necessarily indicate a causal relation. For example, our analyses cannot determine the causal pathways that precipitated patient and companion expression and whether they were self-initiated or elicited in some way by the genetic counselor. It is

possible that patients who were more satisfied with the session communication felt more comfortable to disclose more emotions.

External validity is limited due to the small sample size in this dissertation. Also, the patients enrolled in the REVEAL IV study were largely self-referred and well-educated and may have had different motivations and levels of concern than a broader population of older adults who are at risk for AD. Our findings may not apply to other AD risk disclosure sessions, due to the constraints of REVEAL IV as a controlled trial and that only three genetic counselors took part in the study. It is possible that these counselors are not representative of others and their practices do not reflect common practice but rather idiosyncratic approaches to communication driven by a research protocol.

## IMPLICATIONS FOR PRACTICE

We expect that potential for wide dissemination of the study findings is high. This dissertation addresses AD, a condition that effects 11% of people age 65 and older (Alzheimer'sAssociation 2014), and an area in which the need to identify at risk populations and effectively communicate AD risk information is widely recognized as essential for high quality, patient-centered care.

We adapted empirically-tested theoretical frameworks to identify strategies used when conveying abstract and complex information that are particularly effective in facilitating cognitive and emotional processing. Those findings may guide health care providers on how to effectively communicate abstract information to patients with cognitive impairment, as well as their family members. Findings of this dissertation contribute to a small but important literature, suggesting directions for future theoretically supported communication interventions and education efforts for genetic counselors and other health care providers.

The link of AD risk disclosure session communication to post-session patient and family companion satisfaction is particularly important in the context of recent efforts to increase satisfactory

communication skills in medical encounters (HealthyPeople2020). Satisfaction has been used as a key indicator of quality of care from the patients' perspective and an important component of pay-for-performance (Jacobson 2011). Starting in 2013, Medicare reimbursements are linked to patient satisfaction and surveys completed by patients. Centers for Medicare & Medicaid Services has a specific domain evaluating patient satisfaction regarding "Doctor Communication". Our findings demonstrate that effective AD risk disclosure for older adults with MCI includes active patient and family engagement in the medical dialogue and that patient-centered communication is essential for greater satisfaction outcomes. These results provide guidance for healthcare providers, patients and family companions to accomplish satisfactory communication in AD risk disclosure settings, which may ultimately lead to improved medical care quality.

Another important aspect of this work is the evidence of active involvement of family members in the facilitation of medical visit communication and that their participation is valued by patients and associated with a more satisfying care process. The role of family companions in primary care is increasingly recognized as important, and several position papers and commentaries from professional societies have set forth policies to promote the physician-patient-family partnership (AMA 1993). To this end, efforts are warranted to integrate family members into the AD risk discussions and to optimize their contributions.

## FUTURE RESEARCH

Several areas of future research emerged from the findings of this dissertation. More efforts to design, implement and evaluate interventions addressing communication skills from the vantage point of patient, family member and health care providers will make a novel contribution to the address of patient-centered care for all accompanied older patients, but especially for those with cognitive impairment.

Specifically, the communication strategies identified in this dissertation may be useful in assisting patients with MCI to more fully engage in the communication process, especially in terms of emotional processing and cognitive integration of complex and abstract information. We believe that educational tools targeting these communication skills have the potential to be widely used by clinicians and cognitively impaired patients when facing the kinds of communication challenges discussed in this dissertation and inherent to the clinical care.

Further, given the frequent engagement of family companions in the communication processes in AD risk disclosure, there is a need for more explicit address of ways in which they may be more fully and productively included in session dialogue. Since specific accompanying family member communication behaviors have been associated with patient satisfaction with care, interventions designed to increase the frequency of these behaviors are warranted.

During the AD risk disclosure sessions, accompanying family members also have an opportunity to promote, through their communication behaviors, patient insight and emotional expression. Additional research in this area should examine the role of visit companions in facilitating the patient's adjustment to and understanding of the AD risk information.

Moreover, research is needed to evaluate the significant effects of the AD risk communication on other important patient outcomes, such as distress and anxiety. There remains a need for research on the predictors of individual communication style, as well as facilitators and barriers to active patient (and family) engagement in medical dialogue and how clinicians think about balancing patient and companion engagement in AD risk disclosure sessions.

# APPENDICES

## APPENDIX 1. RIAS REVEAL IV General Codebook

**General Rules:**

1. Code three speakers' talk:
   Genetic counselor to patient
   Genetic counselor to companion
   Patient to genetic counselor
   Patient to companion
   Companion to genetic counselor
   Companion to patient
   If the information receive in an exchange is unclear, default to genetic counselor or patient.
2. Do NOT code "this is subject XXX and the date is XXX".
3. Do NOT code interviewing sections (usually at the beginning or in the end of each session when the doctor asked survey questions and explained follow-up study procedures).

   Survey question examples---*"So before I go through our slides, I just have a couple of questions for each of you, okay. So, Mr. Haines, what do you hope to gain from learning your Alzheimer's disease risk estimate?" "Okay, that's the end. I just have a couple more questions for you."*

   Follow-up study procedure example---*"So let us talk about next steps before we end for this component of things. As I mentioned you have the one- to three-day phone call with me that will schedule after today's session. About six weeks later you will come in for your final in-person visit in the hospital, and that will be a visit -- mainly you will fill some more surveys and do some face-to-face questions and answers with me. And then the final six month follow-up point is a combination of mail surveys, which I will mail to you ahead of time, you will fill out and mail back to me, and then I will set up a phone interview with both of you. And that's pretty much it for the next components of the study. "*

4. The affect rating should be scored based on the overall affective impressions of the speaker. For example, companion affect ratings are based on the companion's talk to both the genetic counselor and the patient.

