



Research Article

Beliefs and Willingness towards Participation in Genetic Sampling for Depression in Hispanic/Latino Mothers at Risk

Shanda Johnson^{1*}, Rahshida Atkins², Tracy Perron³, Tami Jakubowski⁴, Nancy Cresse⁵, Nancy Pontes⁶, Mary Ann Dugan⁷, Victoria Pena-Cardinali⁸, Christine Dertouzos⁹, Anita Kishen¹⁰ and Janet Deatrick¹¹

¹Assistant Professor, New Jersey City University, USA

²Assistant Professor, The College of New Jersey, School of Nursing, Health and Exercise Science, USA

³Associate Clinical Professor, Johnson and Johnson School Health Leadership Fellow, School of Nursing, Health and Exercise Science, The College of New Jersey, USA

⁴Associate Professor, Johnson and Johnson School Health Leadership Fellow, School of Nursing, Health and Exercise Science, The College of New Jersey, USA

⁵Assistant Professor, Assistant Clinical Professor, Clinical Coordinator, Wellness Health Assessment Rutgers School of Nursing-Camden, USA

⁶Assistant Professor, Core Faculty, Rutgers Global Health Institute, Faculty Affiliate, Center on Gun Violence, Rutgers School of Nursing-Camden, USA

⁷Capital Health Systems, USA

⁸School of Nursing, Health, and Exercise Science, The College of New Jersey, School of Nursing, Health, and Exercise Science, USA

⁹Early Intervention Practitioner, USA

¹⁰120 West 7th Street, USA

¹¹Professor Emerita of Nursing, University of Pennsylvania, President Elect Penn Association for Senior and Emeritus Faculty, USA

*Corresponding author: Shanda Johnson, Assistant Professor, New Jersey City University, USA, E-mail: Sjohnson2@njcu.edu

Citation: Johnson S, Atkins R, Perron T, Jakubowski T, Cresse N, et al. (2021) Beliefs and Willingness towards Participation in Genetic Sampling for Depression in Hispanic/Latino Mothers at Risk. J Community Med Public Health Care 8: 097.

Received: November 18, 2021; **Accepted:** December 1, 2021; **Published:** December 8, 2021

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Abstract

Background

Ethnic minority mothers, are at high risk for depression, yet are underrepresented in genetic research that is necessary for investigating ways to prevent and treat depression. Understanding the beliefs that influence participation will help to target interventions to ensure participation in further research.

Purpose

The purpose of this study was to identify behavioral, normative and control beliefs about genetic (DNA) testing in a sample of low-income Hispanic/Latino mothers. The willingness to participate in specified genetic sampling procedures was also determined.

Methods

A descriptive, cross-sectional design was employed. This was a pilot study. A sample of 16 Hispanic mothers (n=16) ages 21 to 44 completed surveys to identify salient beliefs about participating in DNA sampling at 7 community locations in 3 different urban cities. Content and descriptive analysis of text were conducted and percentages were used to summarize the data.

Results

The most salient behavioral beliefs included:

Behavioral Beliefs

Advantages: May help other people, (37.5%), May find a cure/treatment (31.25%)

Disadvantages: Not finding a treatment or help (31.25%), No disadvantages (37.5%)

Salient Referents

Who Approves: Friends (37.5%) and Family (31.25%) members

Who Disapproves: Church associates (25.0%), No one would (43.75%)

Control Beliefs

Facilitators: A convenient location (25.0%) and information and instructions (18.8%)

Barriers: Nothing is hard about it (31.3%), Lack information about the procedures (12.5%)

Most mothers indicated that they would participate in DNA sampling if asked (93.75%)

Conclusion

To encourage participation, interventions should target groups, namely families and friends of the participants and stress the benefits of helping others. Investigators should provide details of sampling procedures, and conduct studies at convenient locations. The impact of religious views can also be explored. Researchers can also use staff familiar to participants to reduce trust issues and foster the willingness of Hispanic/Latino mothers to provide genetic (DNA) samples.

Policy Implications

Policies that address social determinants of health behaviors may improve participation in genetic research among Hispanic/Latino sub-groups of adult mothers.

Beliefs and Willingness to Participate in Genetic Testing Among Hispanic Mothers

According to recommendations from a report by The National Advisory Mental Health Council's (NAMHC) Genomics Workgroup, researchers must select genes from diverse populations to contribute to precision medicine for treatment and preventive interventions for mental illnesses (National Institute of [1,2]. Precision medicine is an approach to treatment and prevention of disease that accounts for individual variability in genes, environment, and lifestyle and thus allows doctors and researchers to accurately predict the treatment and prevention strategies that work best for select groups of people [2]. Despite NAMHC's recommendations, diverse sub-groups of the United States (U.S.) population such as women, low-income, and ethnic minority individuals who are at high risk for clinical depression, are underrepresented in genetic research for [3-6]. Current Genome-Wide Association Studies (GWAS) that examine the association between genes and disease, are lacking in diversity. Most of the participants are from European (78%) and Asian (21%) backgrounds and very little are from African (1%), Hispanic (1%) descent and other ethnicities (<1%) [7-9]. This underrepresentation of diverse sub-groups limits scientists' ability to ensure precision with the application of depression prevention and treatment strategies for these groups [2]. Government agencies are therefore urging researchers to implement strategies that increase inclusion of underrepresented populations in genetic research [2,9].

