Knowledge-base of Hispanic Women about Neural Tube Defects and

Folic Acid Supplementation

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By:

Brian Allen

Department of Psychology

Texas State University

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Folic Acid Supplementation

Approved:

Dr. Heather C. Galloway Director, Mitte Honors Program

Approved:

Dr. Harvey Ginsburg Department of Psychology Supervising Professor

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Abstract

Rates of neural tube defects (NTDs) are up to six times higher than the national average in women of Hispanic ethnicity. This is especially true for Hispanic women of low socioeconomic status residing in the border region of South Texas. A definitive reason for these increases is not clear. Genetic and environmental factors affecting the metabolism of folic acid, a nutrient essential for proper neural tube formation, are most often attributed as the source cause. It is clear that a general ignorance towards folic acid intake prior to pregnancy, catalyzed by insufficient pre-natal care, may be to blame. The focus of this study is to represent the current knowledge base of the local Hispanic population of Texas State in order to establish preliminary statistics for the knowledge base of Hispanic women with respect to folic acid supplementation, neural tube defects, and the ability of folic acid supplementation in serving to significantly inhibit the neural tube defects in a statistically significant way. If this study yields a limited knowledge base to the issues stated within the Hispanic population of Texas State, a population whose level of education surpasses that of the border region de facto, then it would certainly suggest the inadequacies of the medical and pre-natal community in properly addressing the issue of educating Hispanic populations about the risks involved with not appropriately supplementing their diets with folic acid.

Knowledge-base of Hispanic Women about Neural Tube Defects and Folic Acid

Supplementation

The early 1990's saw a dramatic increase in the prevalence of the phenomenon known as a neural tube defect in infants born to the population of Hispanic women living in the valley region of southern Texas, most notably in Cameron county. Interestingly, the number of affected individuals during this time period was heavily oriented towards to women of Hispanic origin. In general, women of Hispanic origin are six times more likely to have a neural tube defect (Miller & Conko 2006). This statistic raises a question of difference. That is, what is it about Hispanic women, in this particular area of the United States, which had made that population especially susceptible to a neural tube defect (NTD) malformation? A number of potential risk factors have been postulated to account for why these malformations had occurred more frequently in the border Hispanic population. The leading current theory revolves around the insufficient intake of the vitamin B9 called pteroylglutamic acid or more commonly, folic acid. This vitamin, if integrated into the diet of a female three months prior to conception via supplement or dietary incorporation, should significantly reduce the occurrence of a NTD during the course of a pregnancy. Aside from folic acid deficiencies, other key elements may also attribute significantly to the occurrence of a NTD. These factors of susceptibility include: age, race, obesity, socio-economic status, medical disorders i.e. diabetes, drug use, environmental factors i.e. toxins, and a possible genetic proclivity towards the inability to properly metabolize folic acid, which, as previously stated, has been found to be intimately related to whether or not a NTD will occur. The other major factor that appears

to be less mechanical and more circumstantially related to the prevalence of NTD in the Hispanic community is that of ignorance regarding the issue. Limited healthcare and a lack of education via language barrier, financial income, and poor access to informative sources, all seem to correlate highly with the primary population afflicted by this disorder.

In addition to the dramatic increase in the prevalence of neural tube defects in the early part of the last decade, a marked decrease was experienced for several years intermittent to the present, when in recent years, the rate of NTD occurrence began to rise again in the same locations without a verifiable explanation. More current NTD statistics show a prevalence of 13.4 per 10,000 as a relatively constant number post the initial Epidemic count of 26 per 10,000 noted in 1991 (Hendricks 1999). Furthermore, recent literature (Harris and Shaw 1995) has shown that in certain populations of Hispanic women, folic acid supplementation has had no effect on the rate of NTD, thus mandating the presence of a confound serving to effectively nullify the effects of any folic acid supplementation. These occurrences have served to only further confuse the true cause and functional treatment for a NTD. The drastic rise in incident in the present also makes researching the factors listed above more important due to the current rate of affliction found within the Hispanic population in the valley region of southern Texas.

The focus of the study presented in this report intends to represent the current knowledge base of the variables listed above as well as to administer a study sampling the local Hispanic population of Texas State in order to establish a preliminary statistic for the knowledge base of Hispanic women with respect to folic acid supplementation,

neural tube defects, and the ability of folic acid supplementation in serving to significantly inhibit the neural tube defects in a statistically significant way. If this study yields a limited knowledge base to the issues stated within the selected Hispanic population, then it would certainly suggest the inadequacies of the medical and pre-natal community in properly addressing the issue of educating Hispanic populations about the risks involved with not appropriately supplementing their diets with folic acid. Aside from this issue, the study will provide preliminary data for a pilot program which will be used to address NTD prevalence within the general Hispanic population. The purpose of administering this test on Hispanics only, results from the dramatically higher rates of NTD prevalence found within that population. The birth defects rates found in other ethnicities may be deemed normal (5 per 10,000) and not significant enough to warrant study in light of comparison to Hispanic individuals (16-26 per 10,000) (TDH 1991). Furthermore, for logistical reasons the Hispanic population of Texas State, which may be consider a close approximation to the border-Hispanic population will be used for this preliminary research. Again, comparing a Hispanic population to others is irrelevant to this study, considering the marked difference between Hispanic rates and that of other ethnicities.

