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Ethnic Identity and Teratogenic Risk Perceptions

Katie M. Chan

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ETHNIC IDENTITY AND TERATOGENIC RISK PERCEPTIONS

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ETHNIC IDENTITY AND TERATOGENIC RISK PERCEPTIONS

A

THESIS

Presented to the Faculty of
The University of Texas
Health Science Center at Houston
and
The University of Texas
MD Anderson Cancer Center
Graduate School of Biomedical Sciences
in Partial Fulfillment

of the Requirements

for the Degree of

MASTER OF SCIENCE

by

Katie Melissa Chan, BS

Houston, Texas

May 2016

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ETHNIC IDENTITY AND TERATOGENIC RISK PERCEPTIONS

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Elevated perceptions of teratogenic risk can cause anxiety and confusion among pregnant women. To assess whether ethnic identity and demographic factors can influence teratogenic risk perceptions, 194 pregnant women in Houston were surveyed using the Multigroup Ethnic Identity Measure (MEIM) and visual analog scales to quantify perceptions of teratogenic risk for common exposures during pregnancy. Overall, participants estimated an elevated baseline risk of 25% for birth defects among the general population. In addition, participants overestimated birth defect risks for specific exposures, such as alcohol and marijuana. Based on the MEIM scores, ethnic identity was not significantly associated with teratogenic risk perceptions; however, some demographic factors were found to be significantly associated. Participant education level was associated with perceptions of the general population risk for birth defects, influenza vaccine, and acetaminophen. Understanding how demographic factors can influence teratogenic risk perceptions can aid in providing effective and accurate counseling to patients with diverse backgrounds. This may help reduce patient anxiety, guilt, and even terminations based on misinformation.

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Introduction

Teratogens are defined as agents that can interfere with the development of the fetus and cause birth defects (Moore & Persaud, 2008). Common teratogens include certain medications, alcohol, and maternal infections such as rubella and cytomegalovirus (Obican & Scialli, 2011). Based on current studies, alcohol use was reported in 9.4% of pregnant women in the National Survey on Drug Use and Health (U.S. Department of Health and Human Services, 2013), and approximately 86% of women are exposed to more than one medication during their pregnancy (Collaborative Group on Drug Use in Pregnancy, 1991). Since there are approximately 4 million births per year in the United States (Martin et al., 2015) and 50% of pregnancies are unplanned (Finer & Zolna, 2011), there is a high potential for exposures to teratogens during pregnancy before they are even known to the women carrying them (Nava-Ocampo & Koren, 2007). Although advances in medicine have allowed for a better understanding of teratogens, many exposures that occur during pregnancy have little to no available data regarding true teratogenic risks. Even though the baseline risk for birth defects is 3-5% (CDC, 2008), most of what is known among teratogenic risks is based on anecdotal reports, animal studies, or small human cohorts. Therefore, the teratogen information that is available for pregnant women is limited.

Due to the perception of elevated teratogenic risk, certain exposures routinely cause anxiety and confusion among pregnant women [Koren et al., 1993; Hancock et al., 2007]. Research has shown that not only do patients have inaccurate perceptions of risk, but they also find it difficult to understand their personal risk (Polifka et al., 1997). In a study that quantified women's perceptions of risk, patients exposed to non-teratogens assigned a mean risk of 24% for major malformations (Koren et al., 1993). Other studies have shown

overestimations of teratogenic risk [Mazzotta et al., 1999; Sanz et al., 2001; Nordeng et al., 2009]. Perceptions of high teratogenic risk have been associated with an increase in psychosocial concerns, such as anxiety, guilt, and fear, which in extreme cases may have led to terminations (Koren et al., 1993).

In addition to the perceived teratogenic risks of common medicinal, occupational, and environmental exposures, it is also well known that there are specific cultural beliefs regarding pregnancy and birth defects. Cohen et al. (1998) established that ethnicity is an influencing factor in how individuals view the causation of birth defects and genetic disorders. Researchers have found that a popular belief in the Latino population is that the “evil eye”, a malevolent eye glance, or a lunar eclipse during pregnancy can cause birth defects such as a cleft lip and/or palate (Meyerson, 1990). Other factors that have been suggested to influence health risk perceptions include certain demographic influences, such as socioeconomic status (Lee et al., 2008).

As a practice-based competency, many genetic counselors find themselves providing teratogen risk counseling to diverse populations. In order for genetic counselors to better serve their multicultural patient populations, cultural competency skills must continuously be developed. This includes appreciating and understanding a patient’s cultural code and using it as a counseling resource (Uhlmann et al., 2009). Therefore, in order to best provide culturally competent counseling, insight into cultural beliefs and how these beliefs may affect healthcare decisions is essential for proper counseling.

While there are several complex factors that influence a person’s cultural beliefs, one important consideration is a person’s ethnic identity. Ethnic identity can be defined as “an individual’s self-concept that derives from his or her knowledge of membership in a social

group (or groups) together with the value and emotional significance attached to that membership” [Tajfel, 1981; Phinney 1992]. Key aspects of ethnic identity include, “a feeling of belonging to an ethnic group and attitudes toward the group” (Phinney, 1992). One method to evaluate an individual’s ethnic identity is to use the validated tool, The Multigroup Ethnic Identity Measure, or MEIM (Phinney, 1992). The MEIM provides a way to assess ethnic identity by measuring three aspects: 1) affirmation and belonging, 2) ethnic identity achievement, and 3) ethnic behaviors. Though many ethnic identity studies exist, no study to date has evaluated ethnic identity as it pertains to perceptions of teratogenic risk.

Although studies have examined the range of cultural beliefs surrounding the causes of birth defects, there is no information available regarding how the degree of ethnic identification affects teratogenic risk perceptions. Learning how the degree of ethnic identity influences risk perception of teratogens can improve the cultural competency of both genetic counselors and teratogen information specialists. Understanding these cultural beliefs and the various degrees of ethnic identity could aid in providing more effective counseling to patients with diverse backgrounds. Providing more culturally competent counseling may help reduce patient anxiety, guilt, and even terminations based on misinformation.

