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Knowledge and Expectations of Support People in Prenatal Genetic Counseling Sessions

Michelle A. McDougale

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KNOWLEDGE AND EXPECTATIONS OF SUPPORT PEOPLE IN PRENATAL
GENETIC COUNSELING SESSIONS

by

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KNOWLEDGE AND EXPECTATIONS OF SUPPORT PEOPLE IN PRENATAL
GENETIC COUNSELING SESSIONS

A

THESIS

Presented to the Faculty of
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of the Requirements

for the Degree of

MASTER OF SCIENCE

by

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KNOWLEDGE AND EXPECTATIONS OF SUPPORT PEOPLE IN PRENATAL GENETIC COUNSELING SESSIONS

Publication No. _____

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Prenatal genetic counseling patients have the ability to choose from a myriad of screening and diagnostic testing options, each with intricacies and caveats regarding accuracy and timing. Decisions regarding such testing can be difficult and are often made on the same day that testing is performed. Therefore, it is reasonable to consider that the support people brought to an appointment may have a role in the decision-making process. We aimed to better define this potential role by examining the incoming knowledge and expectations of support people who attended prenatal genetic counseling appointments.

Support people were asked to complete a survey at one of seven Houston area prenatal clinics. The survey included questions regarding demographics, relationship to patient, incoming knowledge of the appointment, expectations of decision-making and perceived levels of influence over the decisions that would be made during the counseling session.

The majority (79.4%) of the 252 participants were spouses/partners. Overall, there was poor knowledge of the referral indications with only 33.5% of participants correctly identifying the patient's indication. Participants had even poorer knowledge of testing options that would be offered during the session, as only 17.7% were able

to correctly identify testing options that would be discussed during the genetic counseling session. Of participants, just 3.6% said that they did not want to be included in discussions about screening/testing options. Only a few participants thought that they had less influence over decisions related to the pregnancy than over non-pregnancy decisions. Participants who reported feeling like they had a higher level of influence were likely to attend more of the pregnancy-related appointments with the patient.

Findings from this study have provided insight into the perspective of support persons and have identified gaps in knowledge that may exist between the patients and the people they choose to bring with them into the genetic counseling session. In addition, this study is a starting point to assess how much the support people think that they impact the decision-making process of prenatal genetic counseling patients versus how much the prenatal patients value the input of the support people.

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Abbreviations

AMA – Advanced maternal age

CVS – Chorionic villus sampling

FHx – Family history

FTS – First trimester screening

GC – Genetic counselor

NIPT – Non-invasive prenatal testing

US – Ultrasound

UTHSC – University of Texas Health Science Center at Houston

Introduction

At a time when the field of genetics is constantly growing and changing, prenatal genetic counseling patients have the ability to choose from a myriad of screening and diagnostic testing options which include, but are not limited to, fetal comprehensive ultrasound (US), first trimester screening (FTS), chorionic villus sampling (CVS), genetic amniocentesis, and noninvasive prenatal testing (NIPT). There are intricacies and caveats regarding accuracy and timing of each available testing option.

With the many screening and diagnostic testing options available to women during pregnancy, decision-making in a prenatal genetic counseling session can be difficult. Prenatal testing provides prospective parents with information during the pregnancy that will allow them to make informed decisions about moving forward (Lawson & Pierson, 2007). Other factors influence the counseling session and contribute to the complexity of making a decision regarding testing options and include the amount, quality, and type of information provided about each option (Jaques, Bell, Watson, & Halliday, 2004; Santalahti, Hemminikei, Latikka, & Ryyananen 1998). Due to the time sensitive nature of prenatal testing in general, women contemplating some and/or all of these options often make a decision regarding testing on the same day that the testing is performed. Therefore, it is reasonable to consider that the support people brought to the appointments may have a role in the decision-making process.

Earlier studies have attempted to identify sources of support for women making prenatal testing decisions. Among the largest influences are

spouses/partners, parents, siblings, friends, and medical care providers. Most of the studies that evaluate support sources focus on the roles of healthcare providers and spouses/partners. These studies emphasize how support people hinder the autonomy of the women actually making the decisions (Lawson & Pierson, 2007). Lawson and Pierson looked at this topic from a different perspective and concluded that, for many women, the need to feel socially supported by people close to them predominates over their need for autonomy (2007).

