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Roles of Attitudes and Injunctive Norms in Decisional Conflict and Disclosure Following Receipt of Genome Sequencing Results

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Introduction

Genomic sequencing is increasing in both availability and use by medical professionals to improve health outcomes (L. G. Biesecker & Green, 2014). Sequencing can be used for broad carrier screening, in order to aid planning for future offspring. However, undergoing carrier screening may result in concern about family members' future health and decisional conflict, reflecting uncertainty about whether undergoing sequencing was the right choice (O'Connor, 1995). In other domains, decisional conflict is associated with increased likelihood of experiencing regret and delaying decision-making (Becerra Pérez et al., 2016; O'Connor, 1995). It is therefore important to understand the factors that contribute to decisional conflict following genome sequencing.

Roles of psychological and social factors in genomics broadly, and with decisional conflict specifically, have been under-explored (Gray et al., 2014; Koehly et al., 2019). In the present study, participants completed a baseline survey assessing attitudes (i.e., personal evaluations of receiving sequencing results) and injunctive norms (i.e., perceived approval from important others for receiving results). All participants underwent exome sequencing, which identifies variations in the protein producing areas of DNA where many diseases originate, and later learned that they carried at least one variant in a gene that would not affect their

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health but indicated a small increased risk, primarily to their biological grandchildren's health. We examined whether attitudes, injunctive norms, and their interaction predicted conflict about the decision to receive sequencing results and disclosure of results to family members in the six months following receipt of results. The constructs of interest do vary in sequencing trials (Suckiel et al., 2016), as individuals enroll not only to receive their results, but also to contribute to scientific knowledge (Facio et al., 2011).

Broadly, decisional conflict is more likely to occur when individuals lack full knowledge of the benefits and drawbacks of the available options, lack clarity in their own views and values, experience emotional distress, or experience pressure from others to select a particular course of action (O'Connor, 1995). In the present study, choosing to receive sequencing results while holding less positive attitudes or perceiving less positive injunctive norms for learning about such results may produce internal conflict regarding whether the decision to receive genomic information was a good one. Indeed, behaving counter to one's own attitudes or social norms produces cognitive and emotional discomfort (Elliot & Devine, 1994; Giguère et al., 2014) and may manifest as uncertainty about one's decision (Schwarz & Clore, 1983).

In addition to their main effects, misalignment between attitudes and norms may produce "second thoughts" about the selected course of action (Sheeran & Conner, 2017), further heightening decisional conflict. This suggests that decisional conflict should be lowest when attitudes and injunctive norms simultaneously align with the decision to receive sequencing results but should be heightened under all other combinations, in which attitudes and injunctive norms conflict with one another or the decision to receive sequencing results. Given their roles in predicting both health behavior broadly and intentions for managing inherited genetic conditions (Hagger et al., 2019; McEachan et al., 2016), attitudes, injunctive norms, and their interaction should be similarly associated with disclosing results to family members.

Limited research has examined psychological and social predictors of decisional conflict or disclosure (Gray et al., 2014). Regarding attitudinal predictors, perceived benefits of a course of action, but not barriers, predict decisional conflict (Rini et al., 2009). Social determinants, like having close others who nag or provide little tangible assistance, are associated with heightened conflict about surgery (Riffin et al., 2018; Rini et al., 2011). Previous research has examined attitudinal and social factors in isolation, precluding consideration of their unique and interactive contributions to decisional conflict and disclosure. However, research in other domains supports that behavior is most likely when attitudes and norms align (Rice & Klein, 2019).

We examined whether attitudes and injunctive norms for learning genomic sequencing results predicted decisional conflict and disclosure following receipt of sequencing results. Participants enrolled in a genome sequencing trial reported attitudes and injunctive norms at baseline and received carrier status sequencing results, on average, two years later ($SD = 0.56$). Decisional conflict was assessed immediately, 1 month, and 6 months after receipt of results. Disclosure of results to children, siblings, and spouses was assessed at 1 and 6 months, allowing examination of predictors of early versus later disclosure (Rini et al.,

2009); these individuals were among the referents whose approval was assessed in injunctive norms.

We expected higher decisional conflict and less disclosure to family when attitudes, injunctive norms, and the decision to receive sequencing results were not aligned with one another. Specifically, we hypothesized that less positive attitudes and injunctive norms would be associated with higher decisional conflict and less disclosure to family. We also hypothesized that attitudes and injunctive norms would interact, such that decisional conflict would be lowest and disclosure highest when attitudes, norms, and the decision to receive results were all aligned. We therefore expected attitudes to be negatively associated with decisional conflict and positively associated with disclosure when injunctive norms were high, but weakly associated with outcomes when injunctive norms were low.

