

Communication about Alzheimer’s Disease Risk Information Among Latino Adults

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- Among Latino adults, communication of Alzheimer’s disease (AD) risk was common and shaped by receipt of *APOE* result, gender, and perceived AD stigma.
- Participants weighed family responsibility, caregiving preparation, worry, distance, and children’s readiness when deciding whether and when to share results.

INTRODUCTION

- Communicating Alzheimer’s disease (AD) risk and *APOE* genotype information with relatives can help family members understand their potential risk, consider available testing or prevention opportunities.^{1,2}
- Prior research on the familial patterns of communication of results has focused on predominantly non-Latino White, highly educated samples.³
- **This study aims to** (1) examine with whom Latino adults shared AD risk and/or *APOE* genotype information, (2) identify predictors of sharing, and (3) explore motivations and barriers of communicating results with family members.

METHODS

- We used convergent mixed-methods analysis of English- and Spanish-speaking **Latino adults ages 40-64** in northern Manhattan from the IDEAL study.
- Participants were randomized to receive AD risk information based on family history (non-disclosure) or the same information plus *APOE* genotype (disclosure).
- Survey participants (**N=338**) reported at 6 weeks and/or 9 months whether they shared their results and with whom.
- Demographic and psychosocial factors were assessed; variables significant in bivariate analyses were included in multivariable logistic regression models.
- Interviewed participants (**N=153**) completed a 6-week and/or 9-month interview. Interview data were analyzed thematically to identify motivations and barriers to communicating results with family members.

RESULTS

Table 1. Sample demographic and psychosocial characteristics

Characteristic	Surveys	Interviews
	n (%)	n (%)
Age (years)		
40-49	115 (34.0)	44 (28.8)
50-59	150 (44.4)	71 (46.4)
60-64	73 (21.6)	38 (24.8)
Randomization		
Non-disclosure	161 (47.6)	46 (30.1)
Disclosure, 0 ε4 alleles	92 (27.2)	48 (30.4)
Disclosure, ≥1 ε4 allele	85 (25.1)	59 (37.3)
Gender		
Man	101 (29.9)	45 (29.4)
Woman	237 (70.1)	108 (70.6)
Perceived AD stigma (Mean)		
Lower (<2)	223 (67.6)	108 (73.5)
Higher (≥2)	107 (32.4)	39 (26.5)

Table 2. Frequencies of communication of *APOE* or risk estimate at 6 weeks or 9 months post-disclosure survey (N=338)

Shared information with	Ever Told (%)
Anyone	259 (76.6)
Family	220 (65.1)
Mother	75 (22.2)
Father	24 (7.1)
Children	129 (38.2)
Siblings	141 (41.7)
Grandchildren	6 (1.8)
In-laws	21 (6.2)
Other extended family	73 (21.6)
Spouse/significant other	149 (44.1)
Friend(s) or coworker(s)	138 (40.8)
Friends or neighbors	127 (37.6)
Coworker or colleagues	61 (18.0)
Employer, supervisor, or boss	13 (3.8)

Table 3. Adjusted odds ratios for communication of *APOE* genotype or risk estimate at 6 weeks or 9 months (N=338)

Characteristic	Ever told			
	Anyone	Family member(s)	Spouse/signif icant other	Friend(s) or coworker(s)
Randomization				
Non-disclosure	referent	referent	referent	referent
Disclosure, 0 ε4 alleles	2.5 (1.28-4.91)	1.9 (1.06-3.36)	1.3 (0.74-2.20)	3.0 (1.74-5.26)
Disclosure, ≥1 ε4 allele	3.1 (1.50-6.40)	2.5 (1.33-4.59)	1.4 (0.81-2.49)	1.6 (0.89-2.74)
Age				
40-49	referent	referent	referent	referent
50-59	0.8 (0.45-1.57)	1.1 (0.61-1.84)	0.5 (0.31-0.88)	1.3 (0.76-2.21)
60-64	1.2 (0.57-2.71)	1.3 (0.65-2.51)	0.7 (0.37-1.30)	1.5 (0.80-2.87)
Gender				
Man	0.7 (0.40-1.33)	0.6 (0.34-0.97)	1.7 (1.00-2.77)	1.1 (0.64-1.80)
Woman	referent	referent	referent	referent
AD Stigma (Mean)				
Low (<2)	referent	referent	referent	referent
High (≥2)	0.6 (0.33-0.99)	0.6 (0.34-0.93)	0.7 (0.40-1.06)	1.1 (0.66-1.75)

CONCLUSION

- Communication of AD risk was common among family members and shaped by variety of factors such as receiving genetic test results, being a man, and perceived AD stigma.
- Risk disclosure and genetic counseling should include family-centered, stigma-informed, and language-concordant support to help participants communicate risk information in ways that promote understanding while minimizing distress.

Figure 1. Motivations and barriers to communicating AD risk and/or *APOE* results with family members.

Motivations for communicating results

1. **To inform family members they may also carry the gene or be at risk**
2. To inform family about the availability of testing
3. To continue open family discussions about AD
4. To educate family about AD
5. To prepare potential caregivers

...I told them, you are at risk just like I am because we all come from the same mom. So if you wanna do something about it, talk to your physician, see if, uh, he or she will do some testing.

Barriers to communicating results

1. Did not want to cause worry
2. Too much physical distance
3. **Concern others might treat them differently**
4. Children currently too young to be told

They may... feel sorry for you... They may also start questioning... my capabilities... I don’t want to divulge information that could make them question my capacity to do it

REFERENCES

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