RIAS REVEAL IV coding includes several coding categories not usually employed on the regular coding screen. Some coding categories are described below, and appropriate examples are provided.

1. "Self" category includes information that refers to personal knowledge or to a relationship that is relevant to the speaker, and "General" includes information that refers to other people in the abstract or to information that is of a more general nature.
2. Discussion about the patient's cognitive function (e.g. memory, emotional problems, and stress management) is in the psychosocial category as in "I think I've had some issues with my memory". Mild cognitive impairment (MCI) and Alzheimer's Disease are coded as MED as they are specific diagnoses.

3. "Counsel" includes talk that directs behavior as well as talk that is used as persuasion to direct behavior. For example, the genetic counselor may say, "You should begin an exercise program if you haven't already. Research indicates that exercise actually helps the brain to…"
4. Talk about the REVEAL study is coded as "other," as in "There are two arms of the study." However, specific information about what arm of the study the patient was in and when the patient can return to find out more information, etc, is coded in category.
5. "There are risk factors you can change" begins a Counseling segment in most case. "Risk factors you cannot change" is coded as Gives information.
6. Quality of sleep (sleep hours/wake up frequency/easy to sleep)=Med; sleep habit or hygiene=Lifestyle.
7. "I know you're curious to know/interested/wondering about your test results."= concern=a special consideration of patient. "I know you asked about" could be "check" in some cases.
8. If the speaker is talking about other people's medical problems, code as "GIVES-ls". However, if the purpose is to show "this is what I know about this medical problem", code in category as in "I had a friend who was on Aricept. That medicine helped her a lot."

**Gives-med**

Statements of fact or opinion relating to the medical condition, symptoms, diagnosis, prognosis, past tests and test results, medical background (including history of immunizations or cortisone shots, chemotherapy or radiation treatments in the past), personal and family medical histories, practices and allergies.

***Gives-med/self***

GC: Last time we took a sample of your blood, and we sent it to the lab, and they looked at one particular gene.
GC: If you have two copies of the E4, your risk is a little higher than if you only have only one copy of the E4.
GC: Based on these factors, we would say your risk to develop dementia, the AD type, is estimated to be 8% in the next three years.
GC: The risk factors you can't change, which are going to be your age, your family history, your medical history, and your genetics.
PT: I don't have a genetic risk.
PT: I'm being treated for depression.

***Gives-med/gen***

GC: We're providing an estimated risk of progressing to dementia of the Alzheimer's type in the next three years.
GC: Adults who have MCI do have an increased risk to develop Alzheimer's and other types of dementias.
GC: Some adults with MCI remain stable.
GC: There're lots of risk factors for AD.

**Gives-thera**

Statements of fact or opinion regarding the ongoing or future (beginning with this visit) treatment plan, such as information relating to medications used or drug regimen, drug allergies, specific treatments or tests to be performed, imminent hospitalizations, future medical appointments or doctor-patient contacts. In addition, this category includes information about drugs or medications taken or prescribed in the past.

***Gives-thera/self***

GC: Some medications may be considered to help with your care.
GC: We would have you come back in and disclose the risk information.

***Gives-thera/gen***

GC: Currently there're no proven medications to treat MCI.
GC: That's kind of a neurologist's or a doctor's determination.

**Gives-ls**

Statements of fact or opinion relating to lifestyle (smoking, diet, sleep, alcohol and exercise habits), family and home situations, work or employment, health habits and self-care issues. Includes information regarding daily routine as it relates to the general medical condition and health regimen, and information about medical coverage and costs (e.g., Medicare, prescription plan benefits, availability and cost of medications, treatments and tests). Includes information about past, present and future plans in the above areas. These statements are generally straightforward, matter-of-fact in content and delivery, and affectively neutral (note the exclusion of psychosocial concerns). This category also includes talk about the medical problems and therapeutic plans of other people (e.g., of family members or neighbors, unrelated to the patient's medical condition).

***Gives-ls/self***

PT: I do enjoy walking. That's my exercise.
PT: I'm reading quite a bit. I have a book club.
PT: I keep my stamps in my wallet.

***Gives-ls/gen***

GC: Driving can sometimes become an issue as well.
GC: Limited alcohol use was found to be good for memory problems.
PT: A fascinating book called "The Warmth of Other Suns", the whole history of African Americans. It's a prize-winning book.

**Gives-ps**

Includes statements that relate to psychosocial concerns or problems, including stress, feelings, emotions, general state of mind, philosophical outlook, values and beliefs. These statements may refer to lifestyle, medical and/or therapeutic information, but are distinguished from the other Gives Information categories by their psychosocial or affective dimension. They are, however, less immediate, intimate or intense than the Reassures/Optimism, Concern, Approves (direct) or Disagrees (direct) categories. This content area includes talk about depression, including clinical depression, as well as discussion of alcoholism, drug abuse and ADD (Attention Deficit Disorder). Statements about the use of psychoactive drugs are coded here when the discussion relates to the effects of these drugs.

***Gives-ps/self***

GC: There can be changes in your role and your responsibilities.
GC: Some symptoms do affect your memory. Emotional symptoms like depression, or high stress.
GC: You can feel sometimes anger or frustration or sadness about it.
PT: You ought to have a sense of humor.
PT: Maybe that little Lord is telling me "I want to test how strong you are".

PT: I'm kind of a whip cracker.
PT: I've always been -- had a strong interest in numbers.
PT: I tend to be a dark side person.
PT: Because that gives me the freedom to develop some things that I want to do.