In a given year, about 8.1% of U.S. adults suffer from clinical depression [10] a serious mental illness that is defined by symptoms that primarily include feelings of low mood, such as sadness, loneliness, helplessness, hopelessness, worthlessness, stress, anger, worry and the desire to withdraw socially in low-income, ethnic minority mothers [11-15]. According to national health surveys, Hispanic/Latino adults in the United States are more likely to report symptoms of depression compared to Non-Hispanic White adults, and are twice less likely to get treatment for these symptoms [16,17] Substance Abuse and Mental Health Services Administration [18] US Department of Health and Human Services Office of Minority Health [19]. Although non-Hispanic, White mothers generally report higher incidences of diagnosed Major Depressive Disorder (10%) in nationally representative samples [20,21] Hispanic mothers, are at greater risk. A large majority of Hispanic/Latino mothers report high levels of depressive symptoms (16-24%) [22,23] and average depression levels that are above the cut-off score indicative of clinical depression on widely used depressive symptoms screening tools in published studies [24]. Hispanic/Latino, post-partum mothers report higher levels of depressive symptoms (46.8%) compared to non-Hispanic, African-American (43.9%) and non-Hispanic, White/Caucasian mothers (31.3%) [25,5]. In addition, their socio-economic, parenting, ethnic-minority, single parent [26] U.S. born status and gender intersect to place them at high risk for clinical depression [11,20,4,5,6]. In addition, as a heterogeneous population, Hispanic/Latino sub-ethnicity places some mothers at even greater risk since rates of depressive symptoms often vary by Hispanic/Latino sub-ethnicity; Puerto Ricans (38%) having the highest prevalence compared to other Hispanic/Latino groups (22-28%) [27].

Despite these risks, fewer low-income, Hispanic/Latino mothers receive mental healthcare compared to White/Caucasian and Black/African American mothers [22,28,29] leading to negative physical and psychosocial health consequences for these mothers and their

children. Depressed mothers face many adversities related to financial status, relationships problems, diverse stressors, chronic health conditions and poor health practices [11,22]. These adversities subsequently impact their children who are more likely to have poor academic performance, psychiatric disorders, behavior problems, more frequent exacerbations of chronic health conditions and are more likely to develop anxiety and depression in adulthood compared to children who do not have depressed mothers [11,30,6]. Given this risk, coupled with a lack of treatment, the prevention of depression and subsequently its deleterious effects in mothers at risk have become critical public health [31].

Greater diversity is needed in mental health research to address these disparities related to prevalence, treatment and risk for clinical depression that exists among diverse U.S. subgroups like these mothers [25,3,28,27]. These mothers, however, do not readily participate in biomedical research for mental health that involves genetic testing, thus making it difficult to generalize estimations of genetic risks or apply the knowledge regarding treatment and preventive pathways gained through genetic studies to these women [9,8]. To increase inclusion of this group, researchers must identify the factors that underlie participation and use this knowledge to develop tailored strategies to increase engagement.

The Theory of Planned Behavior (TPB) is a widely used social-cognitive theory that facilitates an understanding of the factors that impact and individual's intention to engage in a particular health behavior [32,33]. This theory proposes that beliefs and attitudes about behaviors influence intention and actual engagement in the behaviors. The TPB has been used to predict a variety of behaviors including exercise and genetic screening for breast and cervical cancer in Hispanic/Latino adults [34-38]. Although this theory posits that an individual's salient beliefs about a particular behavior formulates the basis for engagement in a behavior, salient beliefs about participation in genetic testing have mainly been elicited for non-psychiatric conditions in aggregate samples of Black/African adults and White/Caucasian and Hispanic/Latino women towards genetic testing and bio banking in general [39,40], breast and cervical cancer screening [37,41-44]. A recent literature review uncovered no studies using theoretically based qualitative methods to elicit the beliefs about genetic testing for mental health disorders within the context of depression prevention and treatment from the unique perspective of Hispanics/Latinos. Furthermore, no studies have focused on groups of Hispanic/Latino women such as mothers. Although some are inclined to believe that beliefs of aggregate samples of low-income or ethnic-minorities groups towards these non-psychiatric conditions are transferable to mental health disorders, according to the TPB, the beliefs that underlie the willingness to engage in a defined behavior is context and person specific and therefore must be elicited from the target population [32,33]. An understanding of the unique beliefs that underlie participation in genetic testing for psychiatric disorders from the perspective of Hispanic/Latino mothers is needed to develop strategies to support their inclusion and ultimately prevent depression in this at-risk group of mothers.

This study will utilize the TPB to identify the most salient beliefs about providing salivary samples for genetic Deoxyribonucleic Acid (DNA) testing within the context of depression prevention and treatment in Hispanic/Latino mothers. This study will also determine the willingness of these mothers to participate in DNA testing and examine levels of depressive symptoms. The knowledge gained from this analysis will provide an understanding of the factors that underlie

willingness to participate in psychiatric genetic testing and thereby help researchers employ strategies that ultimately support greater inclusion of Hispanic/Latino mothers in human genetic studies for mental health disorders. The benefits of this research can be gained by this at-risk group of mothers (National Institute of Mental Health [1,2].

Background/Literature Review

Results of a systematic review of qualitative studies found that beliefs about participation in clinical health related research was related to culture in adult African Americans, Latinos, Asian Americans and Pacific Islanders. They shared barriers related to mistrust, lack of information, stigma, competing demands and fear of unintended outcomes [46]. These groups reported that they would be willing to participate in clinical health related research for altruistic reasons, perceived benefits and if it was convenient with low risk of harm [46]. In another report, beliefs that included lack of education, and information and issues of distrust impacted willingness to participation in biomedical research during individual interviews (N=35) and focus group discussions (N=24) with mostly Mexican born, Latino young adults [25]. Beliefs differentiated by types of clinical research (i.e., genetic verses other types) was not reported.