A study by Wohlgemuth and Lawson (2010) revealed that women identify husbands and physicians as the individuals from whom they desire the most support. Moreover, women who have social support in making their prenatal testing decisions reported feeling better prepared to make decisions about testing and were ultimately more confident in the decisions that they made. These findings highlight the importance of support people and the need for additional studies on this topic.

In a genetic counseling session, support people are often included in the discussion about the prenatal testing options and are encouraged to share their feelings about the decisions being made. Support people, like prenatal patients, come from diverse backgrounds and walks of life and therefore come into the genetic counseling session with varying ideas and opinions about what will happen. As far as we know, a study has not been conducted to assess the incoming knowledge of the support people concerning what a genetic counseling session entails. The expectations of how the support person(s) should be included in the decision-making process are also currently undefined.

Since many prenatal patients bring support people with them to their appointments, presumably to help them make decisions about prenatal testing, it is essential to assess what this experience is like from the support person's perspective. If we are able to establish a baseline of what most support people expect from or may wish to contribute to the session, genetic counselors may be able to provide targeted counseling that is more inclusive of support people brought to the appointments.

The objective of this study was to determine how much the support people know about the genetic counseling appointment prior to the session and to reveal how much they expect to be involved in the decision-making process. Findings from this study will provide insight into the perspective of the support person(s) and will hopefully help clinicians understand their expectations. Additionally, this pilot study is a starting point to assess how much the support people think that they impact decision-making of prenatal genetic counseling patients versus how much the prenatal patients value the input of these individuals.

Materials and Methods

The study population consisted of individuals over the age of 18 who spoke either English or Spanish and who came to a prenatal genetic counseling appointment with a patient at any of the seven University of Texas Health Maternal-Fetal Medicine clinics in Houston (University of Texas Professional Building, St. Joseph Medical Center, Memorial Hermann Southeast, Memorial Hermann Southwest, Memorial Hermann Memorial City, Memorial Hermann Sugar Land, and

Memorial Hermann Katy). Human subjects approval was obtained through both the University of Texas Health Science Center at Houston and the Memorial Hermann Hospital System's Institutional Review Boards (Approval # HSC-MS-12-0388).

As genetic counseling patients checked in for their appointments, they were asked 1) if they brought a support person(s) over the age of 18; 2) if they were okay with their support person(s) being asked to take part in a survey; and 3) if that person(s) was willing to complete a survey prior to the genetic counseling session. The support person(s) was then given a letter of invitation (Appendix A) and was asked to complete a one page survey (Appendix B) which included demographics, their relationship to the patient, their incoming knowledge of the genetic counseling appointment, and how involved they expected to be in the decision-making process during the session. Each survey also contained a box for the genetic counselor to indicate the patient's age and indication as well as testing offered to and accepted by the patient.

Surveys were distributed at the seven UT clinics starting on various dates in August and September of 2012 and ending at all sites on January 31, 2013 (see Appendix C for specific dates). A response rate was estimated for this study by collecting information from an existing database used by the UT prenatal counselors. This database includes information about whether or not the patient brought a support person(s) with them into the counseling room in the form of check boxes where the genetic counselor can select one or more relationships out of the following options: spouse, parent, child, sibling, friend, child >18, child <18, other, and none.

All data obtained from the surveys was entered into a secure Microsoft Access database. Data analysis was performed using STATA version 10.0 software. Frequencies and percentages of responses were calculated for each question. Responses were stratified by indication and testing options offered. Chi square analysis was used to determine whether or not participants' knowledge of indications and testing options was statistically significant. Mantel-Haenszel odds ratios were calculated to determine if there was a significant difference between the knowledge of the support persons who identified themselves as spouses/partners of the patient and those who identified themselves as non-spouses/partners of the patient. Wilcoxon-Mann-Whitney tests were used to assess the differences in attendance at appointments and levels of influence specifically between spouses/partners and parents of patients.