Methods

Patient Participants

Eligible participants were English and Spanish speaking pregnant women over the age of 18 years old who were receiving prenatal care at one of the six University of Texas Physicians Women’s Centers, Department Obstetrics and Gynecology. Our study was approved by the institutional review board (IRB) at the University of Texas Health Science

Center at Houston (IRB # HSC-MS-15-0476). Participants were given a paper questionnaire when checking in for their prenatal appointment and asked to voluntarily complete the questionnaire for a research study. Recruitment occurred between August 26, 2015 and January 13, 2016.

Instrumentation

Eligible participants were given a letter of invitation and an anonymous questionnaire. The questionnaire consisted of three parts. The first part documented basic demographic factors. The second part consisted of a validated Multigroup Ethnic Identity Measure (MEIM) to measure how strongly each participant felt towards their ethnic identity based on a set of 12 questions (Phinney, 1992). Permission was not required for the use of the measure and ethnic group names were adapted to our patient population. For the third part of the questionnaire, we used a 10.6 cm visual analog scale (0%-100%) to quantify our patients' perception of teratogenic risks. The exposures were chosen from the MotherToBaby - TexasTips database. MotherToBaby - TexasTips is a teratogen information service at the University of Texas McGovern Medical School in Houston. It is associated with MotherToBaby, an affiliate of the Organization of Teratology Information Specialists (OTIS).

Data Analysis

Data analysis was performed using the statistical analysis software program, STATA (v.13.0, College Station, TX). Descriptive tables and graphs were created using Microsoft Excel (Microsoft Corp., Redmond, WA). Distributions for continuous variables were non-normal and are described as medians (with interquartile ranges, IQR). Frequencies for categorical variables are described using counts (and percentages). A comparison between

groups was performed using Kruskal-Wallis tests or Spearman's rank correlation coefficient tests where appropriate. Statistical significance was assumed at Type I error rates of 5%.

Results

A total of 194 completed surveys were returned. Seven individuals did not meet the inclusion criteria of being at least 18 years of age. Therefore, the final sample size was 187. The total responses for each question varied due to incomplete sections. About 115 (61%) individuals completed all three parts of the survey.

Demographics

A summary of demographics is included in Table 1. The median age of participants was 27 years with an interquartile range of 24 – 31 years. Eighty-seven percent (161/184) of participants spoke English as their primary language, and 7% (13/184) of participants spoke Spanish as their primary language. Other primary languages included Arabic, Cambodian, Chinese, Farsi, French, and Vietnamese. A third (n=60, 33%) of the respondents had graduated from high school or obtained a GED, with another third (n=59, 32%) having some college experience. Only a quarter (n=46, 24%) had an undergraduate or graduate degree. About 45% (83/184) of participants were single and 48% (89/184) were married. Approximately 41% (75/181) of participants worked outside of home and 40% (72/181) were unemployed. For annual household income, 43% (74/174) of participants reported receiving less than \$24,999, 16% (27/174) reported \$25,000-\$49,999, and 14% (25/174) reported \$50,000-\$99,999. About 82% (124/152) of participants were born in the United States of America followed by 7% (10/152) born in Mexico. Other birth countries included Afghanistan, Argentina, Cambodia, Canada, China, Colombia, Honduras, Iraq, Laos, Libya,

Nigeria, Panama, and Vietnam. Approximately 52% (92/177) of participants reported Christianity as their religious affiliation and 23% (41/177) of participants reported Catholicism.

Table 1. Demographic characteristics of participants

Demographic factor	<i>N</i>	Percentage
Primary Language		
English	161	88%
Spanish	13	7%
Other	10	5%
Education		
Did not attend high school	1	1%
Some high school	18	10%
High school/GED	60	33%
Some college	59	32%
College graduate	27	14%
Graduate/Professional	19	10%
Work Status		
Outside of home	75	41%
From home	7	4%
Unemployed/Stay-at-home	72	40%
Student	8	4%

Military	1	1%
Unable to work	9	5%
Other	9	5%
Household Income		
Less than \$24,999	74	43%
\$25,000-\$49,999	27	16%
\$50,000-\$99,999	25	14%
\$100,000-\$199,999	17	10%
\$200,000 or more	6	3%
Declined	25	14%
Country of Birth		
United States of America	124	82%
Other	28	18%

Ethnicity and MEIM

Regarding ethnicity, approximately 39% (63/161) of participants reported African American, 33% (54/161) reported Hispanic, 19% (31/161) reported Caucasian, and 4% (6/161) reported Asian. Out of 150 participants, the median and mean MEIM scores were both 2.83 (SD: 0.589). MEIM scores were significantly different across ethnicities ($p=0.0289$) with the median scores summarized in table 2.

Table 2. Multigroup Ethnic Identity Measure (MEIM) scores among ethnic groups

Ethnic Groups	<i>N</i>	Percentage	Median MEIM Scores (IQR)
Asian or Asian American, including Chinese, Japanese, and others	6	4%	2.79 (2.67-3)
Black or African American	63	39%	3.00 (2.58-3.41)
Hispanic or Latino, including Mexican American, Central American, and others	54	34%	2.83 (2.46-3.21)
White, Caucasian, Anglo, European American; not Hispanic	31	19%	2.63 (2.33-2.88)
Mixed; Parents are from two different groups	5	3%	2.92 (2.83-3.08)
Other	2	1%	3.38 (2.92-3.83)

Risk Perceptions

Participants were asked about the general population risk for birth defects. Out of 123 respondents, the median risk was 25% (IQR: 14% - 42%) for birth defects. In addition, participants were asked about the risk for birth defects for common exposures, some with well-described teratogenic risks and others with unclear or no teratogenic risks associated with them. The median risks for each of the nine exposures as well as the pregnancy recommendations suggested by Briggs & Freeman (2015) are summarized in table 3.