Method

Participants

The National Human Genome Research Institute's IRB approved the parent study; participants provided informed consent prior to enrollment. Participants were recruited from the greater Washington DC metropolitan area and enrolled in the Clinseq cohort. Eligibility for the randomized trial required that individuals were ages 45–65 at enrollment, completed a baseline survey, were heterozygous carriers of at least one genetic variant, and had not previously learned of this genetic variant ($N = 462$). Baseline surveys were conducted in 2012–2013 and the randomized trial occurred in 2014–2016. In all, 459 participants received their carrier results (i.e., learned they had genetic variants that slightly increased risk for health problems among children and grandchildren). Variants ranged from benign to pathogenic; pathogenic indicates high likelihood of disease if the variant is received from both parents. Results were delivered in a trial comparing two education modalities and receipt of psychological counseling versus none. Consistent with trial aims, conditions were equivalent in decisional conflict and disclosure (B. B. Biesecker et al., 2018; Lewis et al., 2018). Inclusion in the present analyses required that participants provided data on all predictors and at least one outcome. In all, 312 participants were included in immediate post-test analyses, 277 at 1 month, and 274 at 6 months.

Measures

Attitudes and injunctive norms items referenced carrier results, described as “a gene variant that does not affect your health, but that may be important to the health of other relatives, such as your children.”

Attitudes.—Six items assessed, on a 1 to 7 scale, to what extent learning carrier results would be: (1) *a bad thing* vs. *not a bad thing*, (2) *not beneficial* vs. *beneficial*, (3) *harmful* vs. *not harmful*, (4) *not a good thing* vs. *a good thing*, (5) *not worthwhile* vs. *worthwhile*, and (6) *unimportant* vs. *important* (L. G. Biesecker, 2012; Dormandy et al., 2006; Montenegro et al., 2011; Solomon et al., 2012). Items were summed (Cronbach's $\alpha = .92$).

Injunctive norms.—Five items assessed perceptions of whether partner's, sibling(s), child(ren), close friends, and doctor “think that I should learn such a result” from 1 (*definitely no*) to 5 (*definitely yes*); “not applicable” was an option. Items were averaged (Cronbach's $\alpha = .86$) for participants who responded to or did not select “not applicable” for at least two items.

Decisional conflict.—Immediately, 1 month, and 6 months following receipt of sequencing results, participants responded to 15 items assessing whether the decision was “easy to make”, they “made an informed choice”, and various factors contributed to decision-making (O'Connor, 1995). Items were rated from 1 (*strongly disagree*) to 5 (*strongly agree*), reverse scored with higher ratings reflecting more conflict, and averaged to form a total score at each time point (Cronbach's $\alpha s = .93-.95$).

Disclosure.—At 1- and 6-month follow-up, participants reported whether they shared their results with a spouse or partner. Participants also reported how many children and siblings they had and to how many they disclosed results. Disclosure to spouses evidenced ceiling effects (93% at 1 month) and, as such, was not analyzed further. Few shared results with only some of their children or siblings (8%–17% over time). Measures were dichotomized to reflect disclosure to all children and all siblings.

Demographics.—Participants reported age, gender, race/ ethnicity (coded as White vs. non-White), educational level (1= *high school*; 5= *post-graduate*), and household income (1= *less than \$25,000/ year*; 5= *more than \$100,000/ year*).

Data Analysis

A log transformation was applied to normalize the distribution of decisional conflict (original skew = 2.07–3.37, kurtoses= 8.92–17.02; transformed skews = 0.83–1.50, kurtoses = 0.19–2.92). Three structural equation models were specified in Mplus using maximum likelihood estimation, one for each time point. The predictors were mean centered attitudes, injunctive norms, and their interaction, controlling for whether participants learned of at least one pathogenic variant (i.e., increased susceptibility to a disorder), age, gender, ethnicity, income, and education. Significant interactions were probed at 1 standard deviation above and below the mean of injunctive norms (Aiken & West, 1991). Data were assumed missing at random. Most participants were excluded ($N=121$ of 147, 82%) because they indicated “not applicable” for more than three of the injunctive norms items (e.g., did not have a child, sibling, or spouse). Missing data were addressed via direct maximum likelihood estimation. Analyses with listwise deletion reduced some associations with 1-month sibling disclosure and 6-month decisional conflict (see supplementary Table 1).