***Gives-ps/gen***

GC: It does have emotional symptoms. We know it can cause, or even worsen, memory problems.
GC: I think some people are most surprised to learn that some people with MCI do improve memory function.
GC: Depression is going to refer more to feelings of sadness, feelings of hopelessness, and anxiety is going to be more like people that are more concerned, or anxious.

**Gives-other**

Statements of fact or opinion about clinic paperwork, exam or study procedures (i.e., statements that do not fall into one of the above sub-categories). This category also includes any neutral statements about the study itself.

GC: You're participating in the REVEAL study. There're two arms of the study.
GC: This is one of the tips that came from our focus group.

**Ask med**

Includes closed- and open-ended questions about medical and family histories, previous treatments, symptoms, physical condition (e.g., the pain or disability), practices related to the medical condition, and allergies (except allergies to drugs).

***Ask med/self***

GC: What do you recall in terms of being told about MCI? Or your diagnosis?
GC: Do you have any questions about your risk estimate?

***Ask med/gen***

PT: If they have two APOE 4, does that increase the risk as the result of having two?
PT: What does APOE stand for?

**Ask thera**

Includes closed- and open-ended questions relating to past, ongoing and future drug regimens, or ongoing or future treatment practices.

***Ask thera/self***

GC: So what can you do to cope with MCI?
PT: Will I find out (genetic test result) that today?
PT: would you go to a neurologist and say, give me a blood test for the E4?

***Ask thera/gen***

PT: Is there medication for people who cannot function?
PT: How does that help to cope with memory problems?
PT: Do you have any guestimate as to whether such a test will be available to the general public or through their doctors at some point in the next five years?

**Ask ls**
Includes closed- and open-ended questions relating to lifestyle (smoking, diet, sleep, alcohol and exercise habits), family and home situations, work or employment, prevention and self-care issues. These questions are distinguished from conversation coded as Personal in that the questioning is more than purely social or of friendly interest (i.e., may be for the purpose of developing an understanding of the other's lifestyle as it pertains to his/her state of health). Also includes questions about health insurance coverage (e.g., Medicare, prescription plan benefits, reimbursement issues, prior approval for tests) and other cost issues.

***Ask ls/self***

GC: Are you taking a trip?
PT: Do they (health insurance) take care of people like me?

***Ask ls/gen***

PT: A person with dementia, they shouldn't even be driving, right? They could still get a license and drive and all of that?

**Ask ps**
Closed- and open-ended questions pertaining to the psychological or emotional state or things directly related to this state. Includes questions about emotions, worries, concerns or such feelings as stress or personal likes or dislikes.

***Ask ps/self***

GC: Is this something you enjoy?
GC: Did you suspect that?
GC: Is that information that you remember getting?
GC: Do you look at the glass half full, half empty, or?
GC: 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?

***Ask ps/gen***

PT: The families naturally are going to be depressed [Gives-ps/gen], what is going on [?ps/gen]?
PT: Is depression and anxiety the same thing?

**Counsel-med/thera**
Includes statements regarding the medical problem, drug regimen, future appointments, and tests. Statements that suggest or imply some resolution or action to be taken by the other person (usually the patient). These statements are characterized by the intent to persuade, influence, direct or change the other's behavior. Included are imperative statements that explicitly direct behavior.

GC: There're some risk factors you can change, things like treating high blood pressure, treating diabetes, high cholesterol, depression or sleep disorders.
GC: Instead of having medications in different bottles, put them in a colored pill box.

**Counsel-ls**

Includes statements relating to lifestyle, family, activities of daily living, work and employment, general health promotion and prevention, These statements suggest actions or changes in behavior that involve the patient's volition or control of habits.

GC: Other things you can do is maintaining physical, social and mental activity, and limiting alcohol use.
GC: Make plans for the future. You know the diagnosis of MCI could impact your insurance coverage, financial plans and legal documents.
GC: Discuss your health wishes with your family members.
GC: The thing that I have recommended to other couples is to think about just having a notebook, like a blue notebook, and that you just kind of record things in that notebook.

**Counsel-ps**
Includes statements relating to psychosocial issues, including emotional problems and concerns. Statements that suggest or imply some resolution or action to be taken by the other person (usually the patient). These statements are characterized by the intent to persuade, influence, direct or change the other's behavior. Included are imperative statements that explicitly direct behavior.

GC: To talk to your doctor to treat emotional symptoms and help in terms of stress management.
GC: To keep records of your memory problems to show your doctor.
GC: To do tasks that require more thought in the morning. You know, when you're sharper.
GC: It's helpful to talk to others, or counsel some of the resources we would be giving you.
GC: Just talk to two of you to see what system is gonna work well. Maybe on your end to recognize that she may be not remembering where she thought she put it.

**Concern**
A statement or non-verbal expression indicating that a condition or event is serious, worrisome, distressing or deserving special attention (such as comforting or other special consideration) and is of particular concern at this point in time.

GC: I know you have been curious about this piece of information for quite a while.
GC: You may be wondering what's your risk to develop dementia, the AD type, beyond three years.
GC: I'm not sure that's really answering your question.
GC: It's hard for the doctor to detect.
GC: It can be stressful.
GC: I'm not quite sure about the exact number.
PT: I'm having really significant problems with my memory.
PT: I mean I have MCI, (which) took us years to find that out. That makes me feel uncomfortable, but not as much as one of the two E4s.
PT: That's pretty discouraging.
PT: I get very stressed when I think about it.
PT: Not to be able to live with XXX as a phenomenal relationship, splendid relationship, it's a very depressing thought.
PT: I was much more concerned about how much this would affect my family.
PT: I sure wish I could remember the names of the ones I know.
PT: I get frustrate when I can't remember something that I know I should.