Table 3. Risk for birth defects among common exposures during pregnancy

Exposure	Median Risk	IQR	Pregnancy Recommendation ¹
Methamphetamine (n=116)	86%	66%-99%	Risk Suggested
Alcohol (n=115)	75%	50%-86%	Contraindicated
Cigarette smoking (n=116)	74%	49%-94%	Contraindicated
Marijuana (n=117)	70%	32%-88%	Contraindicated
Medications for anxiety or depression (n=113)	51%	25%-76%	Risk suggested depending on medication
Ibuprofen (n=112)	30%	17%-54%	Risk suggested in 1 st and 3 rd trimesters
Cold/Flu Medicines (n=112)	25%	11%-51%	Compatible
Influenza Vaccine (n=113)	14%	2%-48%	Compatible
Acetaminophen (n=113)	14%	2%-36%	Low Risk

¹ As suggested in Briggs, G.G. & Freeman, R. K. (2015). *Drugs in Pregnancy and Lactation: a Reference Guide to Fetal and Neonatal Risk*. Philadelphia, PA: Lippincott Williams & Wilkins.

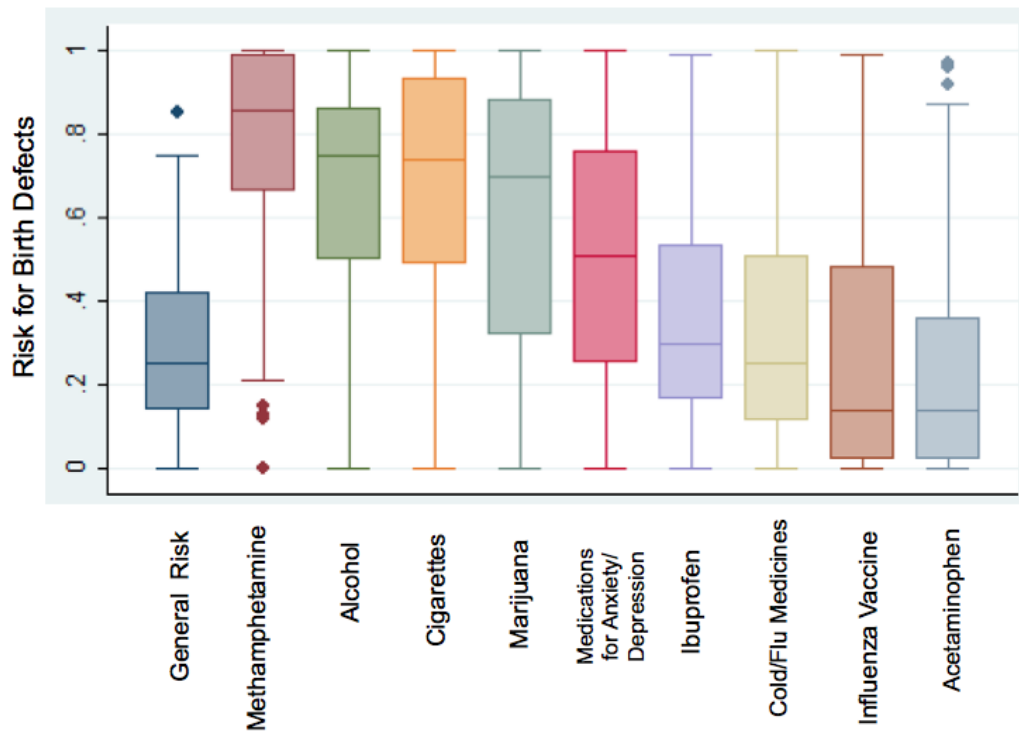


Figure 1. Box plot of participant risk perceptions for common exposures during pregnancy

Ethnic Influence

Participants were asked to select a number that corresponded to how much they believed their ethnic group influenced their risk perception on a Likert scale ranging from 0 to 10 (0=Not at all, 10=All the time). Out of 140 participants, 44% (61/140) believed that ethnic group did not influence risk perception at all and 6% (9/140) believed that ethnic group influenced risk perception all the time.

The perception of ethnic influence was positively associated to MEIM scores ($p=0.0003$, Spearman's $\rho=0.3098$). The higher the MEIM score, the more that individual believed their ethnic group influenced their risk. However, there was no significant correlation found between MEIM scores and risk perceptions for each exposure. Thus, ethnic identity was not found to influence risk perceptions for each exposure.

Demographic Associations

Education level was significantly associated to risk perceptions for the general population risk for birth defects ($p=0.0039$), flu vaccine ($p=0.0033$), and acetaminophen ($p=0.0095$). The higher the education level, the lower the risk perception.