Results

Sample Descriptives and Attrition

At baseline, participants were, on average, 60.1 years old ($SD = 5.62$), male (56%), White (91%), had a graduate degree (64%), and earned more than \$100,000 per year (78%), a common demographic profile for participants in genomic sequencing research (Alford et al.,

2011). Most (71%) learned of at least one pathogenic variant. Average decisional conflict was low over time (raw *Ms*: 1.36–1.42, *SDs*: 0.50–0.55), but spanned the full range (i.e., 1–5; see supplementary Table 2). In all, 51% and 28% shared results with all children and siblings at 1-month versus 70% and 41% at 6 months. Individuals excluded at post-test were equivalent on most variables ($p > .21$) but had marginally lower incomes ($p = .08$) and were 1.57 years older than those retained ($p = .01$).

Primary Analyses

Covariates were generally unrelated to outcomes (results not shown). Learning of a pathogenic variant predicted lower 6-month decisional conflict. White participants reported lower 1-month decisional conflict and greater 6-month sibling disclosure than participants of color.

At immediate post-test (see Table 1), participants reported higher decisional conflict when their personal attitudes were lower, and therefore less consistent with the decision to receive sequencing results. Injunctive norms did not predict conflict, but the attitudes by norms interaction was significant. When injunctive norms were highly positive, attitudes were negatively associated with decisional conflict ($B = -0.007$, $SE = 0.002$, $p = .004$). However, when injunctive norms were less positive, attitudes were unrelated to decisional conflict ($B = -0.002$, $SE = 0.002$, $p = .19$). Consistent with our hypothesis (see Figure 1), decisional conflict was lowest when both attitudes and injunctive norms were highly positive and aligned with the decision to receive results but slightly higher under all other combinations. Attitudes, injunctive norms, and their interaction explained 3% of the variance in post-test decisional conflict.

At 1 month, attitudes and injunctive norms were both negatively associated with decisional conflict. Thus, decisional conflict was higher when attitudes or norms conflicted with the decision to receive sequencing results. Likewise, associations of injunctive norms with disclosure to children and siblings indicated that higher perceived approval for learning results was associated with greater likelihood of sharing results. We probed the marginal attitudes by norms interaction to examine whether the pattern was consistent with our hypothesis. However, associations of attitudes with disclosure were non-significant at high ($B = 0.067$) and low ($B = -0.048$) levels of injunctive norms ($p > .24$). Attitudes, norms, and their interaction explained 7–9% of the variance in 1-month outcomes.

At 6 months, only lower injunctive norms were associated with higher decisional conflict. None of the predictors were associated with disclosure. Attitudes, norms, and their interaction explained 1–4% of the variance in 6-month outcomes.

Exploratory Mediation Analysis

Given research demonstrating that decisional conflict predicts behavior, we explored whether post-test and 1-month decisional conflict mediated associations between the primary predictors and 1-month and 6-month disclosure, respectively, in two path models. Bias-corrected bootstrapped confidence intervals (MacKinnon, 2008) indicated that there were no indirect effects of attitudes, injunctive norms, or their interaction on 1-month disclosure outcomes via post-test conflict or on 6-month child disclosure via 1-month

conflict (95% *CI* LCLs -0.001 , UCLs 0.002). However, attitudes (indirect effect = $.006$; 95% *CI* $[-.001, .015]$) and injunctive norms (indirect effect = $.05$; 95% *CI* $[-.002, .119]$) had indirect effects on 6-month sibling disclosure via 1-month decisional conflict.

Discussion

Genomic sequencing holds great promise for enhancing health management. However, as participants varied in decisional conflict, some may experience substantial conflict as sequencing increases in use. Results indicated that less positive attitudes toward sequencing were associated with higher post-test and 1-month decisional conflict (see Table 1). Perceiving less approval predicted higher 1- and 6-month decisional conflict and lower early disclosure of results to children and siblings, at 1-month. The attitudes by norms interaction provided some evidence that decisional conflict was reduced when attitudes, norms, and the decision to receive sequencing results were all aligned, but heightened when beliefs conflicted with the decision (see Figure 1). Finally, exploratory analyses indicated that attitudes and norms had indirect effects on 6-month sibling disclosure via 1-month decisional conflict.

The results are consistent with psychological theories suggesting that, among Western individuals, inconsistencies between actions and beliefs result in psychological discomfort (Elliot & Devine, 1994). Unexpectedly, attitudes predicted conflict at earlier time points, whereas injunctive norms predicted at later points (see Table 1). The increased importance of injunctive norms over time may have co-occurred with disclosure of results to relatives. As information was shared, others' approval may have become a more relevant basis for decisional conflict. Conversely, if attitudes became more positive as a means for creating consistency with the decision to receive results, baseline attitudes may have become less relevant over time.