**Reassure**
Includes statements indicating optimism, encouragement, relief of worry or reassurance. Includes statements that show an awareness of the other's feelings in a positive upbeat way, or respond to a request for reassurance.

GC: Just like last time, if you think of any questions, feel free to ask.
PT: Nothing could make me happier, absolutely.
PT: This makes me happy not only for myself, probably more for my family.
PT: That's better than I have expected.
PT: This is the most cool, calm person you will ever meet. None of this would apply.
PT: That's why I'm happy I'm on that Exelon patch.
PT: I feel relieved.

**Approve**
Compliments, expressions of approval, gratitude, praise, reward, respect or admiration directed to the other person present.

GC: Sounds like you're in good shape on that one.
GC: There you go. Sounds like you get some tips that can be added to this list.

PT: Got that covered [Reassure].
GC: Wonderful. It's great to hear [Approve].

**Compliment**
Compliments, expressions of approval, gratitude, praise, reward, respect or admiration directed to another not present during the exchange.

PT: I have been impressed by the fact that almost every one of them (magazine) has an article about this (healthy lifestyle).
PT: That was one of the best articles I have seen.
PT: They've got that fairly well organized.

**Laughs**
Includes friendly jokes, trying to amuse or entertain, kidding around, good-natured teasing, morbid jokes (e.g., "I might blow away in a strong wind"), and all forms of laughter.

GC: We have the word "crap" on there. We're tape recording now.
PT: We've been fighting about this iPad.
PT: Wonder what he's planning. I thought he was a nice -- never mind.

**Disapprove**
Any indication of disapproval, criticism, complaint, rejection, coolness or disbelief directed expressly to the other person present.

PT: You made me sounds really bad.
PT: I hoped you can come up some ideas I don't know.

**Criticism**
Any indication of disapproval, complaint, rejection, coolness, or disbelief directed toward another not involved in the exchange.

PT: If you put it there, you put it there, why are you bugging me?
PT: I find myself wondering why this study was obviously limited to whites only.
PT: I have never in my mind been asked by a doctor about AD in my family.
PT: I don't have a lot of confidence in the amount of knowledge the average doctor has regardless the field they are in.

**Emp/legit**
Statements that paraphrase, interpret, name or recognize the emotional state of the other person present during the visit. Statements that indicate that the other's emotional situation, actions, or thoughts are understandable and normal.

GC: Actually some of these sound typical, some interactions between spouses.
GC: It's a common question.
GC: What you're talking about is very common I think in people who are in a similar situation.
GC: It's hard to lose people you care about.

**Partnership**
Statements that convey the physician's alliance with the patient in terms of help and support, decision-making, or the development of the therapeutic plan.

GC: We can work our schedule around fishing season.
GC: We can seek greater clarification for it.

**Self-disclose**
Statements that describe the physician's personal experiences in areas that have medical and/or emotional relevance for the patient.

GC: I cannot live without a calendar.
GC: Speaking from my experience, it can be stressful when you're trying to look for things, like I thought I put it there, how come it is moved, where is it.
GC: I proved this morning just because I was up, didn't mean I could find my keys.

**Agree**
Included in this category are signs of agreement or understanding. Includes conceding a point, social amenities and apologies that do not indicate particular concerns for the other's feelings.

GC: Yes, that's right.
GC: Excuse me.
PT: Okay.

**?Reassurance**
Questions of concern that convey the need or desire to be reassured or encouraged. Voice tone, intonation and emotional content may be of significance when distinguishing questions that ask for reassurance from other questions.

GC: Does this all sounds familiar?
GC: Does that definition help at all?
PT: Do you mind if I write that down?

PT: Can I ask you a question? [?reassurance]
GC: Absolutely! [R/O]

**?Permission**
Questions that specifically ask for permission to give information or to proceed.

PT: Can I write this down?

**Orient**
Orientation statements tell the other person what is about to happen, what is expected during the interview or exam, or serve to orient the other to the major topics of discussion or the physical flow of the visit.

GC: Now I have some slides to guide us here.
GC: We have a few figures to show you.
GC: We have a few tips on living with memory problems.
GC: Tell me more what you're wanting to know more about.

**BC**
Indicators of sustained interest, attentive listening or encouragement emitted by the doctor when he or she does not hold the speaking floor.
GC: Mmm-huh.
PT: Yeah [I'm listening]…
PT: Right [go on…]...

**Trans**
Sentence fragments that indicate movement to another topic or area of discussion, train of thought or action. Includes statements or fragments that are place-holders, if the utterance stands alone and is separated from other utterances by a pause of one second or more.

GC: Now...
GC: Let's see.
GC: All right…

**Check**
Mechanisms by which the speaker re-states or reflects back information he or she has just been told by the other for the purpose of checking for accuracy of information, or for confirming a shared understanding of the facts or issues being discussed. These re-statements may be in either question or statement form, but the function of the speaker's utterance is to clarify, or ask for clarification of, the other's communication.

PT: What can you do with MCI? [?med/gen]
GC: About mild cognitive impairment? [check]

PT: When you say your doctor, you are talking about family doctor at home?

**?Understand**
Mechanism by which the doctor or patient quickly checks with the other to see if information that was just said has been followed or understood.

GC: Do you understand?
GC: OK?
GC: Does that make sense?

**?Bid**
Mechanism for requesting repetition of the other's previous statement. Bids are used when words or statements have not been clearly heard, and therefore need repetition, and are often signs of perceptual difficulties. They follow right after or shortly after the statement needing repetition.