A neural tube defect is a malformation of the neural tube during the first 28 days of pregnancy. The neural tube serves as the precursor to the central nervous system during the embryonic phase of pre natal development, and may occur as an "opened" or "closed" NTD. In an "open" NTD, a literal opening is found in the spinal cord or skull leaving the part of the brain or spinal cord exposed or missing; where the "closed"

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variety, which is much less common, results in skin covering similar malformations to that of the open.

The "open" occurs in three major varieties: anencephaly, spina bifida (myelomeningocele), and encephalocele (Duke Center for Human Genetics ND). Anencephaly is a medical condition where the critical parts of the central nervous system are missing, and is usually associated with the absence of the hypothalamus, forebrain, and large portions of the skull associated with the parietal, frontal and occipital lobes. As a side effect of this severe cranial malformation, visceral organs requiring hormonal signals from the developing brain also lack essential mechanical elements for their development. Infants born with this condition if not stillborn are permanently unconscious retaining only limited brain stem function (Fishman 2003).

The second other common condition, spina bifida, which is a spinal malformation that leaves the neural tube exposed to the environment, may occur along any point in the vertebra. This variety is generally treatable with surgery and may produce an increase in early mortality. Other possible side effects of this NTD may include motor and cognitive deficiencies as well as the failure of sphincter control (Padmanabhan, 2006).

Finally, Encephalocele is a herniation of the brain, dura matter, pia matter, or a combination of the three through the skull. This condition is often concurrent with spina bifida and may produce hydrocephalus (excess spinal fluid applying pressure on the brain), mental deficiencies including mental retardation as well as chiari (a malformation of the cerebellum) (Padmanabhan 2006, Fishman 2003).

The definitive cause of a neural tube defect is presently conjectured at best. It may be attributed, as stated before, to a number of causes mainly revolving around environmental forces acting upon genetic factors causing neural tube deficiencies expressed on chromosomes 7 and 10 during the embryonic period (Girolami 2005). There are many areas along the biochemical pathways that determine proper neural tube formation. Any gene mutation rendering integral enzymes or proteins ineffective may influence function and lead to the disorder.

Research has suggested that genetic factors alone may be responsible for an estimated 30 percent of spinal cord defects, involving a central malformation of a gene referred to as "shroom" (mushroom), which triggers cell embryos to conform into their neural tube state. This gene, in rat and frog studies, expressed a protein which elongated and curled the neural tube where expressed and left the neural tube flat where the protein was absent (Sanders, 2003). In instances where the expression of the protein is inhibited, malformation of the neural tube may be potentially observed. Other research has shown that the presence of a gene variant called C677T may increase the risk of a NTD by one and a half to two and a half times. The expression of this gene is manifested in the form of the enzyme 5,10-methylenetetrahydro –folate reductase (MTHFR), which is integral in the processing of folate, a constituent of folic acid that serves as a major component of proper neural tube folding. Around 50 percent of the North American and European populations carry at least one copy of this gene variant, but not all of them are afflicted by NTD. This would indicate that other undefined factors may be central to the degree in which this variant causes malfunction (Whitehead 1995).

This synthesis of MTHFR by C677T paired with the noted prevalence of the C677T variant in the genetic map of individuals suffering from a neural tube defect served to implicate lack of folate metabolism as a key factor in the disorder. However, this knowledge accounts for less than 50-70 percent of NTD prevalence (Padmanabhan 2006). A possible explanation for this is that some other biochemical factor in the metabolic processing of folate may be compromised to a mutant form. Such is found to be the case in the methionine synthase (MTR) and Methionine synthase reductase (MTRR) enzymes, which show a high prevalence of mutant form, producing excess homocysteine, in populations living on the border of the United States and Mexico (Zhu 2003). These enzymes, when functioning properly, essentially convert folate into a form that is used in the correct forming of the neural tube during the embryonic state (Brody 1999). When malfunctioning, they produce excess homocysteine, which is an alternate metabolic form of processed folate, despite the amount of folate included in the diet of a number of pregnant mothers of NTD affected fetuses (Mills 1995). One final point to make in NTD prevalence in correlation of insufficient folate uptake, is that of a protein present in the small intestine called reduced folate carrier (RFC). When the gene that produces this protein exists in a variant state, the functional form of this protein is compromised, leading to increased incidence of NTD (Zhao 2001). These well researched findings are a sample of the hundreds of possible gene mutant variations found in the general population that may induce NTD occurrence despite the amount of dietary folate included in a diet.

