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Willingness of Mexican-American Adults to Share Family Health History with Healthcare Providers

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Abstract

Background—Collecting family health history (FHH) information to share with healthcare providers is an important aspect of health-risk assessment.

Purpose—To examine associations between the content of FHH-informed risk feedback and willingness to share the information with a healthcare provider.

Methods—Data were collected between June 2008 and July 2009 from 475 Mexican origin adults residing in 161 households. Participants completed surveys 3 months after receiving FHH informed risk feedback. Households were randomly assigned to feedback conditions in which household members received one or more of the following: a FHH pedigree; personalized risk assessments; and tailored behavioral recommendations. Logistic regression models were fitted using generalized estimating equations, with exchangeable covariances, to account for the clustering of responses within and the random assignment of feedback condition to household. Analyses were completed in May 2010.

Results—Participants who received personalized risk assessments were more willing to share their feedback with a provider than those who received a pedigree only (OR=2.25, $p=0.02$). The receipt of tailored behavioral recommendations did not significantly increase willingness to share feedback with a provider (OR=0.79, $p=0.48$).

Conclusions—The provision of PRAs in FHH assessments appears to motivate participants to consider sharing their FHH with a healthcare provider.

Introduction

Sharing family health history (FHH) with healthcare providers is critical for personalized health care.¹ Individuals with higher than average disease risks based on FHH may need to undergo medical screening more frequently at younger ages and implement preventive behaviors.^{2–4} However, FHH is underutilized within the primary care setting.^{5, 6}

In an effort to move collection of FHH outside the clinical setting, various tools have been developed to assist the general public in compiling their FHH.^{7–9} Some tools generate a list

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of affected relatives or pedigree representing the constellation of disease within the family;^{8, 10, 11} whereas others provide personalized risk assessments (PRAs) and/or tailored behavioral recommendations.^{12–14} Currently, there is limited information regarding which content elements provided by FHH tools might motivate individuals to share the information with their healthcare providers.⁷

The current paper identifies the elements of FHH-based feedback (i.e., a FHH pedigree; PRAs;¹⁵ and tailored behavioral recommendations) associated with willingness to share feedback with a healthcare provider within a sample of Mexican origin families.

Methods

Procedures

Participants for Project Risk Assessment for Mexican Americans (RAMA) were recruited from the Mexican American Cohort Study, a population-based cohort of Mexican origin households maintained by the Department of Epidemiology at The University of Texas MD Anderson Cancer Center.¹⁶

A total of 162 multigenerational households with at least three adult members (i.e., 497 adults aged 18–70 years) participated, of 347 contacted households.

During a home visit, each participant completed the baseline survey via computer. A follow-up telephone survey was completed on average 99 days later with a 96% retention rate.

The Intervention

Participant feedback was generated using the CDC's Family Healthware tool.¹⁴ Feedback packets contained three possible elements: (1) a pedigree representing participants' FHH; (2) FHH-based PRAs;¹⁵ and (3) behavioral recommendations tailored to participants' FHH and current lifestyle and screening behaviors. Feedback considered risk of diabetes, heart disease, breast and colon cancer. Each feedback element was modified to a Grade 6 reading level¹⁷ and translated into Spanish by certified translators.

All participants received a FHH pedigree and a one-page interpretation primer for the pedigree. Households were randomized to four feedback conditions defined by two factors: (1) number of PRA receivers (all versus a single household member), and (2) PRAs only versus PRAs and tailored behavioral recommendations. Feedback packets, in Spanish or English, were mailed within 1 week of the baseline assessment and receipt of feedback was verified by telephone.

Measures

Willingness to share feedback—Participants who had read their feedback were asked two questions assessing if they had or will share their feedback with a healthcare provider at follow-up. Responses were combined for the analysis.

Feedback elements—Two categorical variables indicated feedback content: whether participants received (1) a pedigree only (referent category) or a pedigree and PRAs, and (2) behavioral recommendations with the PRAs.

Demographic Characteristics—Assessed at baseline include marital status, parenthood, gender, age, educational level, and language in which the survey was completed.

Healthcare Access—At baseline, participants indicated whether they had health insurance coverage (e.g., through work, Medicare/Medicaid, county-funded programs) and where they normally sought health care (e.g., private physician's office, community clinic, emergency room). A dichotomous variable indicated if participants had a private physician as usual healthcare provider.

Health Status—The number of conditions associated with metabolic syndrome (heart disease, diabetes, high cholesterol, and hypertension) with which participants reported as being diagnosed was summed. Colon and breast cancer were excluded due to low prevalence.

Analytic Strategy

Logistic regression models were fitted using generalized estimating equations, with exchangeable covariances, to account for the clustering of responses within and the random assignment of feedback condition to household. All analyses controlled for demographic characteristics, healthcare access, and current health status. Analyses were completed in May 2010 using SPSS 17.0.

Results

On average, participants were aged 41 years ($SD=15$ years), female (55%), married (70%), parents (74%), Mexican immigrants (69%), and had not completed high school (57%). Participants were affected by one ($M=0.87$, $SD=1.07$) condition associated with metabolic syndrome; the majority (64%) had health insurance, and half normally receive health care through a private physician (see Table 1).