PT: What did you say?
GC: Huh?

**?Opinion**
Questions that ask for the patient's opinion, point of view or perspective relating to diagnosis, treatment, etiology, prevention or prognosis. Includes questions that invite the patient's judgment, or ask for the patient's preferences or choice when presented with options (what the patient wants or would like), expectations, or survey of the problem.

GC: Were you expecting that?
GC: What questions do you have?

**APPENDIX 2: Satisfaction Survey**

**REVEAL IV – Patient Satisfaction:**

Please think about your experience with the clinician who discussed your Alzheimer's disease risk estimate with you. Please indicate how strongly you agree or disagree with each of the following statements about how your clinician acted and how you felt during your risk disclosure session.

When you are finished with the questionnaire, place it in the envelope provided. The clinician who met with you today will **NOT** see your responses to these questions.

| | | **Strongly Disagree** | **Disagree** | **Neutral** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|---|
| | | 1 | 2 | 3 | 4 | 5 |
| **1** | Your clinician was able to explain the Alzheimer's disease risk estimate and its meaning in a way that you could understand. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **2** | You were comfortable asking your clinician questions. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3** | Your clinician acted warm and open to you, for example, by sitting near you, smiling, or using eye contact. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **4** | Your clinician understood what you were going through emotionally. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5** | Your clinician acted supportive and gave you the feeling that he/she was a partner with you. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **6** | Your clinician discussed how the risk assessment might affect how you and your family think about your health and your future. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7** | Your clinician seemed interested in what you had to say. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **8** | You trust your clinician to tell you the truth about your health and medical condition. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **9** | You trust your clinician to keep what you tell him or her confidential. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **10** | You trust your clinician to look out for your best interests. | ☐ | ☐ | ☐ | ☐ | ☐ |

**REVEAL IV – Family Companion Satisfaction:**

Please think about your experience with the clinician who discussed your study partner's Alzheimer's disease risk estimate. Please indicate how strongly you agree or disagree with each of the following statements about how your clinician acted and how you felt during the risk disclosure session.

When you are finished with the questionnaire, place it in the envelope provided. The clinician who met with you today will **NOT** see your responses to these questions.

| | | **Strongly Disagree** 1 | **Disagree** 2 | **Neutral** 3 | **Agree** 4 | **Strongly Agree** 5 |
|---|---|---|---|---|---|---|
| **1** | Your clinician was able to explain the Alzheimer's disease risk estimate and its meaning in a way that you could understand. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **2** | You were comfortable asking your clinician questions. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **3** | Your clinician acted warm and open to you, for example, by sitting near you, smiling, or using eye contact. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **4** | Your clinician understood what you were going through emotionally. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **5** | Your clinician acted supportive and gave you the feeling that he/she was a partner with you. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **6** | Your clinician discussed how the risk assessment might affect how you and your family think about your health and your future. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **7** | Your clinician seemed interested in what you had to say. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **8** | You trust your clinician to tell you the truth about your study partner's health and medical condition. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **9** | You trust your clinician to keep what you tell him or her confidential. | ☐ | ☐ | ☐ | ☐ | ☐ |
| **10** | You trust your clinician to look out for your study partner's best interests. | ☐ | ☐ | ☐ | ☐ | ☐ |

**APPENDIX 3: The REVEAL Study Risk Summary Sheet**

**Genotype Nondisclosure Group**
**3-year risk of progressing to dementia of the Alzheimer's disease type**

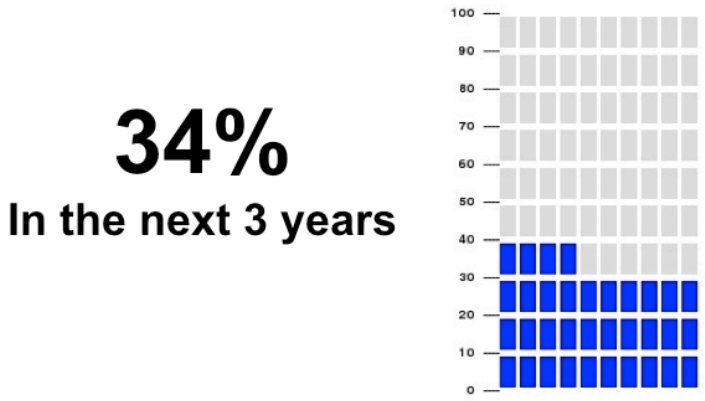
This sheet summarizes the risk information provided to you as part of your participation in the REVEAL Study. If you have any questions about this information, please feel free to contact ***Insert Contact Name*** at ***Insert Phone number***

Based on the following factors:

- Your diagnosis of mild cognitive impairment (**MCI**)
- Your current **age** being between 71 and 77 years

Your estimated risk of developing Alzheimer's disease (AD) over the next 3 years is **34%**.

To say this another way, out of **100** people who also have a diagnosis of MCI and are in the same age group, **34** of them would progress to dementia of the Alzheimer's disease type over the next 3 years and **66** would not.