With regard to minority participation specifically in reference to providing biological samples, studies have mostly examined aggregate populations of African Americans with specific clinical conditions. For example, beliefs related to lack of trust and information about study purposes, procedures and results influence the acceptability of providing biological blood samples by finger stick in eight African American adults of low-income [46]. Most studies that have addressed providing biological samples for genetic testing have examined non-Hispanic groups. African Americans adults (n=35) reported beliefs about personal (lack of knowledge of testing purpose/outcomes), familial (conflicts) and societal (lack of trust) factors that impact their participation in Sickle Cell Disease genetic testing [47]. Beliefs that facilitate participation in genomic research (bio banking) included contributing to individual and community health, trust with societal application of the results, and commitment to the community as reported by 46 African American adults [39]. Another study examined only African American women (N=87) who reported beliefs such as lack of knowledge as a barrier for participation in HPV DNA testing [48]. Differentiation of beliefs by sex/gender, parenting status, or race/ethnicity did not occur in these studies.

The dearth of research that focuses on Hispanic/Latino beliefs about genetic testing have centered on testing for breast and ovarian cancer risk. In a sample of 51 Hispanic/Latino adults, beliefs and attitudes that facilitate or impede participation in genetic screening for ovarian and breast cancer included lack of knowledge/information about genetic screening, stigma, fear of cancer results and death, costs, lack of insurance, lack of awareness, language barriers, reduced feelings of susceptibility, immigration status and fear of deportation that may result [41]. Lack of knowledge/information about testing, fear of results, and lack of physician referral/recommendation and information impacted beliefs/barriers towards genetic testing for breast cancer for 53 Hispanic women [42].

A systematic review revealed only one study where views about genetic testing for mental health disorders in U.S. patients were reported; three U.S. studies reporting the views of medical professionals alone and all other studies in patients were conducted abroad with

[49]. The combined beliefs of 18 Black and eight White adults included barriers such as lack of knowledge about genetics, concerns about study procedures, and issues related to distrust and confidentiality with mental illness status that affected their willingness to participate in genetic research for mental health disorders. Facilitators of participation in this sample included direct monetary and educational benefits, explanations of procedures, and willingness to follow-up with the results [50]. Hispanics/Latinos were not part of this sample and the majority of the Black adults in this study was male (14/18).

The majority of aforementioned studies about genetic testing examined the combined beliefs of aggregate samples of mainly non-Hispanic racial/ethnic groups regarding non-psychiatric conditions. These findings, therefore, have limited generalizability to sub-groups of ethnically diverse women, such as Hispanic/Latino mothers. These aggregate results also do not allow for differentiation of beliefs by sub-ethnicity nor among specific sub-groups such as women and parents. Information about sub-groups is needed since Hispanics/Latinas experience psychosocial and cultural stressors related to levels of acculturation, and language barriers which have the potential to impact engagement in health promoting behavior [11, 42, 51]. Hispanic/Latino mothers experience additional challenges related to parenting and complex family relationships which potentially impact their beliefs about genetic testing [52]. The results of the literature review above did not uncover studies that identified beliefs specifically in reference to genetic testing for mental health disorders, such as depression in Hispanic/Latino adults. This extensive review also failed to uncover studies that used the TPB to elicit salient beliefs about genetic testing for mental health disorders in Hispanic/Latina women.

Methods

Theoretical background

The Theory of Planned Behavior (TPB) guided the development of an open-ended questionnaire to elicit salient beliefs [32,33]. The questions elicited behavioral beliefs (i.e. what is good/advantages or bad/disadvantages), normative referents (i.e., referents or people who approves/would participate or disapproves/not participate), and control beliefs (i.e., facilitators/what makes it easy or barriers/what makes it hard) towards providing a saliva sample for genetic (DNA) testing to examine ways to prevent and treat depressive symptoms. The theory of planned behavior proposes that these beliefs affect an individual's intention to engage in a particular behavior that in turn impacts actual engagement in the behavior [32,33].

Design

This study employed a descriptive, qualitative, cross sectional design. This study was part of a larger study that examined beliefs about genetic sampling in multi-ethnic mothers. In that analysis, differences by racial groups were found. This study therefore takes a subset of that sample and presents an in depth analysis of the beliefs of solely the Hispanic/Latino mothers.

Sample

In the larger pilot study, convenience, purposeful sampling [53,54] was used to obtain a sample of multi-ethnic [55] mothers (i.e. White/Caucasian, Black/African American, Hispanic/Latino, Pacific Islander) to elicit salient beliefs about genetic (DNA) testing for depression prevention and treatment. According to the recommendations from the TPB protocols [56] salient beliefs about a behavior should be elic

ited from at least 30 mothers [32,33]. A larger sample size of 41 mothers was recruited to get a larger representation of mothers from each racial background. The data from the 16 Hispanic/Latino mothers, who made up 39% of this original sample was used for this analysis. Women were included if they were socioeconomically (low-income) [57,58] or ethnically [55] disadvantaged and had at least one child less than 18 years of age living with them. Women were excluded if they had a current diagnosis or were being treated for depression because this study was about prevention of depression. For this same reason, women were excluded if they had any children less than one year of age or were currently pregnant to avoid women who may have had postpartum depressive symptoms. In the original study, mothers were also excluded if they were unable to read and understand English since all of the instruments were written in English.

