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Latinos interest in knowing and using genetic risk information about obsessive compulsive disorder

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ABSTRACT

There is limited research examining the perspectives on the use of genetic testing in psychiatric care among individuals of non-European ancestry. Adults with obsessive–compulsive disorder (OCD) of Latin American ancestry (n = 1,513) completed a survey assessing their interest in receiving genetic testing for OCD, their level of comfort with disclosing this information, views on the use of genetic testing to inform reproductive decisions, and their concerns about stigma and discrimination. Most participants indicated they would be interested in learning their genetic liability for OCD; however, their level of comfort with sharing this information varied. Participants also reported high levels of mental health stigma and experiences with discrimination based on their OCD. Taken together, findings suggest there is interest among the Latino community to engage with genetic testing should it become available; however, there also are concerns that must be addressed to ensure responsible and ethical implementation in this population.

Introduction

In recent years, efforts to better understand the genetic architecture of obsessive–compulsive disorder (OCD) have accelerated [1,2]. Research has consistently demonstrated a moderate genetic component to OCD, with heritability reported to be approximately 50 % [3], and a recent genome-wide association study (GWAS) estimating approximately 11,500 genetic variants explain 90 % of the genetic heritability of OCD [4]. Given the known genetic contributions to OCD, this condition may be an appropriate target for genetic testing in the future. However, before genetic tests become available for OCD, it is critical to examine the ethical, legal, and social implications of integrating this information into psychiatric care as this information may be misused to discriminate against individuals or exacerbate existing

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stigma surrounding psychiatric conditions [5,6].

Research examining the perspectives of individuals with psychiatric conditions from Latin American ancestry on the topic of genetic testing is also lacking [7]. This may be in part due to the lack of ancestral diversity within genetics research, with less than 1 % of GWAS studies examine individuals from Latin American ancestry, and continued dominance of studies among participants of European ancestry [4,8,9]. The current study begins to address this gap, by examining attitudes toward psychiatric genetic information in a sample of individuals of Latin American ancestry who met criteria for OCD.

Method

Approach

As part of a large multi-site international collaboration aiming to recruit individuals with OCD who are of Latin American ancestry [10], 1513 adult participants completed a battery of assessments including clinical interviews, saliva sample collection for genetic testing, and a series of self-report questionnaires completed via REDCap [11]. Individuals who were born in a Latin American country, or had a grandparent who was, were considered to be of Latin American ancestry. Baylor College of Medicine IRB served as the presiding IRB for all US-based sites. All international sites received IRB approval from their respective institutions to implement a harmonized protocol. All participants provided written informed consent.

Survey measures

The Ethical, Legal, and Social Implications Survey was developed by two researchers (GLM, SP) in collaboration with psychiatric genetics researchers and mental health clinicians to examine attitudes about genetics and mental health and included ten questions total in the following domains: 1) interest in genetic information related to OCD symptoms for one's self and for their children; 2) sharing of OCD genetic information; 3) acceptability of IVF and attitudes toward genetic risk testing for embryo selection; 4) mental health stigma and discrimination.

Each respondent indicated their interest in receiving genetic information related to their OCD symptoms, and their child's OCD genetic risk using three response options (i.e., Yes, No, and Not Sure). Respondents were asked to rate how comfortable they would be sharing their own genetic information related to OCD symptoms with their family, friends, clinicians, and employer on a 4-point Likert scale ranging from 'Very Uncomfortable' to 'Very Comfortable.' When asked about attitudes related to IVF and embryo selection, we queried respondents about their views on the use of IVF in general, followed by their level of agreement with using an embryo's genetic risk for developing OCD and cancer, respectively, to inform embryo selection. For each of these questions, respondents indicated their level of agreement on a 5-point Likert scale ranging from 'Completely Disagree' to 'Completely Agree".