Results

The total number of patients seen at the clinic sites where surveys were collected within the dates specified was 964. An estimated 687 (71.3%) patients brought at least one support person into the genetic counseling session. A total of 252 surveys were completed yielding an estimated response rate of 36.7%. Of the 687 patients who brought at least one support person, 73 (10.7%) were Spanish-speaking and 614 (83.4%) were English-speaking. Although the vast majority of the surveys collected were in English (n = 225, 89.3%), with the remainder in Spanish (n = 27, 10.7%), estimated response rates were similar between the two languages (36.6% and 37.0% respectively). The average age of the patients whose support

person completed a survey was 32.0 ± 7.1 years and ranged from 15 to 49. Average gestational age in weeks was 17.7 ± 5.6 and ranged from 6 weeks to 35 weeks. The average age of the support people, henceforth referred to as participants, was 36.0 ± 9.8 years and ranged from 18 to 67 years. One hundred and ninety three (76.6%) of the participants were males, 50 (19.8%) were females, and 9 (3.6%) did not provide information about gender.

Most participants (79.4%) were spouses/partners of the patients. Patients who brought a parent were significantly more likely to be younger than patients who brought a spouse/partner ($p < 0.001$). Participants were most often Hispanic (35.7%), Caucasian (27.4%), African-American (14.7%), or Asian (12.3%). The level of education of participants varied but the majority indicated that their highest level of education was high school graduate with or without some college (39.7%). The majority of participants identified themselves as Protestant Christians (27.4%) or Roman Catholics (27.4%). See **Table 1** for participant demographics.

Table 1. Demographic information of study participants

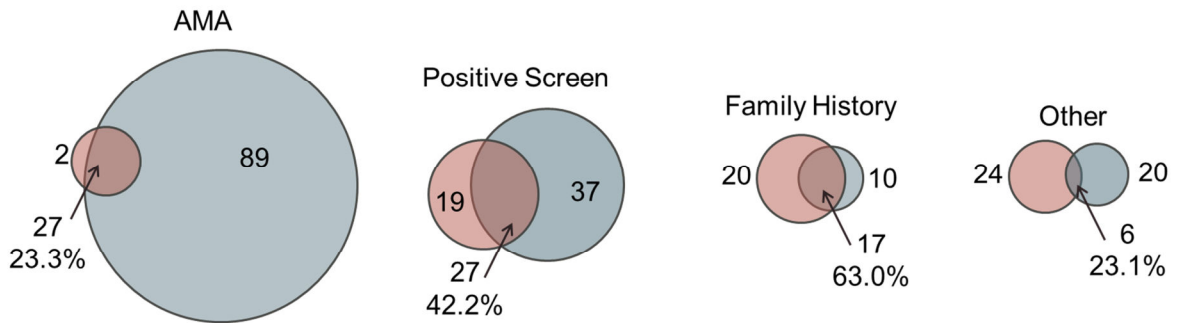
| Total n = 252 | n | % |
|--------------------------------|----------|----------|
| Race | | |
| American Indian | 2 | 0.8 |
| Asian | 31 | 12.3 |
| African American/Black | 37 | 14.7 |
| African | 3 | 1.2 |
| Hispanic/Latino | 90 | 35.7 |
| Hawaiian/Pacific Islander | 1 | 0.4 |
| White/Caucasian | 69 | 27.4 |
| Multiracial | 13 | 5.2 |
| Other | 4 | 1.6 |
| Not Answered | 2 | 0.8 |
| Education | | |
| Some High School | 17 | 6.8 |
| High School Grad | 50 | 19.8 |
| Some College | 50 | 19.8 |
| Trade/Tech/Voc | 10 | 4.0 |
| College Grad | 45 | 17.9 |
| Some Postgrad | 4 | 1.6 |
| Postgrad Degree | 40 | 15.9 |
| Other | 10 | 4.0 |
| Not Answered | 26 | 10.3 |
| Religion | | |
| Protestant Christian | 69 | 27.4 |
| Catholic | 69 | 27.4 |
| Jewish | 0 | 0.0 |
| Muslim | 8 | 3.2 |
| Hindu | 3 | 1.2 |
| Buddhist | 1 | 0.4 |
| Other | 56 | 22.2 |
| Not Answered | 46 | 18.3 |
| Relationship to Patient | | |
| Spouse/Partner | 200 | 79.4 |
| Parent | 27 | 10.7 |
| Child | 0 | 0.0 |
| Sibling | 8 | 3.2 |
| Friend | 4 | 1.6 |
| Other | 12 | 4.8 |
| Not Answered | 1 | 0.4 |

Participants who marked a particular indication for genetic counseling were usually correct about advanced maternal age (AMA) and were correct around half of the time when selecting a positive screening result or a family history of a specific condition. However, out of all patients that the genetic counselor identified as AMA (46.0%), only 23.3% of participants were able to identify this as the reason for the appointment. Positive screen patients (25.8%) and family history patients (10.7%) were identified correctly by their support person about half of the time (42.2% and 63.0% respectively). These results were statistically significant with p values < 0.001. Although we did not have a large enough sample size in each of the relationship categories to stratify these results by relationship to the patient, we did compare the spouse/partner group to all other groups combined. There was no significant difference in the knowledge about the reasons for the patient's appointment between spouses/partners and non-spouses/partners.