Procedures

After approval was received from a University's Institutional Review board (IRB), recruitment took place at seven community locations in four different urban cities in two different states. Mothers were recruited from three pediatric offices, a daycare center, a dance school, a low-income housing complex and a social service agency. Prior to recruitment, site owners/directors and administrators received flyers for display and distribution. Those who inquired, contacted the site administrators who organized a time for recruitment that took place weekly over a two-month period. At the pediatric offices and dance school, women were approached in waiting areas and screened for eligibility in writing. At the housing complex, social service agency, and daycare center screening and questionnaire completion took place on a scheduled day and in a room designated by the site administrators. All those meeting study delimitations provided written informed consent, completed a demographic data sheet, an open-ended survey to elicit salient beliefs and a scale to measure levels of depressive symptoms. After questionnaire packet completion, the women received a \$10.00 VISA bank card as compensation for their participation.

Instruments

The centers for epidemiologic studies depression (CES-D) scale

Current levels of depressive symptoms were measured using the Centers for Epidemiological Studies Depression (CES-D) Scale [15]. This is a self-report instrument with 20-items that were designed to measure levels of depressive symptoms in the general population of US adults. Respondents respond to a 4-point summated rating scale (0 = situation occurred rarely or none of the time and 3 = most or all of the time or 5-7 days) and subjects indicate the frequency and duration of times which they have experienced certain situations or feelings. After reversing the scores on items 4, 8, 12, and 16 a total score is obtained. Scores ranged from 0 to 60 and higher scores indicated higher levels of depressive symptoms. Radloff (1977) provided evidence of content and construct validity and reliability has been established in low-income and ethnic/ minority mothers [12,14]. The Cronbach's alpha reliability coefficient for internal consistency was 0.88. in this analysis.

Salient Beliefs about DNA Sampling

Participants completed an open-ended, free response questionnaire composed of nine items. This scale was constructed based on the instructions specified in The Theory of Planned Behavior [32,33].

The questions ask participants about their behavioral, normative and control beliefs about providing saliva samples for DNA analysis for the purpose of examining ways to prevent and treat depressive symptoms.

Genetic (DNA) Sampling Acceptability Questionnaire

A 13-item questionnaire was developed for this study to assess participants' willingness to participate in genetic sampling and its step-by-step procedures. The procedures were outlined according to the instructions for providing a DNA salivary sample as outlined in the insertion packet instructions for the Oragene salivary DNA self-collection kit developed by DNA Genotek [59,60]. Use of this test kit and its results have been found to be valid and reliable in diverse populations [59,60]. Respondents answer "yes" or "no" nine questions that ask about to each willingness to perform each step of the testing process. Two questions concerned study participation procedures after the sample was collected. The last question asked about fears about genetic testing in general. This questionnaire was necessary since in prior studies, the availability of information about study procedures were reported as a factor that would increase participation of genetic testing beliefs among African Americans and Aggregate samples of Hispanic/Latino's, [25,61]. This questionnaire is found in Appendix A.

Data Analysis

Descriptive statistics was generated using IBM's SPSS computer program and used to summarize and describe the demographic data. Qualitative analysis took place to analyze the questionnaire data [52,54]. Directed content analysis was employed [62] to identify codes consistent with the theoretical constructs (i.e. normative, behavioral and control) representing the beliefs proposed to influence behaviors [32,33]. Primary coding took place resulting in the identification of 16 codes for behavioral beliefs, 20 codes for normative beliefs and 11 codes for control beliefs in the original study. During secondary coding these initial codes were collapsed into categories resulting in six categories for behavioral beliefs, seven for normative beliefs, and eight categories for control beliefs. Themes emerged from these categories and were organized according to the TPB's main constructs. This analysis was completed by seven doctoral prepared nursing professors, and a masters prepared social worker, and an occupational therapist. All have experience conducting research and providing care to ethnic/minority residents who reside in under resourced communities that include Hispanic/Latino women. A senior researcher who is an expert in qualitative analysis reviewed the codes, and categories and made recommendations for final themes. The percentage of mothers willing to participate in genetic testing and its procedures was calculated via a frequency count.

Findings

The 16 Hispanic/Latino mothers in the original study ages ranged between 21 to 44 years. ($M = 29.50$, $SD = 7.07$). Most indicated they were single having never been married (10; 62.5%) while rest were married (12.5%; 2/10) separated (12.5%; 2/10) or divorced (12.5%; 2/10). Most of the mothers were of low-income (87.5%; 14/16), were employed full-time (68.8%) and had a high school education only (68.8%). Of the mothers indicating their Hispanic origin, 37.5% (6/16) self-identified as Puerto Rican, two identified as Mexican, 1 identified as Honduran and 7 chose to identify only as Hispanic/Latino without specifying a background. Half of the mothers reported that

Spanish was their first language spoken at home while growing up (50%; 8/16), while 37.5% (6/16) indicated English and 12.5% (2/16) indicated English and Spanish. The majority (75%; 11/16) were born in the United States, while the rest were born outside of the United States; 2 from Mexico, one from the Honduras and one who did not write the birthplace. Additional demographic information can be found in Table 1. Exactly 25% (4/16) of mothers scored greater than 16 on the CES-D scale indicating clinically significant levels of depressive symptoms. Average depression scores were slightly higher among mothers born outside of the US (M = 16.75; SD 13.67) compared to US born mothers (M = 14.50; SD 12.76). Average depression scores were higher in those identifying as Mexican (M = 24; SD 18.38)

English and Spanish	2	12.50%
Hispanic Background	16	100%
Hispanic	7	43.75%
Puerto Rican	6	37.50%
Honduran	1	6.25%
Mexican	2	12.50%

Table 1: Frequency Distribution of Selected Demographic Variables (N = 16).

compared to those identifying as Puerto Rican (M = 15.50; SD 14.54) and in those whose first language was Spanish (M = 15.75; SD 12.67) compared to those whose first language was English (M = 8.33; SD 1.03). Higher average depression levels were found among single mothers (M = 13.10; SD 9.21) compared to married mothers (M = 4.50; SD 3.53). None of these differences were statistically significant ($p < 0.05$).