Respondents indicated the extent to which they believe a person's genes contribute to their risk of developing OCD using a 4-point Likert scale ranging from 'Not at all' to 'A lot.' We then asked respondents to report how concerned they would be that information regarding someone's genetic risk for OCD could be used to discriminate against them using a 5-point Likert scale ranging from 'Not at all concerned' to 'Extremely concerned.' Participants were then asked to indicate whether or not they have felt discriminated against because they have OCD using three response options (i.e., Yes, No, Not Sure). Finally, respondents were asked to report their perception of the level of mental illness stigma in their country using a 6-point Likert scale ranging from 'None' to 'Very high.' See online supplementary materials for the survey.

Data analysis

Data were analyzed using JASP version 0.18.3.0 [12]. Response frequencies are provided for each survey item and we note cases in which response levels may be combined for interpretation (e.g., 'at least slightly concerned' would include all responses of "slightly concerned," "very concerned," and "extremely concerned").

Results

Participant characteristics

In total, 1,513 participants completed the survey. Eleven respondents did not complete the survey and data from 11 respondents were removed because they did not have symptoms of OCD as reported during the study screening, resulting in a final analytic sample of 1,491. Participant demographic information can be found in Table 1.

Interest in and access to OCD genetic information

When asked whether they would be interested in knowing how much their genes contribute to their OCD symptoms, 95.7 % of respondents indicated they would want to know this information, 3.2 % were unsure, and 1.1 % indicated they would not want to know. Respondents reported the highest levels of comfort with sharing this information with clinicians, with 92.2 % reporting they would be Comfortable or Very Comfortable sharing genetic information related to their OCD symptoms with clinicians. Respondents indicated progressively lower levels of comfort sharing with family (83.0 % Comfortable/Very Comfortable), followed by friends (67.5 %), and employers (33.7 %).

Table 1
Participant demographics.

	N Total = 1491
Gender	
Female	61.5 % (N = 916)
Male	35.6 % (N = 531)
Genderqueer/Non-binary	1.8 % (N = 27)
Transgender male	0.1 % (N = 2)
Prefer to self-identify	0.4 % (N = 6)
Missing	0.6 % (N = 9)
Mean Age (*SD*)	31.9 years (11.2)
Mean Age of OCD Onset (*SD*)	13.2 years (7.4)
Mean Age of OCD Diagnosis (*SD*)	23.5 years (9.9)
Site Country	
Brazil	21.8 % (N = 325)
Peru	21.3 % (N = 318)
United States and Puerto Rico	19.1 % (N = 285)
Mexico	12.9 % (N = 192)
Chile	10.5 % (N = 156)
Bolivia	4.7 % (N = 70)
Colombia	4.7 % (N = 70)
Argentina	2.3 % (N = 34)
Ecuador	1.1 % (N = 16)
Paraguay	0.9 % (N = 14)
El Salvador	0.7 % (N = 11)
Education	
Did not finish elementary	0.3 % (N = 4)
Completed elementary	2.3 % (N = 35)
Completed high school	14.2 % (N = 212)
Trade school	10.1 % (N = 151)
Some College	29.9 % (N = 445)
Graduated from college	31.6 % (N = 471)
Post-college education	10.5 % (N = 156)
Missing	1.1 % (N = 17)

Interest in and attitudes toward the use of genetic information in reproductive decisions

A majority of respondents (89.7 %) were interested in knowing their hypothetical children's genetic risk for developing OCD. When asked about their level of agreement with the use of IVF as an assistive reproductive technology, the majority of respondents indicated they Agree or Completely Agree with its use (77.2 %). Of those who agreed with the use of IVF, 81.8 % agreed with using genetic information related to cancer to select for embryos created through IVF, though slightly fewer respondents agreed with using genetic information related to OCD to select embryos (70.4 %).