It is important to state that a NTD phenomenon does not follow the standard Mendelian model of inheritance. This conclusion is not surprising considering the high mortality rate in those afflicted by the more severe varieties of NTD. Those who suffer from the more mild conditions, i.e. spina bifida, are generally found to be incapable of reproduction (Padmanabhan 2006). Therefore, placing blame on a definitive contributing genetic factor by traditional means is a very difficult process. Observable trends within the affected population show increased rates within individuals who have trisomy autosomal chromosomes (3n instead of the normal 2n), and identical twins show higher rates of expression than fraternal twins. In addition, contrary to the suggested Mendelian patterns of dominant or recessive genetic expression NTD, which may be inferred to be an evolutionarily inferior "non-selected" trait, shows no decline in prevalence within the confines of studied family genetic trees. This observation compounded with the observed presence of over 100 mutant neurogenic gene variants identified so far within the human genome, and the probability that most people carry some of them, suggests that certain environmental factors help to determine the particular genetic epitope within an individual that regulates whether or not these variants are expressed resulting in a neural tube defect.

The discussion of environmental factors within the context of birth defects is well documented. For the sake of the scope of this study, environmental factors will be limited to those applicable to Hispanic populations located on the United States-Mexico border, who claim the highest NTD rates in the country (six times the national average). Essentially, it may be assumed that because of the generally impoverished conditions of the border Hispanic community compounded with cultural dietary confines, topographic location, an exceedingly hot environment, and occupations revolving around agrarian culture, the number of participating confounding interactions associated with malformation within the neural tube is astronomically high. It has been stated in several dietary studies of the Hispanic population of interior Mexico, that women do have an appropriate folic acid component in their diets (Harris and Shaw 1995). It seems that if this is the case, then environmental effects inhibiting the proper metabolism of folic acid metabolism must be at work within the population. Due to the relative homogeneous nature of the Hispanic populations of south Texas and Mexico on a genetic level, it may be assumed that these epistatic factors may apply to border Hispanics as well.

A good starting place for discussing environmental factors would begin with an examination of the local teratogenic factors that may be affecting the Hispanic population within the border region. These teratogenic factors produce an epistatic effect which interferes with the various reactions in the biochemical pathway of folate metabolism. It may be noted that a number of chemicals, which may be considered teratogenic in nature do exist commonly within the geographical location of the border region of Texas, most notably, fumonisin. The Hispanic border population is known to utilize a tremendously large portion of unprocessed corn products in their diet. A link exists between these products and neural tube defects via fumonisin, a myotoxin produced by the fungus fusarium that grows on the unprocessed maize that has been left in bins for long periods of time without being treated with proper pesticides (Missmer, Suarez, Felkner, Wang, Merrill, Rothman, and Handricks 2005). This unprocessed variety is consumed regularly

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by the border community and is used traditionally in the corn meal employed in the making of tortillas. The fumonisin toxin once ingested through these tortillas, which serve as a vector, has been shown to inhibit appropriate uptake of folic acid. The consumption of these contaminated tortillas led to a doubled increase in NTD rate for the studied populations (McEver 2006).

Another local teratogen linked to NTD occurrence comes from the Mexican side of the border. The industrial chemical polychlorinated bi-phenyl (PCB) has been suggested to cause even higher rates of NTD in the Hispanic population than fumonisin. This chemical has been identified, in unhealthy amounts, in the local fish population, drinking water, and cooking oils which are all utilized by the local population, and is associated with NTD, low birth weight, and other developmental issues. Upon the rectification of the extremely high PCB levels NTD rates dropped markedly (Saurez, Gilani, Felkner, Brender, Henry, Hendricks 2005).

Finally, there is evidence suggesting that high nitrate levels in drinking water facilitated by runoff from agricultural sites have a correlation with instances of birth defects in other areas of the world (Sever 1995). This finding would certainly hold congruent with the population of the valley-border region of South Texas and Northern Mexico, the latter of which has infamously side-stepped improvements in the vein of environmentally friendly pesticides and fertilizers.

The Saurez, Gilani, Felkner, Brender, Henry, Hendricks study (*et a 2005*) mentioned above raised the issue of socio-economic concerns as correlated factors with respect to NTD prevalence. Their findings suggest higher rates of NTD occurrence within Hispanic women of lower socio-economic class than those of a higher category. This conclusion was reached after examining age and income demographics for a number of counties in south Texas. The research found that young, poor, Hispanic women had a higher incidence rate of NTD than other comparable race demographics or socio-economic populations studied. A separate study via Wasserman, Shaw, Slevin, Gould, and Syme (et a 1998) contains similar findings. They noted that higher neural tube defect levels were linked to neighborhoods of a lower socio-economic status. They postulated that women reared in these environments were more susceptible to producing affected offspring than women in that same area but of a higher socio-economic status.