At follow-up, 71% ($n=338$) indicated that they read their feedback. Feedback readers were more likely to be women ($p<.01$), have at least a high school education ($p=.03$), and report poorer health status ($p=.03$) than those who did not read. Of those who read their feedback, 70% indicated that they had ($n=35$) or would share ($n=202$) feedback with a healthcare provider. Results from the logistic regression (Table 2) show that participants with children were more likely ($OR=5.86$, $p<.01$) to indicate a willingness to share than participants without children. Those who received PRAs with their pedigree were more willing to share than those who received a pedigree only ($OR=2.25$, $p=.02$). The receipt of tailored behavioral recommendations, in addition to the PRAs, was not associated with willingness to share ($OR=0.79$, $p=.48$).

Discussion

Provision of PRAs with a pedigree was associated with increased willingness to share FHH information with providers compared to those receiving a pedigree only. Interpretation of the pedigree requires a conceptual understanding of the complex interactions resulting in disease risk. Levels of genetic knowledge required to interpret the pedigree may be limited among the general public,^{18,19} as many have insufficient levels of health literacy.²⁰ Thus, providing an interpretation of family risk (i.e., PRAs) can potentially enhance the public's understanding of the information, thereby motivating them to share feedback.

Considering that healthcare providers may have difficulty interpreting the pedigree^{6, 21,22} due to limited training in this domain,^{21,23} provision of disease-specific PRAs may further enhance care in the primary care setting²⁴.

Provision of behavioral recommendations tailored to current health behaviors did not appear to influence participants' willingness to share feedback with their provider. However, such

information may be important in identifying risk-reducing behaviors for participants. Future research should examine whether these recommendations motivate individuals to adopt healthful behaviors, particularly if shared with family members.²⁵

Parenthood, the only demographic predictor of willingness to share, is an important predictor of several health-related behaviors including uptake of genetic services.²⁶ Because FHH-based disease risk is conferred through generations, parents may be modeling health seeking behavior in the hopes of reducing their own risk and that of their children.^{27,28} The literature suggests Spanish language is a substantial barrier to patient–provider health communications for Hispanic populations^{29,30}. Surprisingly, survey language was not significantly associated with willingness to share feedback with a provider in the current study; this conflicting result may reflect regional differences in providers' cultural competency.

All participants were adults of Mexican origin residing in multigenerational households; thus, findings may not generalize to individuals with different familial and cultural backgrounds. The limited impact of adding behavioral recommendations may be due to reduced statistical power; future research with a larger sample will provide more information regarding the unique contribution of behavioral recommendations. The short time-interval between assessment and feedback receipt limits the ability to evaluate whether willingness to share leads to actual FHH information sharing within the clinical setting.

Complete and accurate FHH is a key component of personalized health care. Given the limited time to obtain detailed FHH during the clinical encounter, identifying avenues for the public to collect this information outside of the clinical setting, in a format that increases individuals' willingness to share the information with their providers, is critical. The results herein suggest that PRAs that ascribe meaning to the constellation of disease observed within the family appears to be a key component to sharing this information, and thus a crucial aspect to the promise of personalized health care.

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Table 1Sociodemographic characteristics of study participants ($n=475$ from 161 families)

	Frequency (%)
Male	212 (45)
Place of birth	
U.S.	142 (30)
Mexico	327 (69)
Unknown	7 (1)
Marital status	
Married	332 (70)
Never married	119 (25)
Separated/divorced	16 (3)
Widowed	4 (1)
Parent	352 (74)
Educational level	
< High School education	273 (57)
High School graduate / GED	93 (20)
Vocational training / some college	90 (19)
Bachelor's degree or Higher	16 (3)
Location where Completed Formal Education	
U.S.	217 (46)
Mexico	238 (50)
Other Country	3 (1)
Insurance status	
No health insurance	177 (36)
Normal healthcare provider	
Private doctor's office	254 (51)
Did not go to the doctor	46 (9)

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Table 2

Participant willingness to share family history information with healthcare provider, by sociodemographic characteristics

	OR	95% CI	p-value
Covariates			
Marital status: Married (vs single/widowed/divorced/separated)	0.87	0.22; 3.38	0.84
Parent (vs not a parent)	5.86	1.62; 21.20	<0.01
Gender: Male (vs Female)	0.87	0.52; 1.46	0.60
Age	0.98	0.95; 1.01	0.27
Survey Language: Spanish (vs English)	0.65	0.33; 1.28	0.22
Educational Level: < HS vs HS+	1.11	0.65; 1.89	0.71
Insurance Status: Not Insured (vs some form of insurance)	0.87	0.50; 1.50	0.61
Health Status: Sum of metabolic syndrome diagnoses (heart disease, diabetes, high cholesterol, high blood pressure)	0.98	0.74; 1.29	0.87
Personal Physician	1.17	0.70; 1.95	0.55
Feedback Content:			
Received Personalized Risk Assessment vs Pedigree Only	2.25	1.13; 4.50	0.02
Received tailored behavioral recommendations with Risk Assessment vs Did not receive behavioral recommendations	0.79	0.42; 1.52	0.48

* Analyses used a generalized estimating equation to control for household-level clustering.

Note: $n=332$ people from 153 families who read their feedback.