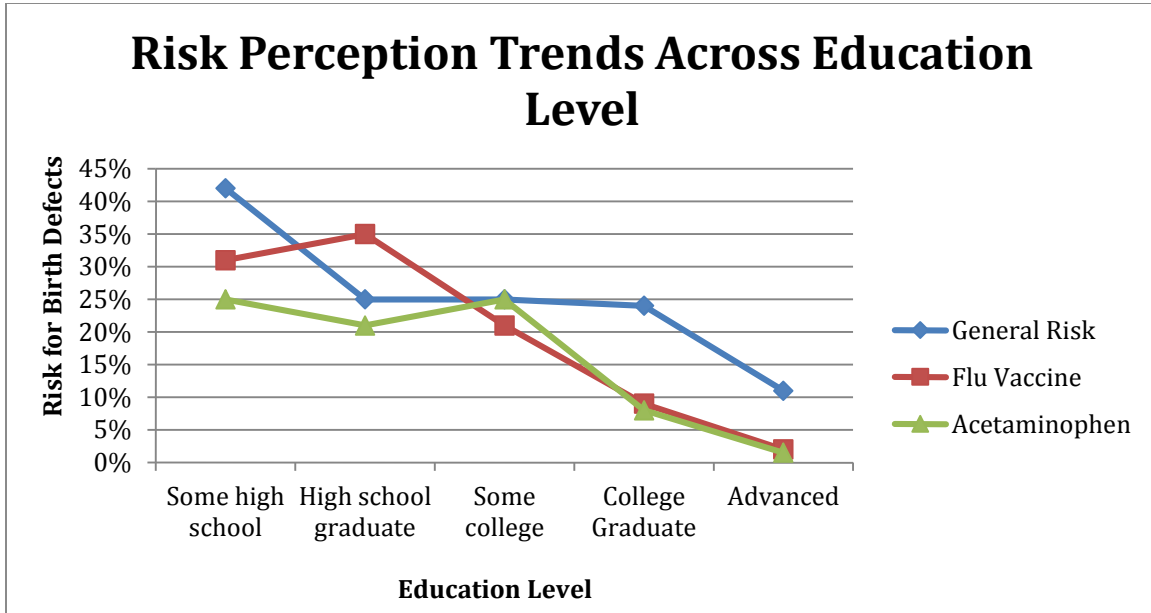


Figure 2. Risk perceptions across education level

Household income was significantly associated to risk perceptions for the general population risk for birth defects ($p=0.0023$), flu vaccine ($p=0.0064$), methamphetamine ($p=0.0419$), acetaminophen ($p=0.0269$). The higher the household income, the lower the risk perception.

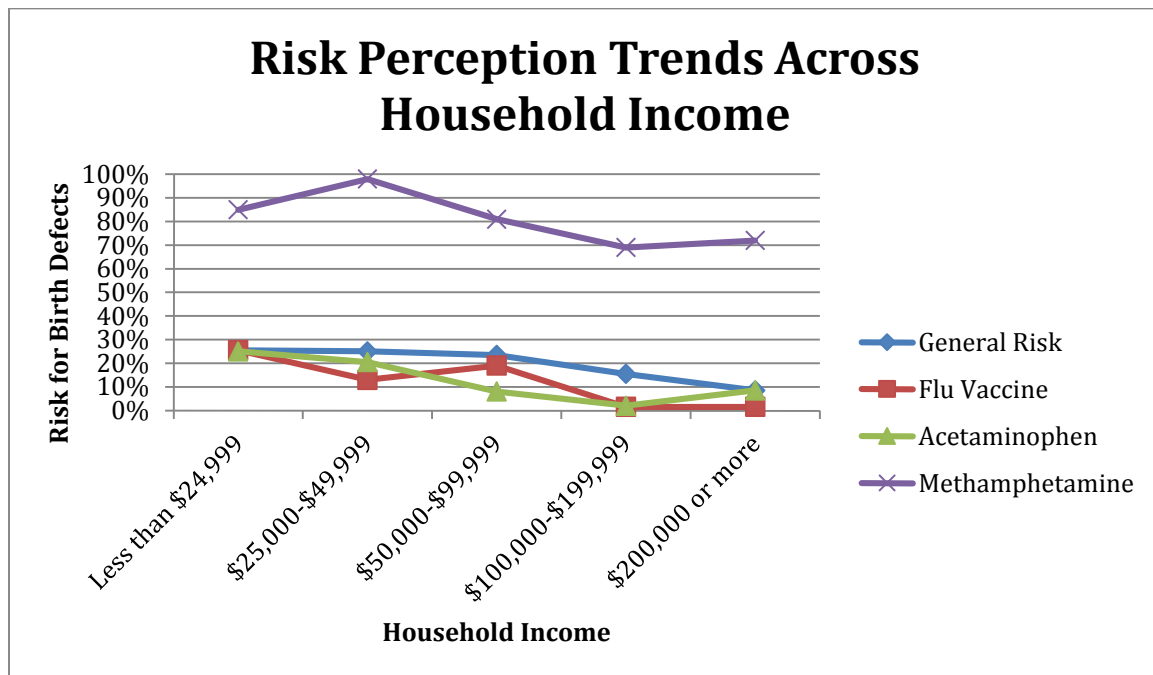


Figure 3. Risk perceptions across income level

Education and household income were found to have a significant correlation ($p<0.001$). A multivariable model was performed, and there was evidence that education was confounding income. It is likely that the true trend of these risk perceptions was mostly due to education level.

Country of birth was significantly associated to risk perceptions for marijuana ($p=0.0097$) and medications for anxiety or depression ($p=0.0177$). Those born in the United States of America had a lower risk perception compared to those born in other countries. The

sample of individuals born outside of the United States was too small to determine if there was a correlation to the amount of years lived in the United States.

Adjusted multivariable models were performed. The only factor consistently significant was participant education level. There was a significant trend of decreasing risk perception with increasing education. Furthermore, alcohol, cold/flu medicines, acetaminophen, influenza vaccine, and cigarettes shared similar trends but failed to reach statistical significance.

Patient Comments

Nineteen participants provided additional teratogens in the space provided for comments. It included environmental exposures (3/19), second-hand smoke (2/19), radiation (2/19), and antibiotics (2/19). In addition, maternal disease, cat litter, cleaning supplies, stress, Vitamin A, herbal teas, lack of folic acid, and maternal injury were mentioned. One Spanish-speaking participant born in Mexico mentioned eclipses could cause birth defects. Another patient stated, “I feel very ill-informed filling out this survey.”

Discussion

While it is well established that the general population risk for birth defects is 3-5% (CDC, 2008), and that common exposures during pregnancy have a low, unclear or no associated teratogenic risk (Briggs & Freeman, 2015), the current study clearly demonstrates that pregnant women tend to overestimate these risks. Unfortunately, this is a trend that has continued for many years, as demonstrated in the 1993 study by Koren that showed an interestingly similar overestimation of 24% risk for major malformations from non-teratogens. One of the most striking findings in our study is that the participants’ perception

of the general population risk for birth defects is 25%, close to the known risk of thalidomide [Lenz, 1962; McBride, 1961]. Additionally, while it is suggested that most medicines for cold/flu and the influenza vaccine are compatible during pregnancy (Briggs & Freeman, 2015), participants perceived these exposures to have median birth defect risks of 25% and 14%, respectively. Furthermore, whereas exposures such as marijuana, some analgesics, and certain medications for anxiety and depression during pregnancy have unclear teratogenic risk associations (Briggs & Freeman, 2014), participants perceived these exposures to have median birth defect risks of 14 – 70%.