Mental illness stigma and concerns about discrimination

Approximately three-quarters of respondents (77.0 %) felt that genes at least moderately contributed to someone's risk of developing OCD. Nearly half (48.2 %) responded that they were 'Very Concerned' or 'Extremely Concerned' that genetic testing for risk of OCD could be used to discriminate against someone, and 88.9 % of respondents indicated they would be at least slightly concerned that this type of testing could be used to discriminate against someone. The majority of respondents felt the level of mental illness stigma in their country was 'High' or 'Very High' (78.9 %) and 33.5 % of respondents reported some degree of discrimination because of their OCD.

Impact of OCD severity on responses

Exploratory analyses were conducted to examine the potential influence of OCD severity in participant responses to questions on the Ethical, Legal, and Social Implications Survey. There were no significant relationships between OCD severity and beliefs that genes contribute to OCD, interest in genetic testing for oneself or their children, willingness to share information with clinicians or employers, use of genetic screening for cancer risk, or concerns about potential discrimination based on OCD genetic risk. However, there were significant relationships between OCD severity and willingness to share genetic information with family ($r = -0.07$; $p = 0.007$) and friends ($r = -0.08$; $p = 0.002$), as well as agreement with the use of IVF overall ($r = 0.07$; $p = 0.011$) and use of embryo screening for OCD risk ($r = -0.07$; $p = 0.004$). Finally, perceptions on stigma were significantly correlated with OCD severity ($r = -0.07$; $p = 0.005$) and feelings of being personally discriminated against because of OCD were also related ($r = -0.19$; $p < 0.001$). Given the size of the sample and the small effect sizes, these findings suggest the relationships between OCD severity and views of genetic testing queried by the survey are weak and will need to be replicated.

Discussion

This study examined how individuals with OCD of Latin American ancestry view genetic information related to their condition. Although the majority of participants indicated they were interested in receiving genetic information, many participants also reported they were concerned about stigma and potential discrimination. These concerns have also been raised by child and adolescent psychiatrists, with clinicians noting that even in the future when genetic testing may be more accurate and have more clinical utility, there would still be hesitation to order genetic risk testing due to the potential for discrimination [13,14]. Notably, more than three-quarters of the sample reported that stigma surrounding mental illness was 'high' in their country, and one third of respondents indicated they have personally experienced discrimination due to their OCD. Taken together, these results suggest that patients with OCD experience a tension between being interested in genetic testing and concerns about the potential societal impacts that will need to be addressed to ensure responsible implementation of genetic testing in psychiatry.

Participants generally supported the use of IVF as a reproductive technology; however, their views on using genetic testing alongside IVF to select embryos were more complex, with participants expressing greater support for genetic testing for cancer risk than OCD risk. This finding is consistent with a recent public attitudes survey in which respondents expressed slightly more support for the use of embryo screening for physical conditions than for psychiatric conditions [15]. In part, concerns about eugenic practices may influence people's views on these topics; however, future research should explore the driving factors behind these ratings of acceptability for physical versus psychiatric conditions [16].

This study provides novel insights into the perspectives of Latino individuals with OCD regarding interest in genetic testing in psychiatry. Although we were able to survey individuals across several countries, responses came predominantly from only five countries (i.e., Brazil, Peru, United States, Mexico, and Chile), which may ultimately limit the generalizability of our findings. Future work should use purposive sampling to ensure adequate data from each country that would allow for rigorous comparisons to be made. It is also important to consider potential variability in education levels within and across participating countries, which may impact base knowledge of genetic testing. Future studies should also examine how experiences of discrimination and stigma associated with varying acculturation levels for Latinos in the United States may influence their comfort with disclosing genetic information, experiences of OCD-related discrimination and stigma, and interest in genetic testing. Moreover, though we examined comfort levels with sharing genetic information with clinicians, we did not explore participant perspectives on using genetic testing to inform approaches to treatment. However, findings glean preliminary insights into concerns regarding mental illness stigma and genetic discrimination that merit closer examination in order to ensure responsible integration of genomics in psychiatric care.

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Declaration of competing interest

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Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pmip.2025.100171.

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