At 6-month follow-up, 30% and 59% still had not shared results with all of their children and siblings. On the one hand, this may reflect an informed decision since the likelihood of developing the conditions associated with these variants was low (Wiens et al., 2013), and the information may be of little utility to children who already have had children of their own. On the other hand, as 71% had at least one pathogenic variant, this carrier information would be most useful if shared with children and other family members who are making reproductive decisions.

Given the direct and indirect associations of attitudes and norms with decisional conflict and disclosure, educating professionals about the role of psychological and social factors in reactions to sequencing may be important. Eliciting and discussing attitudes and norms prior to sequencing may facilitate more informed choices and reduce decisional conflict. Although guidelines promote disclosure (Forrest et al., 2007), disclosure often may not occur. Lack of disclosure may reflect low self-efficacy in accurately communicating the results or concern about upsetting relatives for various reasons, including their perceived disapproval of learning about or sharing results (Fiallos et al., 2019; Wilson et al., 2004). As such, patient interventions to enhance understanding and provide strategies to compassionately convey the information to relatives are in great need.

Limitations

The present results should be considered in light of the study limitations. Given the two-year delay between baseline and receipt of results, analyses may underestimate associations with outcomes. However, the predictive roles of attitudes and norms suggests stability between baseline and receipt of results. Likewise, attitudes and norms may be stronger predictors when receiving genetic information relevant for one's own, rather than family members' health. Conversely, unassessed factors may also contribute to decisional conflict, disclosure, and evaluations of carrier testing, such as prior familial experience with a variant (Rini et al., 2011). The present participants were post-reproductive and enrolled in a research study. Among individuals in their reproductive years who receive carrier sequencing results, decisional conflict may be heightened, especially if a spouse's profile increases risk; the predictors of outcomes may differ under these circumstances. Finally, predictors of conflict and disclosure following sequencing may vary among more ethnically and socioeconomically diverse samples, given variation in sharing and seeking family health information (Welch et al., 2015).

Conclusions

Genomic sequencing is increasingly being utilized to inform and improve health. It is therefore important to understand the ways in which psychological and social factors contribute to reactions to and actions following receipt of sequencing results (Koehly et al., 2019). The present results support that reactions to sequencing may be less positive when psychological and social factors, such as attitudes and injunctive norms, are not fully aligned with the decision to receive sequencing results. Having a comprehensive understanding of the roles of such factors in decisional conflict and disclosure will enhance ability, not only to address sequencing recipients' concerns, but also to achieve the ultimate goal of utilizing genomic sequencing to enhance population health.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Research Highlights

- Attitudes and norms may be associated with reactions to genomic sequencing results
- Attitudes predict greater decisional conflict up to 1 month after return of results
- Injunctive norms predict greater decisional conflict 1 to 6 months after return of results
- Injunctive norms predict less disclosure to relatives 1 month after return of results
- In the interaction, decisional conflict was higher when attitudes and norms were not aligned

PREDICTORS OF DECISIONAL CONFLICT AND DISCLOSURE

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Figure 1. Attitudes by injunctive norms interaction predicting post-test factors contributing to uncertainty.

Main Effects and Interactions of Attitudes and Injunctive Norms on Decisional Conflict and Disclosure

Table 1:

	Decisional conflict			Disclosure to all children			Disclosure to all siblings		
	<i>B</i>	<i>SE</i>	<i>P</i>	<i>B</i>	<i>SE</i>	<i>P</i>	<i>B</i>	<i>SE</i>	<i>P</i>
Immediate post-test									
Attitudes	−0.004	0.002	.01						
Injunctive norms	−0.015	0.012	.21						
Attitudes × Injunctive norms	−0.003	0.001	.03						
1 month follow-up									
Attitudes	−0.005	0.002	.01	−0.02	0.037	.58	0.010	0.040	.81
Injunctive norms	−0.042	0.013	<.01	0.692	0.244	.01	0.653	0.299	.03
Attitudes × Injunctive norms	−0.002	0.002	.21	−0.007	0.053	.90	0.083	0.045	.07
6 month follow-up									
Attitudes	0.000	0.002	.80	0.037	0.040	.35	0.016	0.042	.71
Injunctive norms	−0.034	0.013	.01	0.096	0.256	.71	−0.037	0.246	.88
Attitudes × Injunctive norms	−0.001	0.002	.53	0.026	0.051	.61	0.043	0.045	.33