It is unclear why teratogenic risk perceptions to common exposures are elevated. Some possibilities include stigmatization from the media, popular books dealing with pregnancy, and possible misinformation from uninformed physicians (Koren et al., 1993). Regardless, health care providers tend to be conservative with their advice, cautioning women to be on the safer side when in contact with exposures that may perpetuate elevated risk perceptions (Ratnapalan et al., 2003). In addition, there may be an increased sensitivity to exposures during pregnancy that could potentially distort the risk perception (Koren et al., 1993).

When demographic factors were taken into account, education was found to be significantly associated with specific exposures. The more educated an individual was, the lower the risk perception was for the general population risk, flu vaccine, and acetaminophen. While individuals with a higher level of education had more accurate risk perceptions, their risk perceptions were still elevated compared to the actual risk. There are many possible reasons why individuals with a higher level of education had a lower risk perception. First, health literacy increases with higher levels of educational attainment

(Kutner et al., 2006). In a study by Lupatteli et al. (2014), women with a lower health literacy level had a higher perceived risk for various exposures during pregnancy, including medications and herbal remedies. In addition, it may be that individuals with a higher level of education have more knowledge about exposures during pregnancy or seek resources that provide more information regarding pregnancy.

While the main focus of the study was to look at ethnic identity, there was no association found between the degree of ethnic identity and its influence on teratogenic risk perceptions. Women who were more strongly associated to their ethnic identity did not have a different risk perception compared to women weakly associated to their ethnic identity. Since ethnic identity in the MEIM is measured by evaluating how closely a participant relates and identifies with their ethnicity, such as how often an individual participates in cultural practices or how much pride the individual feels towards their ethnic group, the lack of association could be due to the expansion of multiculturalism in America, as well as participant acculturation. Acculturation refers to “a phenomena, which results when groups of individuals having different cultures come into continuous first-hand contact with subsequent changes in the original culture patterns of either or both groups” (Redfield et al., 1936). Even though cultural beliefs regarding the causes of birth defects have been largely studied, it is likely that these beliefs are fading due to acculturation in our population. Therefore, participants in our study may have a lower degree of ethnic identity due to various aspects of acculturation, such as being born in the United States, speaking English as their primary language, and attending school in the United States.

These findings have important implications for the genetic counseling profession. First, it reinforces the four basic skills of cultural competency within the genetic counseling

practice outlined by Uhlmann (2009): 1) an understanding of your own cultural code, 2) knowledge of your clients' way of perceiving reality, 3) attitude of humility that recognizes and appreciates the diversity of human cultures, and 4) ability to use other people's cultural codes as a counseling resource. While it is important for genetic counselors to be aware of how cultural beliefs may influence various aspects of personal healthcare beliefs and choices, such as specific teratogenic beliefs, it is equally important not to make assumptions based on counselor perceptions of patient ethnic identity. It would be presumptuous to determine a patient's understanding based on ethnic identity. The low degree of ethnic identity found in our study is a reminder that while specific healthcare beliefs may be influenced by culture, it is important to allow the patient to express her own personal healthcare beliefs and concerns, which can typically be clarified through effective communication.

Our finding emphasizes the importance of contracting in the genetic counseling session. Contracting goals in genetic counseling include eliciting client concerns, expectations, and perceptions as well as assessing a client's background, traditions, beliefs, attitudes, and values (Hampel et al., 2009). By doing so, genetic counselors are able to evaluate a patient's ability to understand health information and tailor explanations based on the patient's level of understanding. While education level and health literacy are closely linked, it is more valuable to allow a patient to express her understanding rather than simply knowing the patient's level of education. Open communication is important to a successful genetic counseling session.

Additionally, elevated risk perceptions not only still exist but also are exceedingly common. While genetic counselors can work towards correcting these misperceptions, much more needs to be done from a public health perspective. Genetic counselors must raise

awareness about this issue and provide education about teratogen counseling to various healthcare providers. Genetic counselors also have an important role to their patients because they have the requisite teratogen counseling training that can help them identify and address elevated risk perceptions that their patients may not have even recognized as being inaccurate and potentially anxiety-inducing. Teratogen information specialists affiliated with Teratogen Information Services (TIS), such as MotherToBaby, can also guide individuals in reducing elevated risk perceptions. Studies have shown that TIS are effective in correcting misinformation and reducing anxiety [Einarson et al., 2005; Hancock et al., 2007]. Genetic counselors are encouraged to explore patients' fears regarding exposures during pregnancy and provide resources for a local TIS to both healthcare providers and patients.

The results from our study can help genetic counselors understand the current trend in teratogenic risk perceptions in order to enhance the counseling session. Previous literature has shown that contact with certain exposures can cause psychosocial concerns, such as anxiety, guilt, and fear, that in extreme cases may lead some women to have terminations. By learning about these risk perceptions, we can better counsel our patients and guide them towards more accurate information. Understanding the background of our patients allows us to focus on effective and accurate risk communication. By doing so, we may reduce the anxiety, fear and even terminations based on misinformation.

Study Limitations

The sample reflects the demographics of lower to middle class women who are receiving prenatal care in Houston, Texas. There are multiple groups missing from our study. Women of all classes, ethnic groups, education levels, income levels, and languages should all be included. The study was provided in English, but in order to measure ethnic identity,

providing surveys in the patient's primary language would be favorable. Also, individuals have difficulty comprehending their own risk, and it is possibly due to low health literacy including fewer numeric skills and thus poor comprehension of percentages (Polifka et al., 1997). In addition, there are limitations in using visual analogue scales (VAS). Research has shown that the VAS showed high rates of non-completion and missing data (Couper et al., 2006). Also, since each VAS had prominent demarcations a 0%, 25%, 50%, 75%, and 100% to aid in the systematic interpretation of responses, some participants may have chosen these risk numbers simply because they were explicitly indicated.