There are a variety of issues surrounding quality-of-life which separates high socio-economic and low socio-economic individuals. Clearly they may all be condensed to the single factor of income. It is obvious that higher income individuals may provide for themselves a higher grade diet, less exposure to harmful environmental factors i.e. contamination, and better health care. Based on the noted socio-economic difference in NTD occurrences between the social classes stated above, it is not too much of a stretch to assume that issues such as diet, exposure, and healthcare access are all determining factors for the observed difference.

The amount of folic acid determined to be minimal amount consumed daily by women of childbearing age is determined to be .4 mg daily (Texas Department of Health, ND). Certain foods contain higher amounts of folate than other foods. The majority of the daily consumed folate comes from fruits and vegetables, primarily beans. It is important to note that the preparation of these foods can drastically alter the folate content within these sources (Ohio State University Fact sheet, 2006). This means that heavily processed foods i.e. fast food, contain much less folate than is normally found within the fresh produce. It is clear that a link exists between poverty and obesity as well as lack of education as shown via Drewnowski and Specter (*et a 2004*). The primary correlating factor with obesity, in low income communities, has been shown to be high fat/high carbohydrate energy-dense foods (Uauy, Albala, and Kain 2001). Foods of this type are low in folate for the reasons listed above. Therefore, it may be verified logically that obesity and folate levels are inversely correlated within low socioeconomic families. This reasoning holds true to the findings of the Wasserman, Shaw, Selvin, Gould, and Syme and the Saurez, Gilani, Felkner, Brender, Henry, Hendricks studies. Further evidence of this comes from a 2006 study by Fernandez, Dutton, Ponder, Sosa, & Peltz, which found that low income border residence were more likely to be obese, physically inactive and failed to meet the daily suggested fruit and vegetable requirements, and remained lower than Caucasians in vegetable and fruit intake.

Diabetes is associated with obesity (Uauy, Albala, and Kain 2001) and has also been associated with NTD occurrence (Janssen 1996). This disease has also been found to exist in high proportions in border regions. Death rates from diabetes are abnormally high compared to the national average within this region (Pinkerton 2002).

Another by-product of low income is exposure to detrimental factors which may be avoided easily enough by individuals of a higher socioeconomic class. Low income individuals may be forced to live in less desirable real-estate exposing themselves to hazardous dump sites, radiation, and contaminated drinking water. Another welldocumented variable that is considered to be a factor in the prevalence of neural tube defects is hyperthermia (Birth Defects Epidemiology and Surveillance Texas Department of State Health Services 2007). It is easy to see how low income women who cannot afford air-conditioning or that hold jobs agrarian in nature are subjected to incredible heat throughout most of the year. Other labor intensive industrial jobs i.e. textile or other industries requiring frequent exposure to chemicals have also been linked with NTD occurrence (Castilla, Campana, & Camelo 2000). Finally, it may be noted that the cost required to visit a doctor, use vitamins, or eat healthy food is simply outside of the means of the impoverished border counties.

Despite all of the physical factors that appear to influence the occurrence of neural tube defects within individuals of low socioeconomic status, lack of healthcare may be the most significant contributing factor. It has been found that two-thirds of the border population does not have health insurance. In Brownsville, as of the year 2000, twenty-seven percent of the population lived below the poverty line. Along with this statistic thirty-one out of thirty-two border counties were deemed medically under staffed (Pinkerton 2002). This all adds up to a population subjected to minimal healthcare, comparable by some to the status of a third world country. The Pinkerton analysis had grim prospects for future intervention based on the fact that there is no money for doctors or other healthcare professionals to find work in the valley. Essentially, no health insurance means few reimbursements for doctors, which creates an environment in which doctors barely pay the bills in most instances. Aside from this fact the doctors that are in the valley are grossly overworked which is translated to the quality of care that the average border patient receives. These inadequacies also translate to lack of facilities where folic acid supplements may be obtained, or are either too expensive or far away that the ability of the average Hispanic to utilize the services that do exist is considerably reduced.

This inadequate healthcare support is readily felt regarding folic acid knowledge within the Hispanic community. In the studies conducted by (Canfield et a 2006) and Canfield, Anderson, Waller, Palmer, and Kaye (2002) only one-third of women were found to be regularly taking folic acid prior to and during pregnancy. More disconcerting was that the latter study found that Hispanic women were found not to take folic acid in spite of being informed by their primary care physicians of the consequences. This kind of non-adherent behavior seems to be common place among the Hispanic population with regard to medical advice, with non-adherence rates sitting around fifty percent (Antshel 2002). The three main reasons for this behavior as specified by the Antshel study are the treatment characteristics, disease attributes, and family/cultural issues. There also seems to be a disconnect between the physician and the patients due to cultural issues. Doctors are often distrusted by the border Hispanic population simply because of the perceived demeanor i.e. kinds of questions asked, impersonal contact. Aside from this, many Hispanics are described in the study as maintaining a deterministic point of view, attributing sickness and healing to the will of God.