How do you feel about performing each step below?

Characteristic	n	Percentage
Ages	15	93.80%
Mean	29.5	
Stand Dev	7.07	
Range	21-44	
20-29	8	50.00%
30-39	5	31.25%
40-45	2	12.50%
Marital Status	16	100%
Single/Never Married	10	62.50%
Married	2	12.50%
Separated	2	12.50%
Divorced	2	12.50%
Head of Household	16	100%
Yes	15	93.80%
No	1	6.25%
Number of Children	16	100.00%
2 or fewer	12	75.00%
3-4 children	3	18.75%
5-6 children	1	6.25%
Education	16	100.00%
High School	11	68.75%
Technical School	5	31.25%
Employment	16	100.00%
Full-Time	11	68.75%
Unemployed	5	31.25%
Income	16	100.00%
Less than \$5000	5	31.25%
Between \$5,000 and \$ 20,000	4	25.00%
Between \$20,000 and \$30,000	4	25.00%
Between \$30,000 and \$40,000	2	12.50%
Between \$40,000 and \$50,000	1	6.25%
Place of Birth	15	93.80%
US	12	75.00%
Mexico	2	12.50%
Honduras	1	6.25%
First Language Spoken at Home	16	100%
English	6	37.50%
Spanish	8	50.00%

Salient Behavioral Beliefs	N	Quotations
<i>Advantages</i>		
Helping others	6	“What comes to mind is that I will be able to help other people” “Helping people benefit health wise” “Helping people”
Treatment/cure for depression	5	“To find out ways to...treat depression” “Helping other people to better treat them” “Maybe the use of saliva can help completely cure depression.”
Diagnosis or detection of depression	4	“Properly Diagnosing” “Find out what’s wrong” “Sometimes we don’t know if we can avoid having depression and I think a saliva test will be easy to take instead of asking questions because people can always lie on questions” “It could help figure out what different about everyone and their illness” “there would probably be a lot more depressive symptoms findings
Prevention of depression	1	“find out ways to prevent...depression” “Not being able to know how to prevent it”
Empowerment to take action	1	“People will be able to see things positively and feel happier taking action in changing things they don’t like.”
No Advantages	1	“To be honest none”
Not Sure of Advantages	2	“unsure”
<i>Disadvantages</i>		
Uncertainty	5	“It might not work” “wouldn’t be able to help them out” “I don’t think it would help”
Trust	3	“as long as everything stays confidential” “may fall into the wrong hands”
Procedure	1	“drawing blood or something”

No disadvantages	6	"It's just saliva so I don't see a problem with it" "nothing's bad" "I don't mind doesn't bother me" "I don't see too many" "none"
Not sure of disadvantages	2	"I don't know" "not sure"

Table 2: Salient Behavioral Beliefs (N=16).

Most Salient Behavioral Beliefs

Advantages

Mothers reported altruistic and diagnostic benefits to providing saliva samples for DNA testing. Most of the mothers believed that testing would help other people in general (6/16; 37.5%) as one mother stated "it could help others." Other advantages mentioned included that testing would help find a cure or treatment for depression (5/15; 31.25%) a on mother stated, "find a treatment for depression." Mothers (4/16; 25%) also believed that depression and types of depression would be detected, diagnosed or ruled in or out in others stating, "this would help in determining a mental illness such as depression." Mentioned less often were beliefs that participating would help prevent depression (1/16; 6.25%) or empower women to be proactive about addressing their own depressive illness (1/16; 6.25%). One woman believed that there were no advantages and two women were unsure of the advantages (2/16; 12.5%). Additional statements of behavioral beliefs are found in Table 2.

Disadvantages

The majority of women believed that there were no disadvantages to participating (6/16; 37.5%). These statements included, "I don't see any disadvantages." Others reported the disadvantages related to uncertainty about how to respond to the outcomes of the testing as opposites of the advantages such as not being able to help/ prevent it or not finding a treatment (5/16; 31.3%). Statement included, "it may not help," and "not finding any treatment." Some mothers (3/16; 18.8%) indicated lack of trust or confidence in how the samples will be used stating, and "the personal

information given was given to 3rd party company." Two mothers reported that they were unsure or did not know of any disadvantages and one woman indicated that taking blood is a disadvantage. Additional statements are found in Table 2.

Most Salient Normative Beliefs

Referents who approve

Mothers named people, organizations, institutions and agencies when asked who would approve of testing. Most mothers indicated that friends (6/16; 37.5%) and family members (5/16; 31.3%; mothers and sisters) would approve of them providing saliva samples for DNA testing. Other mothers reported that their significant others (2/16; 12.5%; boyfriends), work associates (2/16; 12.5%; bosses and coworkers), doctor (1/16; 6.5%), church associates (1/16; 6.3%; churches), and agencies/organizations (1/16; 6.5%; law enforcement, government, prisoners, teachers, child care providers) would approve. Two women said no one would approve.

Referents who disapprove

Most mothers indicated that no one (7/16; 43.8%;) or church associates (4/16; 25%; church group, church) would disapprove of them providing samples for DNA testing. Other mothers reported that their family members (3/16; 18.8%; mother, sister, brother, parents), women's group (1/16; 6.3%) and strangers would disapprove (1/16; 6.3%).