Future Directions

In future studies, a larger and more diverse population among all demographic factors would be favorable. Additional studies involving a less homogenous population or a less acculturated population would provide more information regarding ethnic identity. Surveys could be distributed in other languages to overcome any language barriers. Additional studies to elicit where participants learned these elevated risks would be informative. In-depth personal interviews could provide more information as to why they perceive these risks to be so high.

Appendix A: Letter of Invitation



INFORMED CONSENT FORM TO TAKE PART IN RESEARCH
Title: The Influence of Ethnic Identification on Teratogenic Risk Perceptions
Letter of Information
(HSC-MS-15-0476)
Primary Investigator: Katie Chan

You are invited to take part in a research study called, "The Influence of Ethnic Identification on Teratogenic Risk Perceptions", conducted by Jennifer Lemons, of the University of Texas Health Science Center at Houston. For this research project, she will be called the Principal Investigator or PI.

The purpose of this study is to see if demographic factors such as ethnic identification influences teratogenic risk perceptions. If you decide to take part in the study the total time commitment is 10 minutes. You are invited to take part in this study because you are pregnant and you have an OB/GYN appointment today. You can refuse to answer any questions asked or written on any forms. Participation in this study is voluntary. A decision not to take part in this study will not change the services or your employment with UT Health.

If you agree to take part in this survey you will agree to a 10 minute survey.

You may not receive any benefit from taking part in this study. The information you provide will help us better understand the role of ethnic identification in teratogenic risk perceptions. There are no known risks to take part in this study. The only possible risk may be stress or anxiety when thinking about ethnic culture or teratogenic risks. This information collected will not contain identifying information. You have the alternative to choose to not take part in this study and can withdraw at any time.

There is no cost and you will not be paid to take part in this study. You will not be personally identified in any reports or publications that may result from this study. Any personal information about you that is gathered during this study will remain confidential to every extent of the law.

If you have any questions about this project please contact Jennifer Lemons or Katie Chan at (713) 500-6801. You can also email at: Jennifer.M.Lemons@uth.tmc.edu or Katie.Chan@uth.tmc.edu.

If you agree to take part in the study your agreement is completion of the survey.

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston (HSC-MS-15-0476)
For any questions about research subjects rights call CPHS at (713) 500-7943.

Appendix B: Survey

Directions: Please answer the following questions by filling in the blank or marking the best answer.

Date: ____/____/____

Part I: Demographic Information

1. Is English your primary language? ☐ Yes or ☐ No
 - a. If no, what is your primary language? _____
2. What is the due date of your current pregnancy? ____/____/____ (If you are not currently pregnant, do not continue the survey. Please give the survey back to the receptionist.)
3. What is your age? _____ years
4. Including this pregnancy, how many times have you been pregnant? _____
 - a. How many of your previous pregnancies were:
 - Born living: _____
 - Miscarriages: _____
 - Stillbirths (Not alive at birth): _____
 - Elective abortions: _____
 - Child deaths (Born living, passed away after birth): _____
5. What is the highest level of education you have completed?

<input type="checkbox"/> Did not go to high school	<input type="checkbox"/> Some college or 2 year/associates degree
<input type="checkbox"/> Some high school	<input type="checkbox"/> 4-year college graduate
<input type="checkbox"/> High school graduate or GED	<input type="checkbox"/> Graduate or Professional degree
6. What is your current marital status?

<input type="checkbox"/> Single, never married	<input type="checkbox"/> Divorced
<input type="checkbox"/> Married or domestic partnership	<input type="checkbox"/> Widowed
<input type="checkbox"/> Separated	
7. What is your current work status?

<input type="checkbox"/> Working outside of home	<input type="checkbox"/> Student
<input type="checkbox"/> Working from home	<input type="checkbox"/> Military
<input type="checkbox"/> Stay-at-home mother	<input type="checkbox"/> Unable to work
<input type="checkbox"/> Unemployed	
8. Which category best describes your annual household income?

<input type="checkbox"/> Less than \$24,999	<input type="checkbox"/> \$200,000 or more
<input type="checkbox"/> \$25,000 to \$49,999	<input type="checkbox"/> \$_____ every 2 weeks
<input type="checkbox"/> \$50,000 to \$99,999	<input type="checkbox"/> Decline to answer
<input type="checkbox"/> \$100,000-\$199,999	
9. Including yourself, how many total people are in your household?

<input type="checkbox"/> 1	<input type="checkbox"/> 5
<input type="checkbox"/> 2	<input type="checkbox"/> 6
<input type="checkbox"/> 3	<input type="checkbox"/> 7 or more
<input type="checkbox"/> 4	

10. What is your religious affiliation?

- ☐ Agnostic
- ☐ Atheist
- ☐ Buddhist
- ☐ Catholic
- ☐ Christian
- ☐ Hindu
- ☐ Jewish

- ☐ Mormon
- ☐ Muslim
- ☐ Orthodox
- ☐ Protestant
- ☐ Unaffiliated
- ☐ Other: _____

11. What is your country of birth? _____ (If born in the USA, please continue to Part II.)

a. If you were not born in the USA, how old were you when you first moved to the USA? _____ years

b. How much total time have you lived in the USA? _____ years

Part II: Multigroup Ethnic Identity Measure (MEIM)

In the USA, people come from many different countries and cultures, and there are several different words to describe the different backgrounds, or ethnic groups, that people come from. Some examples of the names of ethnic groups are: Hispanic or Latino, Brazilian, Black or African American, Ethiopian, Asian American, Chinese, Filipino, American Indian, Pakistani, Mexican American, Caucasian or White, Italian American, German and many others. These questions are about your ethnicity, or your ethnic group, and how you feel about it or react to it.