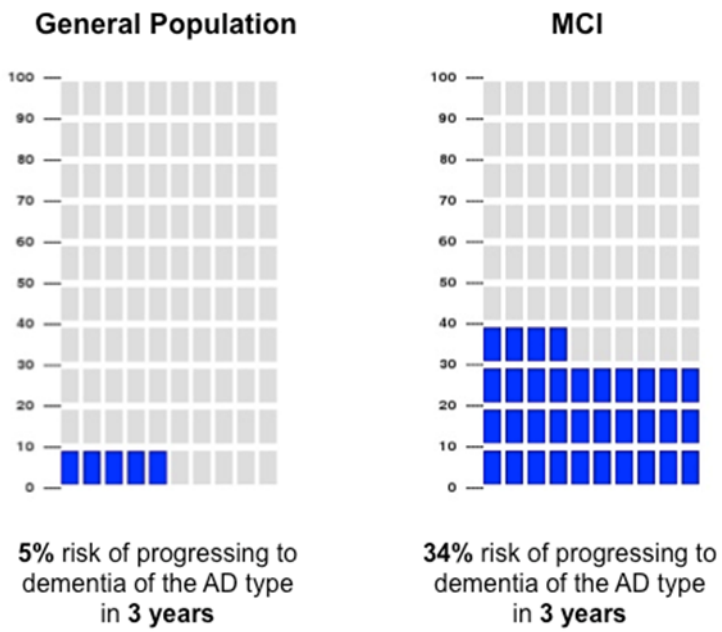

**Risk beyond 3 years**

- You may be wondering what your risk of progressing to dementia of the Alzheimer's disease type is beyond three years.
- It is believed that risk for dementia of the Alzheimer's disease type continues to increase over time.
- Research is being done to determine the long-term risk.

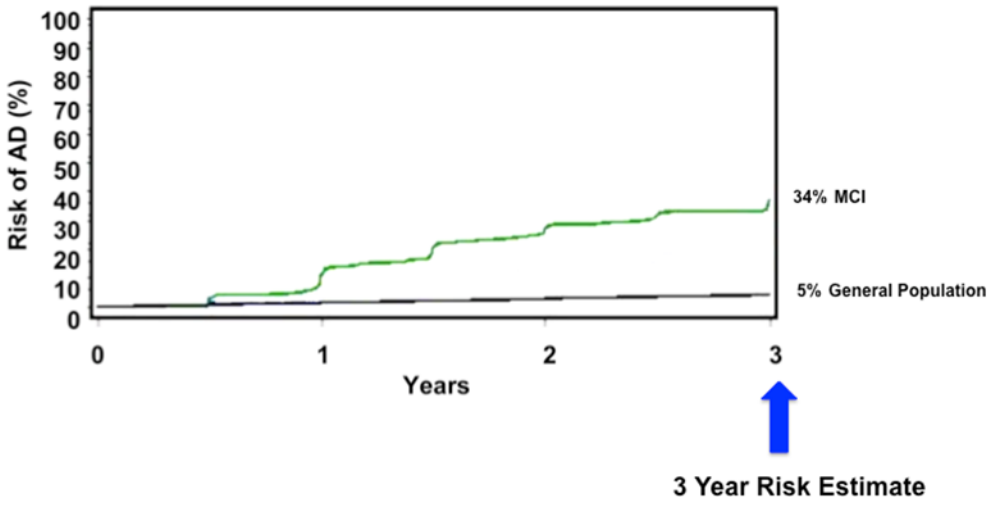
**Limitations of the risk estimate**

- The risk figure that we provided you is our best estimate at this time and is based on one large study. We are still learning about other factors, both genetic and environmental, that determine risk for AD.
- Additionally, the risk information we are sharing with you is drawn from a study in which the majority of participants were White. We suspect the risks are similar for all racial and ethnic groups, but we do not know for sure.

# Risk of progressing to dementia of the Alzheimer's disease type




# Risk increases over time



**Genotype Disclosure Group**
**3-year risk of progressing to dementia of the Alzheimer's disease type**

This sheet summarizes the risk information provided to you as part of your participation in the REVEAL Study. If you have any questions about this information, please feel free to contact ***Insert Contact Name*** at ***Insert Phone number***

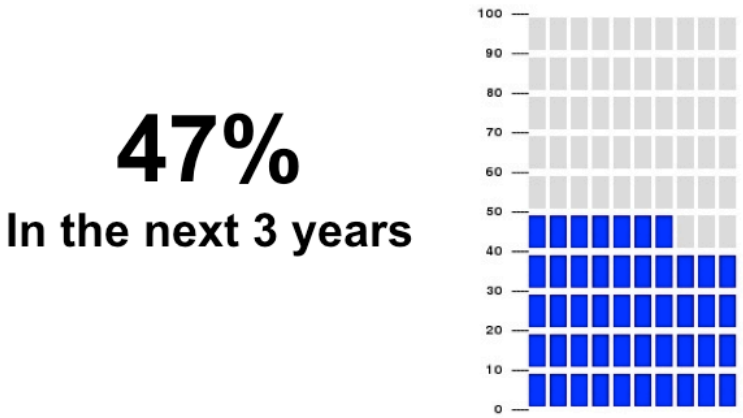
Your *APOE* genotype result is: **__ / ε4**

Based on the following factors:

- Your diagnosis of mild cognitive impairment (**MCI**)
- Your current **age** being between 71 and 77 years
- Your gene test result: ***APOE* ε4 present**

Your estimated risk of developing Alzheimer's disease (AD) over the next 3 years is **47%**.

To say this another way, out of **100** people who also have a diagnosis of MCI, are in the same age group and who have an *APOE* ε4 gene present, **47** of them would progress to dementia of the Alzheimer's disease type over the next 3 years and **53** would not.