Another troubling reason for the lack of cooperation with medical personnel demonstrated by the Hispanic community is ignorance. Most uneducated Hispanics do not understand the gravity of what it means to have cancer or some other possibly terminal condition. (Palmer et *al. 2005*) shows that Hispanic women who had less knowledge about breast cancer were five times less likely to have annual mammograms. Likewise, women of lesser education were found as a whole to take less folic acid than those of a high level. Astonishingly, less than fifteen percent of women knew to take folic acid before pregnancy, and less than sixteen percent knew why (Texas Department of Health 1999). Also within this study was information suggesting that the border region sees the lowest folic acid intake in women in the state. The level of ignorance towards folic acid supplementation suggests that their physician had not addressed the matter with them.

To validate this point an example may be drawn from the Bazargan, Bazargran, Farooq, and Baker study (*et a 2004*) on cervical cancer which demonstrated that only twenty-nine percent of individuals reported ever having heard a physician tell them that they need screening for cervical cancer. Among the population studied cost and inadequate advice from health care providers were listed as chief reasons not to have annual screenings.

It is necessary to determine several factors regarding folic acid intake, primarily the amount of folate that the average Hispanic woman consumes on a daily basis. Secondly, the average amount of knowledge that a Hispanic female knows about folic acid intake or NTD phenomena in general must be ascertained. A knowledge based questionnaire needs to be administered to an appropriate demographic in order to extrapolate how folic acid intake is being treated and if adequate knowledge about its associated benefits are being imparted to Hispanic females of child bearing age. If a lack of knowledge is found, how does that relate to the level of general medical care and socio-economic factors revolving around a general ignorance? The immediate answer would seem to indicate a failure and pre-natal community in properly addressing the issue of educating Hispanic populations about the risks involved with not appropriately supplementing their diets with folic acid, or the prevalence of NTD phenomena within their population demographic. The focus of the study presented in this report intends to sample the local Hispanic population of Texas State in order to establish a preliminary statistic for the knowledge base of Hispanic women of childbearing age with respect to folic acid supplementation, neural tube defects, and the ability of the prior in serving to significantly inhibit the latter in a statistically significant way. If this study yields a limited knowledge base to the issues stated within the Hispanic population of Texas State, a population whose level of education surpasses that of the border region de facto, then it would certainly suggest the inadequacies listed above.

Methods

Participants:

Approximately 150, 18-40 year old undergraduate Hispanic women at Texas State University will be recruited for this study. Selected participants may or may not have children. As stated before, the Texas State population has been selected for logistical reasons, but may be considered, as a Hispanic population, as a relative approximation to the population of the Texas-Mexico border.

Materials:

Psy 312c and Psy 316 will be utilized for the location of this study. A scale and Ruler will be used in order to approximate the body mass index of each participant. This data may be used as a covariable during analysis. A three part questionnaire and consent form will be given to the participants in order to obtain their knowledge regarding folate, NTD, and the connection between the two (see Appendix). The SPSS (Statistical Package for the Social Sciences) computer software will be used to analyze data. Five dollar gift cards from HEB & Wal-mart will be given to the participants as compensation for their participation. They will also be asked to sign a signature release form for the gift cards. *Procedures*:

Participants will be weighed and have their heights measured by a medical quality scale in order to ascertain their respective body mass index value. The participants will then be administered a knowledge-based questionnaire designed to extrapolate dietary habits as well as attitudes towards pregnancy/pre-natal care. In addition to these items, questions addressing their knowledge of folic acid supplementation, neural tube defects, and neural tube defect prevention will be included. Compensation will be received at the end of this study in the form of \$10 gift cards.

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Appendix Consent Form

Professor Roque V. Mendez, Texas State University Department of Psychology is conducting this investigation. The purpose of this study is to examine your attitudes, beliefs and knowledge about maximizing your opportunity for having a perfectly normal, healthy baby. The study requires about 45-60 minutes. In compensation, you will receive a \$10 gift card of your choice from HEB or Wal-Mart, upon completion of the study.

If participating in a study of this nature makes you feel uncomfortable for any reason, do not participate. If you decide to participate, you will be asked some biographical and family information, including any past pregnancies, pregnancy loss, and whether or not you use contraceptives as well as provide written comments and numerical ratings about family and social support, women you know who have had normal, healthy babies and any those having babies born with problems, your desire and timeline for having tour own baby or another one, actions you may plan preparing for a baby; persons and places where you could seek advice your own estimates of you weight, height, health, nutrition, typical groceries you buy, exercise, vitamins in foods and vitamin supplements, both now, before and during possible, future pregnancy; knowledge about family planning; and your sources of information about certain birth complications and how to help prevent them. You will be weighed and measured. You are not obligated to participate in this voluntary study and may withdraw at any time without penalty, this is your right.

This is an anonymous survey and individual responses will never be revealed to anyone, nor will your name appear in any part of the survey. Results will only be reported in aggregate. To affirm your understanding of your rights and willingness to take part in this study you must read and **understand** this consent form and provide your name and signature **only on the consent form**. To ensure your anonymity, the consent form will be collected separately from the surveys preventing your responses from being linked to you.