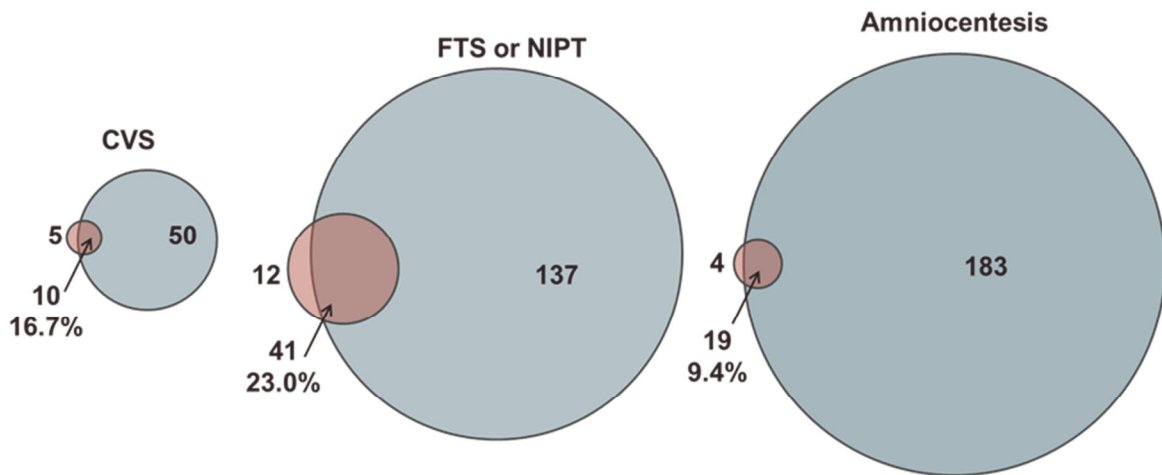
Similarly to knowledge about indication, participants had little knowledge about which screening and testing options would be offered during the genetic counseling appointment. When participants marked a specific screen or test that they expected would be discussed, they were more often correct than incorrect. However, out of all patients that were offered each screening or testing option, only a small percentage of participants were able to identify the screens and test that would be offered. These results were all statistically significant with p values < 0.001. Again, there was no significant difference in the knowledge about testing options between spouses/partners and non-spouses/partners. Information regarding indications and testing options is summarized in **Figure 1**.

Figure 1. Knowledge of indications and screening/testing options. Blue circles represent the number of patients for each indication and testing option as identified by the genetic counselor. The red circles represent the number of participants who marked the indication or testing option. The intersection of the two circles represents the number of participants who correctly identified the indication or testing option. (A) Knowledge of indications. (B) Knowledge of screening/testing options.

A.



B.



Finally, we wanted to describe the expectations of support people about involvement in decision-making and the levels of influence they believe they have over those decisions. Eighty-nine point seven percent of participants reported that they planned to go with the patient to both the genetic counseling session and the

ultrasound. Fifty-two point eight percent of participants said that the patient had made a decision about testing prior to the counseling appointment. Of those, 45.9% reported that they helped make that decision, 47.4% did not answer the second part of the question, and only 6.8% marked that they did not help the patient make a decision about testing prior to the genetic counseling appointment. Although about half of participants stated that a decision about testing had been made prior to the appointment, 66.3% reported that they expected to help the patient make some type of decision during the genetic counseling session. Only 3.6% of participants marked that they did not want to be included in discussions about screening and/or testing options for the pregnancy.