Please fill in:

In terms of ethnic group, I consider myself to be: _____.

Use the numbers below to indicate how much you agree or disagree with each statement.

(4) Strongly agree (3) Agree (2) Disagree (1) Strongly disagree

- 1- I have spent time trying to find out more about my ethnic group, such as its history, traditions, and customs. _____
- 2- I am active in organizations or social groups that include mostly members of my own ethnic group. _____
- 3- I have a clear sense of my ethnic background and what it means for me. _____
- 4- I think a lot about how my life will be affected by my ethnic group membership. _____
- 5- I am happy that I am a member of the group I belong to. _____
- 6- I have a strong sense of belonging to my own ethnic group. _____
- 7- I understand pretty well what my ethnic group membership means to me. _____
- 8- In order to learn more about my ethnic background, I have often talked to other people about my ethnic group. _____
- 9- I have a lot of pride in my ethnic group. _____
- 10- I participate in cultural practices of my own group, such as special food, music, or customs. _____
- 11- I feel a strong attachment towards my own ethnic group. _____
- 12- I feel good about my cultural or ethnic background. _____

13- My ethnicity is

- (1) Asian or Asian American, including Chinese, Japanese, and others
- (2) Black or African American
- (3) Hispanic or Latino, including Mexican American, Central American, and others
- (4) White, Caucasian, Anglo, European American; not Hispanic
- (5) American Indian/Native American
- (6) Mixed; Parents are from two different groups
- (7) Other (write in): _____

14- My father's ethnicity is (use numbers above): _____.

15- My mother's ethnicity is (use numbers above): _____.

Part III: Personal Views Of Risk for Certain Exposures During Pregnancy

Directions:

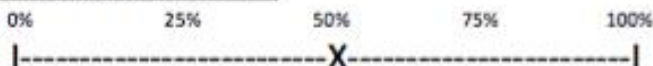
For each of the following, what is the overall chance the exposure in each example can cause a birth defect? Birth defects are changes in the expected development of a baby that can sometimes cause serious health problems. Examples include heart defects, cleft lip/palate, clubfoot, an opening along the spine, called spina bifida, and more. Please mark an **X** along the scale to indicate your answer, as seen in the examples below. Then, choose your answer for the questions following each exposure.

Examples:

10 % Chance For Birth Defects

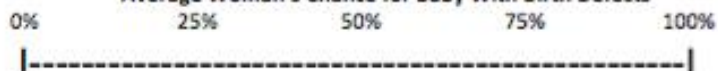


50 % Chance For Birth Defects

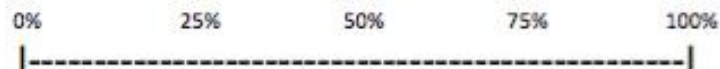


12. What is the average woman's chance for having a baby with a birth defect?

Average Woman's Chance for Baby With Birth Defects



Chance Alcohol Can Cause Birth Defects



13a. Alcohol

- b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐ Yes or ☐ No
- c. Does the amount of alcohol make a difference? ☐ Yes or ☐ No

Chance Cold Medicines Can Cause Birth Defects

0% 25% 50% 75% 100%

14a. Cold/Flu Medicines |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of cold medicine make a difference? ☐Yes or ☐No

Chance Flu Vaccine Can Cause Birth Defects

0% 25% 50% 75% 100%

15a. Flu Vaccine |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the type of vaccine make a difference? ☐Yes or ☐No

Chance Marijuana Can Cause Birth Defects

0% 25% 50% 75% 100%

16a. Marijuana |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of marijuana make a difference? ☐Yes or ☐No

Chance Meth Can Cause Birth Defects

0% 25% 50% 75% 100%

17a. Methamphetamine ("Meth") |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of methamphetamine make a difference? ☐Yes or ☐No

Chance Tylenol Can Cause Birth Defects

0% 25% 50% 75% 100%

18a. Tylenol (Acetaminophen) |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of Tylenol make a difference? ☐Yes or ☐No

Chance Advil Can Cause Birth Defects

0% 25% 50% 75% 100%

19a. Advil (Ibuprofen) |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of Advil make a difference? ☐Yes or ☐No

20a. Medications for Anxiety or Depression (e.g., Zoloft, Wellbutrin, etc.)

Chance Anxiety/Depression Medications Can Cause Birth Defects

0% 25% 50% 75% 100%

|-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of anxiety/depression medication make a difference? ☐Yes or ☐No

d. Does the type of anxiety/depression medication make a difference? ☐Yes or ☐No

Chance Smoking Cigarettes Can Cause Birth Defects

0% 25% 50% 75% 100%

21a. Smoking cigarettes |-----|

b. Does the timing (beginning, middle, end) during a pregnancy make a difference? ☐Yes or ☐No

c. Does the amount of cigarettes make a difference? ☐Yes or ☐No

22. On a scale from 0-10 (0=Not at all; 10=All the time), how much do you feel your ethnic group influences what you believe can cause birth defects? Please circle your answer on the scale below.

0 1 2 3 4 5 6 7 8 9 10

23. If you would like, you may explain any of your answers to Part III in the space provided below:

24. Are there any other exposures during pregnancy that you feel may cause a birth defect? If yes, please explain in the space provided below:

If you have any questions or concerns, Texas TIPS is a free and confidential telephone counseling service that provides information about exposures related to pregnancy and breastfeeding. You can call Texas TIPS at 1-855-884-7248, submit an online form at <https://med.uth.edu/texastips/>, or email at TexasTips@uth.tmc.edu.