Referents who would participate

Most mothers indicated that family members (8/16; 50%; family, cousins aunts, uncles, mother, sisters, brother, children) and friends (2/16; 12.5%) would participate. Other mothers indicated that their significant other (1/16; 6.3%), or work associate (1/16; 6.3%; co-workers) would participate. Four mothers (25%) indicated that no one would participate and two mothers (12.5%) indicated that they did not know who would participate.

Referents who would not participate

Most mothers indicated that no one (7/16; 43.6%) would refuse to provide samples. Other mothers indicated that family members (5/16; 31.3%; family, parents, siblings, husband, cousins, aunts, uncles, dad father), friends (1/16; 6.3%), and a significant other (1/16; 6.3%) would refuse to participate. One mother (1/16; 6.3%) indicated that everyone would refuse to participate.

Most Salient Control Beliefs

Barriers and facilitators

Most mothers (5/16; 31.3%) indicated that availability of information in general, about the study and its procedures are facilitators or barriers to testing. Mothers individual statements included, "have someone give information about the procedure first," and "not knowing how to get the sample." Mothers also indicated that the location (4/16; 25%) and timing (3/16; 18.8%) of testing can be a barrier or

Salient Control Beliefs	N	Quotations
Information/Explanations	5	"It will be difficult if there is no explanation." "It will be easy for someone to be more informed" "Giving me instructions" "Who will get sample"
Location	4	"If it was mailed to my home and I don't have to go to a facility to do it" "Having to go long distance to give the sample out" "Transportation,"
Time/Scheduling	3	"Proper scheduling for people who work." "Time"
Childcare	1	"No sitter"
Outreach	1	"Just ask"
Financial	1	"Money"
Procedure	1	"have a kit."
No barriers or facilitators	5 barriers 3 facilitators	"If I got hit by a car and was in a coma"... barrier "nothing" "none"
Unsure	6	"Unsure" "I don't know"

Table 3: Salient Control Beliefs (N = 16).

facilitator. Statements referencing these included, “easy locations to come to or and “time.” Five mothers (31.3%) indicated that there were no barriers, three mothers (18.8%) indicated that there were no facilitators of participation, and two mothers (12.5%) indicated that they were unsure of barriers or facilitators. Only one mother (6.3%) indicated that childcare (6.3%; “having a sitter”), and another mother lack of outreach to her (1/16; 6.3%; “not asking”) were barriers or facilitators. Only one mother (6.3%) mentioned “money” as a facilitator and only one mother offered a statement indicating a lack of trust and need for assurance about the benefits as a barrier and facilitator. This mom stated that she would want to have, “Proof it does help and what will be most beneficial for the patient with depression problems,” as a facilitator of testing and having “no proof” as a barrier to participation. Another mother indicated that the type of equipment may facilitate testing (1/16; 6.3%). Additional normative belief statements are found in Table 3.

Willingness to Participate in Genetic (DNA) Salivary Sampling

Out of 16 mothers who responded to the questions, 93.8% (15/16) answered “yes” to the question that asked if they would provide a salivary sample for genetic (DNA) testing indicating their intention to participate. Out of the nine steps of the procedures, 93.8% (15/16) of mother agreed to the performance of all the steps. One mother, who indicated that she would not provide saliva for DNA testing agreed to performing eight of the nine steps of the procedures. None of the mothers documented a fear of testing.

Discussion

We sought to identify the most salient behavioral, normative and control beliefs about participating in genetic (DNA) testing for depression prevention and treatment in this sample of Hispanic/Latino mothers. We also wanted to determine their willingness to provide salivary genetic (DNA) samples for the purpose of developing interventions to encourage participation in biological research. We also examined levels of depressive symptom and differences based on sub-ethnicity.

Behavioral Beliefs

Advantages

Overall, attitudes toward genetic testing were positive. Mothers reported more advantages (6/16), to genetic testing for depression compared to disadvantages (4/16). These results are similar to those found in prior qualitative studies where the majority of Latino men and women expressed favorable attitudes towards participation in genetic testing for ovarian and breast cancer screening (N=51) [41]. In prior studies, similar benefits related to treatment, causes, cures, or prevention for genetic breast and ovarian cancer screening in Latino men and women reported [25,41,63] and in Black American adults for psychiatric genetic testing [50]. Personal and altruistic benefits may impact these mothers willingness to participate in genetic testing.

Disadvantages

Overall, few disadvantages of testing were mentioned and many mothers stated there were no disadvantages. The most salient disadvantage, uncertainty (5/16) about responding to the outcomes of testing were similarly expressed about breast and ovarian cancer

screening among Hispanic/Latino adults [41,42]. However, unlike in prior studies with Hispanic/Latinas, the mothers in the current sample did not express, nor document fear, nor fatalistic attitudes towards the outcomes of genetic testing for depression nor were fatalistic attitudes expressed among 18 Black Americans toward psychiatric genetic [50]. Depression and other mental illnesses are not typically thought of as fatal like the diagnosis of cancer is known to be [50]. Fear, however, of bodily injury from unpleasant study testing procedures and adverse effects from medications have been named in prior studies among Mexican women for breast cancer genetic testing [42], among 18 Black Americans among for psychiatric genetic testing in [50], and among Latino adults [25] and African American women for biomedical research participation in general [45,46,48]. This was not a frequent expression among Hispanic mothers with only one mother possibly indicating a concern with the procedure as she stated “taking blood or something.” Fears of study procedures were more than likely alleviated because the women received detailed instructions about the process for how the sample will be taken. The second most salient disadvantage mentioned by just a few Hispanic/Latino mothers (3/16) concerned trust, namely how genetic information for depression will be handled and kept confidential. These findings are similar to sentiments of 18 Black American adults who also discussed concerns about confidentiality and privacy of genetic information for psychiatric testing due to stigma associated with mental illness [50]. There is stigma associated with mental illness in Hispanic/Latino (National Alliance on Mental Illness [64] and Black/African American [65].