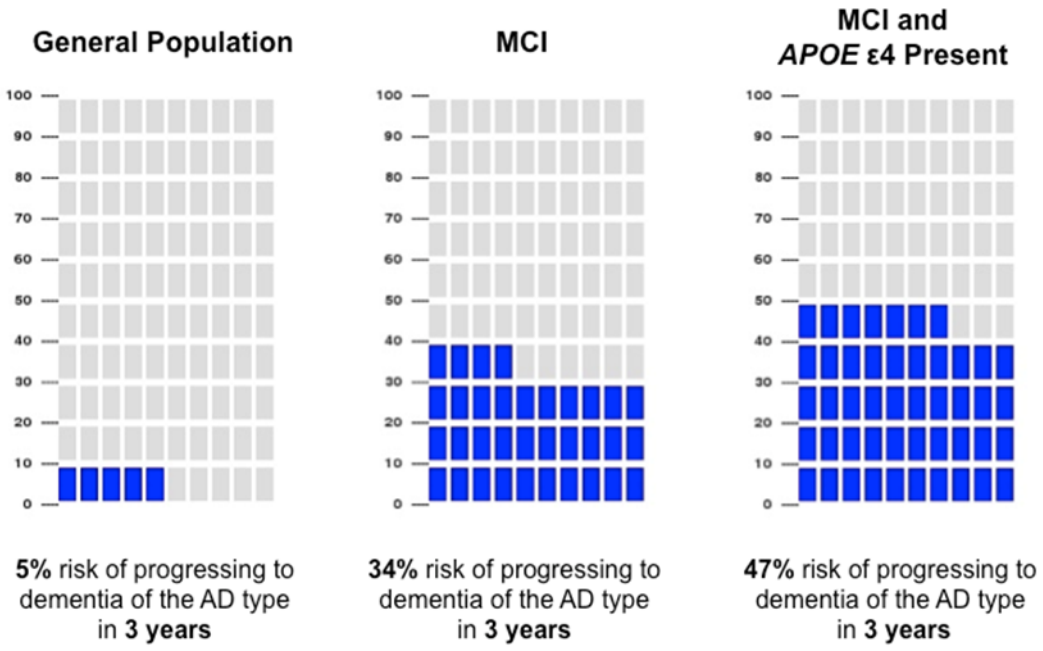

**Risk beyond 3 years**

- You may be wondering what your risk of progressing to dementia of the Alzheimer's disease type is beyond three years.
- It is believed that risk for dementia of the Alzheimer's disease type continues to increase over time.
- Research is being done to determine the long-term risk.

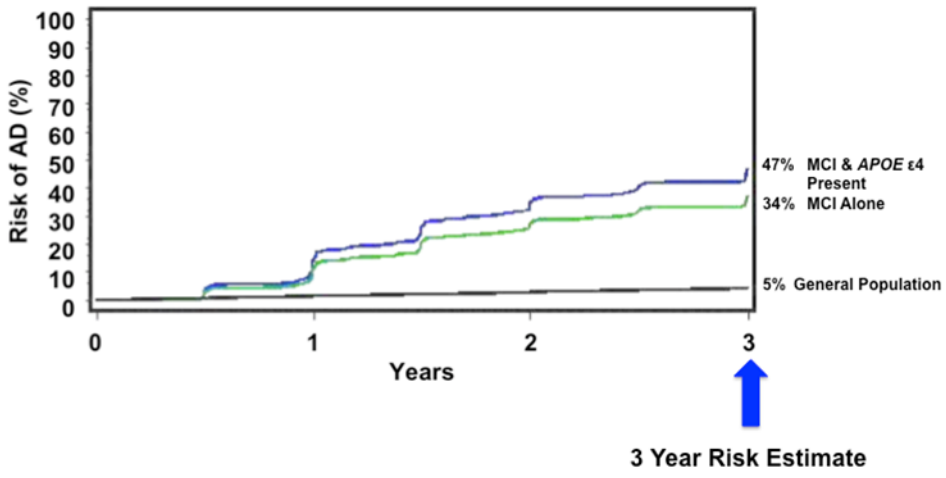
**Limitations of the risk estimate**

- The risk figure that we provided you is our best estimate at this time and is based on one large study. We are still learning about other factors, both genetic and environmental, that determine risk for AD.
- Additionally, the risk information we are sharing with you is drawn from a study in which the majority of participants were White. We suspect the risks are similar for all racial and ethnic groups, but we do not know for sure.

# Risk of progressing to dementia of the Alzheimer's disease type




# Risk increases over time



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# CURRICULUM VITAE

## Yue Guan, ScM, CGC

**EDUCATION**

**Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health** (2012 – 2015)
Degree: Doctor of Philosophy.

**The Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program** (2009 – 2012)
Degree: Master of Science.

**School of Nursing, Peking University, Beijing, China** (2004 – 2009)
Degree: Bachelor of Medicine (5 year nursing program).

**School of Arts, Peking University, Beijing, China** (2005 – 2008)
Degree: Bachelor of Arts (3 year dual-degree focusing on art history and television broadcasting).

**PROFESSIONAL CERTIFICATION**

**Certified Genetic Counselor** (08/2013 - Present)
American Board of Genetic Counselors

**GENETIC COUNSELING EXPERIENCE**

**Genetic Counselor**

- Prenatal Diagnosis and Treatment Center, The Johns Hopkins Hospital (11/2013 – 02/2014, 01/2015 – 06/2015)

  Provided independent perinatal genetic counseling to patients; coordinated informed consent, lab requisition forms and letters of medical necessity for clinical genetic tests; communicated test results to patients and clinicians; responded to inquiries related to genetic testing and counseling services; and assisted in updating and improvements in testing procedures and standard language.