If you feel this study may distress you do not participate. In the event that any participant might experience distress, the contact information for the University Counseling Center is http://www.counseling.txstate.edu/ intro.html. Counselors are available. The email address is counseling.txstate.edu/ intro.html.

At the conclusion of the study, you will be **debriefed** and informed about the exact questions the study examined and what anticipated results may occur. You will be asked to describe and assess any possible risks and benefits of the study. The results of this study will be made available to you through your instructor or a posting outside of room 212C. In the event that you have any questions, please **contact** the principal investigator, Roque V. Mendez: email <u>rm04@txstate.edu</u> or at 512-245-2526. You will be provided with a copy of this signed informed consent form.

Thank You, Roque V. Mendez

Researcher's Signature

I have read and understand the consent form. I voluntarily agree to participate in the research.

Your Name (Printed)

Your Signature

Date

Questionnaire

Part A. Biographical Information

Years of Education

Marital Status

Children

Demographics

Age:

A. 18-21 B. 22-25 C. 26-29 D. 30-34 E. >35 Which best describes your families' income l\level: A. B. C.

D.

E.

Ethnicity

- A. Mexican-American
- B. African-American
- C. Asian-American
- D. Anglo-American
- E. Other (_____) please insert ethnicity

Country of origin

- A. United States
- B. Mexico

C. Other (_____) please insert country of origin

Family & Social Support Network:

Check all those that live in the same household with you

- a. _____ Husband or male companion
- b. ____ Children: How many? _____
- c. ____ Your Father
- d. _____ Your Mother
- e. _____ Husband's (or male companion)Father
- _____ Husband's (or male companion) Mother f.
- g. ____Grandparent: Which one? _____
- h. ____2nd Grandparent: Which one?
- i. _____ Brothers: How many? _____
- j. Sisters: How many?
- k. ____Husband's (or male companion) Brothers: How many? _____
- 1. _____ Husband's (or male companion) Sisters: How many? _____

_____ Other How many?

Check all those that provide for your household (give money, buy food, help you with the chores) and your relation with each person to you

- m. _____ Husband or male companion
- n. _____ Children: How many _____
- o. _____ Your Father
- p. _____ Your Mother
- q. _____ Husband's (or male companion)Father
- r. _____ Husband's (or male companion) Mother
- s. ____Grandparent: Which one? _____ t. ___2nd Grandparent: Which one? _____
- u. _____ Brothers: How many? _____
- v. _____ Sisters: How many? _____
- w. ____Husband's (or male companion) Brothers: How many? _____
- x. _____ Husband's (or male companion) Sisters: How many? _____

_____ Other How many?

Check all those that provide affect and emotional comfort to you.

- y. _____ Husband or male companion
- z. ____ Children: How many? _____
- aa. _____ Your Father
- bb. _____ Your Mother
- cc. _____ Husband's (or male companion)Father
- dd. Husband's (or male companion) Mother
- ee. ____Grandparent: Which one? _____
- ff. ____2nd Grandparent: Which one? _____
- gg. ____ Brothers: How many? _____
- hh. _____ Sisters: How many? _____
- ii. _____Husband's (or male companion) Brothers:
- jj. _____ Husband's (or male companion) Sisters:
- _____ Other How many?

List the first names of all the women you know who have had normal healthy newborn babies, how many babies each woman has had and how you know them (mother, aunt, cousin, in-law, friend, or just someone you know). If this applies to you include yourself by writing 'Me'.

First Names	How many babies	How you know them
1.		
2.		
3.		
4.		
5.		
б.		
7.		
8.		
9.		
10.		

List the first names of all the women you know who have had babies that were born premature, how many premature babies each woman has had and how you know them (mother, aunt, cousin, in-law, friend, or just someone you know). If this applies to you include yourself by writing 'Me'.

First Names	How many premature births	How you know them
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

List the first names of all the women you know who have had miscarriages or stillbirths, how many stillbirths or miscarriages each woman has had and how you know them (mother, aunt, cousin, in-law, friend, or just someone you know). If this applies to you include yourself by writing 'Me'.

First Names	How many miscarriages or stillbirths	How you know them
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

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List the first names of all the women you know who have had babies that were born with physical or other problems, the specific problem her newborn had and how you know each woman (mother, aunt, cousin, in-law, friend, or just someone you know). If this applies to you include yourself by writing 'Me'.

First Names	The specific problem	How you know them
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

Part B. General beliefs and motivation for having a perfectly normal healthy newborn baby

Do you want to have a baby? A. Yes B. No

If yes:

Estimate how much using a scale of 1 to 10 with 10 meaning that you very much want to have a baby.

(1-10 scale here)

Estimate how much by using a scale of 1 to 10 with 10 meaning that you want very much to maximize your opportunity to have a perfectly normal and healthy baby

(1-10).