Normative Beliefs

Mothers named many more referents who would approve of and participate in testing than disapprove and would not participate. Most mothers named family members (11/16) and friends (8/16) as the most salient referents. These results are consistent with Hispanic/Latino cultural values that promotes loyalty and commitment to immediate and extended family members (familismo), which includes close friends [52]. Views of family members and friends who may be impacted by the results of testing would therefore be most important. Concerns about family approval and involvement was also expressed by Black American adults in a study of attitudes towards psychiatric genetic research [50]. Church associates were also mentioned second often by many mothers (5/16), as those who would mostly disapprove of testing. Since faith and religiosity, usually Christian and Catholicism is an important part of Hispanic/Latino culture [52], it is not surprising that the views of church associates would also be mentioned. In a prior study, Latino adults recommended using the clergy to encourage participation in genetic breast and ovarian cancer screening in Hispanics/Latinos [41]. Significant others were mentioned third often by only three mothers. This is not surprising since most mothers were single or not married (14/16; 87.5%) and head of household (15/16: 93.8%), and thus more likely to make decisions independent of a partners’ views. Mothers also named agencies/organizations/es-tablishments who would approve and disapprove.

Single mothers of low-income often use government and social service entities for support and must adhere to their guidelines [66]. Therefore, it is not surprising that the views of these entities would be important to this sample of mostly low-income mothers. These findings indicate that mothers believed most of their personal/social contacts, mostly family and friends would be in favor of their participation and faith-based contacts less supportive. Normative referents that may influence participation have not been elicited, nor rarely

reported in studies that have examined beliefs and perceptions about genetic testing in Hispanic/Latinos [41,42]. This is the first study to elicit normative referents who may influence Hispanic/Latino women's willingness to participate in genetic testing for depression. This study thereby provides new knowledge to support intervention strategies for this sub-population of Hispanic/Latino mothers.

Control Beliefs

Overall, mothers reported fewer barriers compared to facilitators indicating that participation would be under their control if a few barriers were eliminated. The most salient barriers and conversely facilitators reported included the availability of information/explanations in about the study and its testing procedures. These findings are similar to prior studies where Hispanic/Latino women reported the availability of knowledge and information about risk and reliability of the test as facilitators of breast and ovarian cancer genetic screening [41,42]. Lack of information about study procedures and overall goals of the research was a barrier expressed in a sample of Black Americans toward psychiatric research in one study [50]. The second most often mentioned barrier/facilitator in the current study involved issues of convenience (ie. timing, location, childcare, outreach). In a prior study, making studies convenient such as instituting outreach efforts in community locations (i.e., Churches, in the neighborhood, schools, clinics), was reported as a facilitator among Black Americans for psychiatric genetic research [50] and Hispanic/Latina adults for breast and ovarian cancer research [41]. Our study also found that incentives can be facilitators of participation [50]. Even though need for incentives were not frequently reported in this sample of Hispanic/Latino mothers, most of the mothers are low-income, single, and head of their households. As the primary caretakers of their families, financial and social resources to travel to clinical study sites outside of their communities may be most helpful.

A slightly higher proportion of young adult, Hispanic mothers (4/16; 25%) in the present sample reported clinically significant levels of depressive symptoms compared with national samples of Hispanic, young adult women (24%) [27]. This proportion, was also slightly higher but consistent with levels found in prior studies of non-pregnant, young adult, Latino mothers with young children (16-24%) [22], and non-pregnant, low-income, Hispanic mothers (19%) [67], and (23%) [68]. This study therefore contributes to the body of knowledge that substantiates the higher prevalence of depressive symptoms in this sub-group of the Hispanic population of women.

Average levels of depressive symptoms were also higher among mothers identifying with Mexican sub-ethnicity which is contrary to results of current study using a national sample of Hispanic/Latino adult men and women (N = 15,864) where a higher prevalence of depressive symptoms were found among Puerto Ricans (38%) compared to Mexicans (22%) [27]. Rates of major depressive disorder are also often higher among Puerto Rican men and women (11.9%) compared to Mexicans (8.0%) in national samples [69]. The prevalence of depressive symptoms among Mexican mothers in this sample, are consistent with the high rates of depressive symptoms reported in a study of Mexican-heritage mothers (52%) [23]. Low income mothers are less likely to receive treatment for their depression [6] and Mexican Americans with depressive symptoms have lower odds of receiving treatment compared to other ethnic groups (i.e. Puerto Rican, Caribbean black, African American, non-Latino white) [69]. The intersection of Mexican ethnicity, low income and parenting status

may account for the existence of higher levels of depressive symptoms among Mexican mothers compared to Puerto Rican mothers in the current sample. Overall, U.S. born Hispanic/Latino mothers had lower average levels of depressive symptoms compared to foreign born Hispanic/Latino mothers which is contrary to recent findings that US born Hispanic adult men and women (29.1%) have higher prevalence of symptoms than foreign born Hispanics/Latino men and women (26.4%) [27]. These findings however, are consistent with a study that found that Major Depressive Disorder in US born Puerto Rican men and women are lower than those born foreign [69]. The majority of mothers identified as Puerto Rican Hispanic background. Puerto Rican Americans are also more likely to receive treatment for their depressive symptoms compared to other sub-ethnic groups (i.e. Mexican). The receipt of treatment among US born Puerto Rican Americans may possibly explaining the lower prevalence of depressive symptoms in this sample of Hispanic/Latino mothers where most identified as U.S. born Puerto Rican Americans.