**Genetic Counselor Intern: Clinical**

- Prenatal
  Prenatal Diagnosis and Treatment Center, The Johns Hopkins Hospital (10/2009 – 03/2010)
  Howard County General Hospital (07/2010 – 08/2010)

- Pediatric
  Kennedy Krieger Institute (07/2010 – 08/2010)
  Institute for Genetic Medicine, The Johns Hopkins Hospital (03/2011 – 06/2011)

- Adult/Cancer
  The Harvey Institute for Human Genetics of the Greater Baltimore Medical Center (10/2010 – 12/2010)
  The Johns Hopkins Breast and Ovarian Surveillance Service (08/2011 – 12/2011)

**Genetic Counselor Intern: Research**

- ClinSeq, National Human Genome Research Institute (08/2010 – 10/2010)

Provided informed consent counseling for participants in a Large-Scale Medical Sequencing Clinical Research Pilot Study.

- Genetic and Rare Disease Information Center (GARD) (03/2010 – 05/2010)
  Responded to inquiries (phone, Web) about rare and genetic conditions; developed responses that explain very technical and medical concepts into plain language; developed content about genetic and rare diseases for the GARD Web site in plain language.

- National Taiwan University Children's Hospital, Taiwan (06/2010, 06/2011 – 08/2011)
  Participated in pediatric and cancer genetic counseling services; conducted the first study in Asia to relate parental discussion of G6PD deficiency with child health outcomes; acted as PI and project manager with primary responsibility for both administrative and research tasks including the protocol design, enlistment of collaborators, preparation of the IRB applications, financial management, data collection, analysis and manuscript preparation.

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**RESEARCH EXPERIENCE**

**Research Assistant**

- Department of Health Policy and Management, JHSPH (2014)
  Conducted linguistic inquiry word count and thematic content analysis on patient-companion communication during geriatric primary care physician visits as part of the project optimizing family involvement in primary care. PI: Jennifer Wolff

- Department of Health, Behavior and Society, JHSPH (2013)
  Worked on the development of a web-based training module for genetic counseling students on genetic risk communication using a large video archive of simulated counseling sessions conducted by over 170 practicing genetic counselors. PI: Debra Roter

- Department of Health, Behavior and Society, JHSPH (2012-2013)
  Involved in recruitment, data collection and analysis in a project using vitro simulation to understand social contributions to disparities in depression care in the US and UK. PI: Debra Roter

- Department of Health, Behavior and Society, JHSPH (2012-2013)
  Involved in data management and analysis in a longitudinal case-control study about the amelioration of health literacy deficits in prenatal care. PI: Debra Roter

- Department of Health, Behavior and Society, JHSPH (2011)
  Served as a second coder for a meta-analysis on physician-patient interaction using the Roter Interaction Analysis System. PI: Debra Roter

- Peking University Center of Medical Genetics (2006-2007)
  Served as a research assistant for a project on interaction between protein and RNA of neurological disease related genes. PI: Nanbert Zhong

**Publications**

- Roter, D. L., Erby, L. H., Rimal, R. N., Smith, K. C., Larson, S., Bennett, I. M., Cole K. W., **Guan Y.**, Molloy M.,& Bienstock, J. (2015). Empowering Women's Prenatal Communication: Does Literacy Matter?. Journal of health communication, 20(sup2), 60-68.

- Borzekowski, D., **Y. Guan**, K. Smith, L. Erby and D. Roter (2014). "The Angelina effect: immediate reach, grasp, and impact of going public." Genet Med 16(7): 516-521.
- **Guan, Y.**, D. L. Roter, A. Huang, L. A. Erby, Y. H. Chien and W. L. Hwu (2014). "Parental discussion of G6PD deficiency and child health: implications for clinical practice." Arch Dis Child 99(3): 251-255.

**First author presentations**

- Bridging the genomic communication divide: meeting patient challenges across the lifespan (08/2015)
  Invited speaker: University of Maryland School of Medicine
- Disparities and Genetic Counseling (01/2013)
  Platform presentation: Johns Hopkins Bloomberg School of Public Health
- Parental Disclosure of G6PD and Its Relationship to Child Health in a Chinese Population (10/2012)
  Poster: National Society of Genetic Counselors Annual Education Conference
- Sexuality Education for Individuals with Intellectual Disability (09/2011)
  Invited speaker: Genetic clinic conference, National Institutes of Health
- Parental Decision Making Concerning Prenatal Testing (05/2010)
  Invited speaker: Genetic clinic conference, National Institutes of Health

**TEACHING EXPERIENCE**

- Instructor. Introduction to Public Health Genomics (2015)
- Graduate head teaching assistant. Health Literacy: Challenges And Strategies For Effective Communication (2012-2014)
- Graduate guest lecturer. Genetic Counseling Program Thesis Proposal Development (2013-2014)
- Graduate teaching assistant. Interpersonal Influence In Medical Care (2012-2014)

**AWARDS**

- Gordis Teaching Fellowship (2014)
- Doctoral Distinguished Research Award, Johns Hopkins University (2014)
- Second prize, the Delta Omega Alpha Chapter Scientific Poster Competition (2012)

**LEADERSHIP & PROFESSIONAL MEMBERSHIP**

- Program leader, Outreach and Translational Communication Initiatives, Johns Hopkins Center for Genetic Literacy and Communication (2014-Present)
- Member, National Society of Genetic Counselors (2013-Present)
- Member, Graduate admissions committee of The Johns Hopkins University/National Institutes of Health Genetic Counseling Training Program (2013-2014)
- Co-chair, Health, Behavior and Society Student Organization (HBSSO), The Johns Hopkins University School of Public Health (2012-2013)

Vice-president, The Chinese Public Health Forum, The Johns Hopkins University School of Public Health (2012-2014)