If you want to have a baby, when:

- 1. (in the next 3 months from now)
- 2. 3-6 months
- 3. 6-12 months
- 4. 12-18 months
- 5. 18-24 months
- 6. 24-30 months
- 7. 30-36 months
- 8. 36-42 months
- 9. 42-48 months
- 10. > 4 years from now

If you answered 10 above (> 4 years from now) how many more years from now?

1. 4-6 2. 6-8 3. 8-10 4. 10-12 5. 12-14 6. 14-16 7. 16 -18 8. 18-20 9. 20-22 10. >22

Suppose that you were talking to a friend who said that having a perfectly normal healthy baby is determined by things that could be both under your control and things that could be beyond your control.

Please estimate how much of having a perfectly healthy baby could be under your control?

What do you think are your chances of your having a perfectly normal healthy newborn baby?

Part C – Potential Planned Actions

How much planning do you think is needed by you to maximize the opportunity for you to have a perfectly normal healthy newborn baby?

Estimate the amount of planning needed by you by using a scale of 1 to 10, with 1 representing very little planning to 10 representing very much planning

(1-10).

Describe what actions you could take to maximize the opportunity that you will have a perfectly normal healthy newborn baby.

1.
 2.
 3.
 4.
 5.
 6.
 7.
 8.
 9.
 10.
 (If you think of more than 10, please continue with 11)

3. Next, please review the list above (the actions you could take to maximize the opportunity that you will have a perfectly normal healthy newborn baby), and rank the relative importance of each of the actions below. On one (1) list what action you believe to be most important, on two (2) the next most important, and so on, until the least important action is listed.

(Most important) 1. 2. 3. 4. 5. 6. 7. 8. 9. 10 (Less important)

If you wrote more than 10 actions, write the remaining ones here starting with 11. Continue your rankings until the least important one is assigned a number.

Can you think of anything else that you could do to maximize the likelihood that you will have a perfectly healthy newborn baby? Please write it here.

<u>What</u> things could you do at each of the timeline points below to have a perfectly healthy baby? The timeline below shows the months preceding the birth of your baby. Fill in what you would do at each of them to maximize having a perfectly normal healthy baby:

- 1. During birth:
- 2. During labor:
- 3. During the last three months of pregnancy (third trimester)
- 4. During the middle three months (second trimester)
- 5. During the first three months (first trimester)
- 6. During implantation of the fertilized egg to the uterus wall.
- 7. During conception
- 8. 3 months before conception
- 9. 6 months before conception
- 10. 12 months before conception

Part D: SEEKING ADVICE

Who could you talk to about maximizing your opportunity for having a perfectly normal healthy baby?

Where could you go to find out what to do and when to do it? Start with the (1) top specific source (person, place or media) that could provide you the best advice and information: (Most important first)

1. 2. 3. 4. 5. 6. 7. 8. 9. 10 (Less important last) **Part E:** HEALTH

SELF-ESTIMATED WEIGHT

How much do you weigh in pounds?

SELF-ESTIMATED HEIGHT

How tall are you in feet and inches?

How many pounds could you gain or lose to prepare for your pregnancy? (select one)

Lose _____

Gain _____

How many pounds could you gain or lose during pregnancy to maximize your opportunity of having a perfectly normal newborn baby? (select one)

Lose _____

Gain	
EXERCISE	

Describe the kinds of exercise you getting now, how often and for how long.

	Kind of exercise	How long (per session)	How often (per week)
1.			
2.			
3.			
4.			
5.			

What, if any, exercises would you begin or stop at each of the timeline points below to maximize your opportunity of having a perfectly normal healthy newborn baby?

During the last three months of pregnancy (third trimester)

During the middle three months (second trimester)

During the first three months (first trimester)

3 months before pregnancy

6 months before pregnancy

12 months before pregnancy

Part F: NUTRITION - GENERAL

Consume means to take substances into your body by swallowing, by smoking, or injecting. This could include swallowing solid foods, liquids, pills, capsules, etc.

List the 10 most important things that you consume now that you could reduce or stop consuming to maximize your opportunity of having a perfectly normal healthy newborn baby. (What could you consume less or stop consuming completely?)

1. 2. 3. 4. 5. 6. 7. 8. 9. 10.

List the 10 most important things that you consume now that you could continue consuming to maximize your opportunity of having a perfectly normal newborn baby.

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1.

- 2. 3.
- 3. 4.
- ч. 5.
- *6*.
- 7.
- 8.
- 9.
- 10.

List the 10 most important things that you <u>do not</u> consume now that you could start consuming to maximize your opportunity of having a perfectly normal newborn baby. (What could you add)? 1.

2.

3.

- *4*.
- 4.
- 5.
- 6.
- 7.
- 8. 9.
- 10.

List 10 grocery items that you are most likely to buy, if you were to go shopping for groceries now.

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7. 8.
- o. 9.
- 10.

List the 10 grocery items that you are most likely to buy if you could be pregnant three to six months from now.

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

Knowledge and Experience with Folic Acid:

Have you heard or read anything about Folic Acid?