Willingness

Participants' willingness to participate was high. Almost all mothers (15/16) indicated a willingness to provide a sample for genetic testing for depression if ever asked. These results are similar to those found in prior qualitative studies where most Latino men and women had preferences for genetic testing in general compared to whites (N = 428) [63], and high willingness to participate in biomedical research in general (N = 35) [25]. Willingness to participate in psychiatric genetic research was expressed by an entire sample (n =18) of Black Americans [50]. Prior studies have also found that Hispanics (i.e. Puerto Ricans) were more likely to participate in genetic screening for cancer compared to non-Hispanic Whites and Blacks [70]. Although most identified as Puerto Rican sub-ethnicity in the present sample, mothers' responses did not differ by sub-ethnic background.

Research Implications

As indicated, the normative, behavioral, and control beliefs that underlie participation are related to their education/knowledge about the research and its procedures, the environment where research takes place, their probable lack of resources that would make participation convenient, specified persons that make up their social networks and contacts, specified benefits they hope to receive, and psychological fears/apprehensions. These factors are consistent with the social determinants of health [71] that are known to influence health behaviors [72-74]. These factors can be identified by using Community Based Participatory Research (CBPR) approach that is known to be effective for encouraging health promoting behaviors with ethnic/minority or low-income populations [75]. Clearly these mothers are willing, yet are not being asked to participate in genetic research. Outreach efforts and close collaboration can lead to greater inclusions as strategies that facilitate participation are identified and applied [76,61]. Some strategies may include conducting studies at convenient places and times in the community and with accommodations that facilitate participation such as childcare.

Given the history in the U.S. and globally of lack of protection of oppressed human subjects in research for minority and marginalized populations [77,78], detailed instructions about how study procedures will take place for providing genetic samples may encourage participation by alleviating these fears. Researchers can educate mothers during the process of informed consent, sharing general information about the purpose of the research and thoroughly disclosing

information about testing procedures, instructions about use of equipment, potential outcomes, and consequences. During this process, benefits of testing can be emphasized. Strategies that reassure clients that results will be kept private and confidential can also be used. In addition, based on the referents mentioned, immediate and extended family member involvement in decision making may also encourage participation. Perhaps collaboration with clergy and use of faith-based locations may also serve to facilitate participation. Outreach efforts should also be made to identify Hispanic/Latino mothers at risk for depression so that appropriate outreach referral for psychiatric evaluation can take place.

Those who provide support aimed at increasing minority participation in genetic research can require that researchers utilize CBPR research methods to promote effectiveness as a requirement for receipt of research support [79-87]. In future qualitative studies, researchers can further explore the relationship between religiosity and faith and engagement in genetic testing for mental health disorders. Since this was a pilot study and secondary analysis of data, the size of this sample is smaller than the size recommended by developers of the theory of planned behavior for eliciting salient beliefs (N =30) [88-94]. A larger sample size can be utilized in futures studies.

Limitations

The original sample was a sample of convenience that is inherently biased due to self-selection. The sample size is smaller than required for eliciting salient beliefs therefore the frequencies of the responses may increase with a larger sample size. In addition, seven women chose not to indicate their sub-ethnic origin and therefore discussions conclusions based on sub-ethnicity should be viewed with caution. The sites for data collection were located in urban communities where most of the residents resided [95]. These results may therefore not apply to mothers who live in rural or suburban areas. Since the questionnaires were only provided in English; this study may not be representative of the beliefs of Hispanic/Latina mothers with limited English language proficiency.

Appendix A

Saliva Genetic (DNA) sample collection acceptability

We would like to ask about your willingness to perform the steps below to provide a saliva sample for other studies conducted by this researcher. Your honest answers will help us plan for future studies that will continue to help us understand the role of DNA in preventing and treating depression. All of the information that you share will be kept confidential and will not be shared with anyone else besides the research study staff. Please feel free to be honest and open with your answers.

How do you feel about performing each step below?

Before the sample is collected, would you be ok with doing the following: (Check the box under “Yes” or “No”)

	Yes	No	If you said “No” describe why
Not eating or drinking or smoking or chewing gum for 30 minutes before giving your saliva Sample			
Not removing a plastic film from a saliva collection container			
Washing your hands with water if liquid comes into contact with your eyes or skin			

While you are giving the saliva sample, would you be ok with doing the following: (Check the box under “Yes” or “No”)

	Yes	No	If you said “No” describe why
Spitting into a funnel until the amount of liquid saliva (not the bubbles) reaches the fill line to about 2ml.			
Holding the tube upright with one hand.			
Closing the funnel lid with the other hand by firmly pushing the lid until you hear a loud click. Making sure that the lid is closed tightly.			
Holding the tube upright then unscrewing the funnel from the tube			
Using the small cap that will be given to you to close the tube tightly.			
Shaking the caped tube for 5 seconds then throwing away the funnel			

After the sample is collected, would you be ok with doing the following: (Check the box under “Yes” or “No”)

	Yes	No	If you said “No” describe why
Filling out a questionnaire to talk about how easy or hard giving the sample was.			
Receiving compensation in the form of money or gift cards after the sample is given to the person conducting the study			

Would you be willing to provide a saliva sample?

	Yes	No	If you said “No” or “Yes” describe why
Will you be willing to participate in a study that involves collecting your saliva for genetic analysis?			
Do you have any fears about having your saliva collected for genetic analysis? If you do what are they?			

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