References

- Briggs, G.G. & Freeman, R. K. (2015). *Drugs in Pregnancy and Lactation: a Reference Guide to Fetal and Neonatal Risk*. Philadelphia, PA: Lippincott Williams & Wilkins.
- Centers for Disease Control and Prevention. (2008). Update on Overall Prevalence of Major Birth Defects--Atlanta, Georgia, 1978-2005. *MMWR Morb Mortal Wkly Rep*, 57(1):1-5.
- Cohen, L. H., Fine, B. A., & Pergament, E. (1998). An assessment of ethnocultural beliefs regarding the causes of birth defects and genetic disorders. *Journal of Genetic Counseling*, 7(1), 15-29.
- Collaborative Group on Drug Use in Pregnancy. An international survey on drug utilization during pregnancy. *International Journal of Risk and Safety in Medicine* 1991;1:1.
- Couper, M. P., Tourangeau, R., Conrad, F.G., & Singer, E. (2006). Evaluating the effectiveness of visual analog scales: a web experiment. *Social Science Computer Review*, 24: 227-245.
- Einarson, A., Schachtschneider, A., Halil, R., Bollano, E., Koren, G. (2005). SSRI's and other antidepressant use during pregnancy and potential neonatal adverse effects: impact of a public health advisory and subsequent reports in the news media. *BMC Pregnancy Childbirth*, 20, (5): 11.
- Finer, L. B., & Zolna, M. R. (2011). Unintended pregnancy in the United States incidence and disparities, 2006. *Contraception*, 84(5), 478-485.
- Hampel, H., Grubs, R. E., Walton, C. S., Nguyen, E., Breidenbach, D. H., Nettles, S., Callanan, N., Corliss, M., Fox, S., Hiraki, S., Ku, L., Neufeld-Kaiser, W., Riler, B.,

- Taylor, J., & Weik, L. (2009). Genetic Counseling Practice Analysis. *Journal of Genetic Counseling*, 18(3), 205-216.
- Hancock, R. L., Koren, G., Einarson, A., & Ungar, W. J. (2007). The effectiveness of Teratology Information Services (TIS). *Reproductive Toxicology*, 23(2), 125-132.
- Koren, G., Bologa, M., & Pastuszak, A. (1993). How Women Perceive Teratogenic Risk and What They Do about It. *Annals of The New York Academy of Sciences*, 678, 317-324.
- Kutner, M., Greenberg, E., Jin, Y., and Paulsen, C. (2006). The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483). U.S. Department of Education. Washington, DC: National Center for Education Statistics
- Lee, J. E., Lemyre, L., Turner, M.C., Orpana, H.M., & Krewski, D. (2008). Health risk perceptions as mediators of socioeconomic differentials in health behavior. *Journal of Health Psychology*, 13(8), 1082-91.
- Lenz, W. (1962). Thalidomide and congenital abnormalities. *Lancet*, 1:45.
- Lupattelli, A., Picinardi, M., Einarson, A., & Nordeng, H. (2014). Health literacy and its association with perception of teratogenic risks and health behavior during pregnancy. *Patient Education and Counseling*, 96(2), 171-178.
- Martin, J. A., Hamilton, B. E., Osterman, M. J., Curtin, S. C., & Mathews, T. J. (2015). Births: Final Data for 2013. *National Vital Statistics Reports*, 64(1), 1-65.
- Mazzotta, P., Magee, L. A., Maltepe, C., Lifshitz, A., Navioz, Y., & Koren, G. (1999). The perception of teratogenic risk by women with nausea and vomiting of pregnancy. *Reproductive Toxicology*, 13(4), 313-319.

- McBride, W.G. (1961). Thalidomide and congenital abnormalities. *Lancet*, 2:1358.
- Meyerson, M. D. (1990). Cultural considerations in the treatment of latinos with craniofacial malformations. *Cleft Palate Journal*, 27(3), 279-288.
- Moore, K., & Persaud, T. (2008). *The Developing Human: Clinically Oriented Embryology* (8th ed.). Philadelphia, PA: Saunders.
- Nava-Ocampo, A. A., & Koren, G. (2007). Human Teratogens and Evidence-based Teratogen Risk Counseling: The Motherisk Approach. *Clinical Obstetrics and Gynecology*, 50(1), 123-131.
- Nordeng, H., Ystrom, E., & Einarson, A. (2009). Perception of risk regarding the use of medications and other exposures during pregnancy. *European Journal of Clinical Pharmacology*, 66(2), 207-214.
- Obican, S., & Scialli, A.R. (2011). Teratogenic Exposures. *American Journal of Medical Genetics*, 157, 150-169.
- Phinney, J. S. (1992). The Multigroup Ethnic Identity Measure: A New Scale for Use with Diverse Groups. *Journal of Adolescent Research*, 7, 156-176.
- Phinney, J. S. & Ong, A.D. (2007). Conceptualization and Measurement of Ethnic Identity: Current Status and Future Directions. *Journal of Counseling Psychology*, 54(3), 271-281.
- Polifka, J. E., Faustman, E. M., & Neil, N. (1997). Weighing the risks and the benefits: A call for the empirical assessment of perceived teratogenic risk. *Reproductive Toxicology*, 11(4), 633-640.

- Ratnapalan, S., Bona, N., Chandra, K., & Koren, G. (2003). Physicians' perceptions of teratogenic risk associated with radiography and CT during early pregnancy. *American journal of roentgenology*, 182 (5), 1107-9.
- Redfield, R., Linton, R., & Herskovits, M. (1936). Memorandum on the study of acculturation. *American Anthropologist*, 38, 149–152.
- Sanz, E., Gomez-Lopez, T., & Martinez-Quintas, M. J. (2001). Perception of teratogenic risk of common medicines. *European Journal of Obstetrics & Gynecology and Reproductive Biology*, 95(1), 127-131.
- Substance Abuse and Mental Health Services Administration, Results from the 2013 National Survey on Drug Use and Health: Summary of National Findings, NSDUH Series H-48, HHS Publication No. (SMA) 14-4863. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.
- Tajfel, H. (1981). *Human groups and social categories*. Cambridge, England: Cambridge University Press.
- Uhlmann, W., Schuette, J., & Yashar, B. (2009). *A Guide to Genetic Counseling (2nd ed.)*. Hoboken, New Jersey: Wiley-Blackwell.

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