A. Yes B. No

From what source have you heard about Folic Acid? Check all that apply.

А.	TV
B.	Radio
C.	Magazine, Newspaper
D.	Husband (Male companion)
E.	Mother
F.	Father
G.	Sister
H.	Brother
I.	Friend
J.	Sister in law
K.	Brother in law
L.	Neighbor

M. ____Other

13. Have you ever taken Folic Acid supplements in the past? A. Yes B. No

14. Do you currently take any mineral or vitamin supplements? A. Yes B. No

Do you think that you are getting enough vitamins?

A. Not enough	B. Just enough	C. More than enough

Which grains, fruits or vegetables are richest in folic acid?

A. B. C. D. E.

Knowledge about neural tube birth defects

Have you hear or read anything about Neural Tube Defects? A. Yes B. No

Have you heard or read anything about Folic Acid preventing Neural Tube Defects?

A. Yes B. No

From what sources have you heard about Folic Acid preventing Neural Tube Defects? Check all that apply.

- N. ____TV
- O. ____Radio
- P. ____Magazine, Newspaper
- Q. ____Husband (Male companion)
- R. ____Mother
- S. ____Father
- T. ____Sister
- U. ____Brother
- V. ____Friend
- W. _____Sister in law
- X. ____Brother in law
- Y. ____Neighbor
- Z. ____Other

When should a woman, who plans to get pregnant, begin to take Folic Acid?

- A. At least, one to three months prior to pregnancy
- B. At least, one month prior to pregnancy
- C. At pregnancy
- D. At least, one month after pregnancy
- E. At least, three months after pregnancy

What is the minimum Folic Acid intake that is needed to prevent Neural Tube Defects?

- A. 50 micrograms
- B. 100 micrograms
- C. 200 micrograms
- D. 300 micrograms
- E. 400 micrograms

24. Has anyone in your family ever had Neural Tube Complications? A. Yes B. No

25. Have you ever had Neural Tube Complications? A. Yes B. No

List the first names of all the women you know who have had babies born with neural tube defects. These defects include an open spine (spina bifida) or an open skull (anencephaly). Also, note how many babies with neural tube defects each woman has had and how you know them (mother, aunt, cousin, in-law, friend, or just someone you know). If this applies to you include yourself by writing 'Me'.

First Names	How many births with neural tube defects	How you know them
	defects	
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

History:

Are you currently pregnant? A. Yes B. No Have you ever been pregnant? A. Yes B. No If you answered yes to 2, how many times in the past have you been pregnant? A. One B. Two C. Three D. Four E. Five or more Do you want to get pregnant? A. Yes B. No If you answered yes to above, how soon do you want to get pregnant? Have you ever heard of family planning? A. Yes B. No If yes, what kind of information do you think could be provided at a family planning clinic? List" 1. 2. 3. 4. 5. Have you ever been to family planning clinic? A. Yes B. No If yes, what kind was it? A. Public (County or State Health or Family PlanningClinic) B. Private (Privately owned) C. Church (Faith-based) D. Do you use Oral Contraceptives? A. Yes B. No Do you use other forms of Contraception? A. Yes B. No Have you ever had a pregnancy loss? A. Yes B. No If so, explain_____ B. Yes, Type I C. Yes, Type II Are you diabetic? A. No Locus of Control Scale subscales: Indicate the degree to which you strongly disagree or strongly agree with each item below. Using Likert scale below 1 2 3 4 5 Strongly disagree Strongly Agree Disagree Agree

- 31. If I get sick, it is my own behavior which determines how soon I get well again.
- 32. No matter what I do, if I am going to get sick, I will get sick.
- 33. Most things that affect my health happen to me by accident.
- 34. I am in control of my health.
- 35. When I get sick, I am to blame.
- 36. Luck plays a big part in determining how soon I will recover from an illness.
- 37. My good health is largely a matter of good fortune.
- 38. The main thing which affects my health is what I myself do.
- 39. If I take care of myself, I can avoid illness.
- 40. No matter what I do, I 'm likely to get sick.
- 41. If it's meant to be, I will stay healthy.
- 42. If I take the right actions, I can stay healthy.

Social Support questionnaire: Using the Likert scale below, indicate the extent to which you strongly disagree to strongly agree with each of the items below.

1	2	3	4	5
Strongly disagree	Disagree		Agree	Strongly Agree

- 43. There is a special person who is around when I am in need.
- 44. There is a special person with whom I can share my joys and sorrows.
- 45. My family really tries to help me.
- 46. I get the emotional help and support I need from my family.
- 47. I have a special person who is a real source of comfort to me.
- 48. My friends really try to help me.
- 49. I can count on my friends when things go wrong.
- 50. I can talk about my problems with my family.
- 51. I have friends with whom I can share my joys and sorrows.
- 52. There is a special person in my life who cares about my feelings.
- 53. My family is willing to help me make decisions.
- 54. I can talk about my problems with my friends.