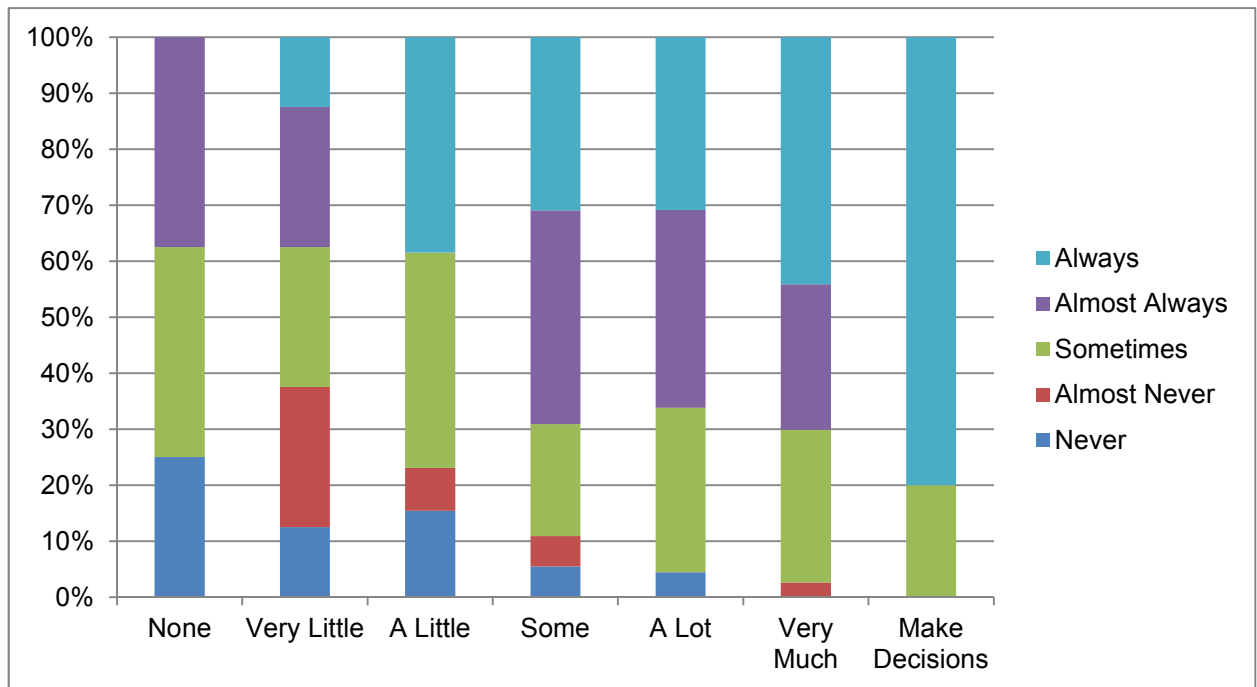
Among the patients that were accompanied to their appointments by participants, 59 (23.4%) were offered first trimester screening and 19 (32.2%) accepted, 60 (23.8%) were offered a CVS procedure and 11 (18.3%) accepted, 202 (80.2%) were offered an amniocentesis procedure and 16 (7.9%) accepted, and 166 (65.9%) were offered NIPT and 81 (48.8%) accepted. When asked about their beliefs about testing for fetal abnormalities during pregnancy in general, the majority of participants said either that their beliefs depended on the situation or that they are strongly for this type of testing. We compared the acceptance rate of each test and the responses to feelings about testing in general. There was no significant difference in the feelings about testing in general between those who were offered FTS ($p = 0.807$), amniocentesis ($p = 0.617$), or NIPT ($p = 0.210$) and declined and those who were offered FTS, amniocentesis, or NIPT and accepted. However, those who accepted the option to undergo a CVS procedure were significantly more

likely to report being strongly for testing than those who declined this procedure ($p = 0.044$). Feelings about testing in general were also stratified by other demographic information. There was no significant difference in feelings about testing among education levels ($p = 0.701$) or religious affiliations ($p = 0.646$). There was, however, a significant difference in feelings about testing among race/ethnicity groups ($p = 0.039$). Although there were a variety of answers in each of the groups, none of the African-American participants marked that they were “strongly against” testing while 10.7% of Asian, 5.9% of Hispanic, and 1.4% of Caucasian participants reported those feelings. In addition, 19.4% of African-American participants marked “I don’t know” as a response to this question and only 10.7% of Asian, 8.2% of Hispanic, and 5.8% of Caucasian participants marked that response. Despite these significant differences, the vast majority of participants across all race categories chose that they were either “strongly for” testing or that it “depends on the situation”.

Participants tended to be present at more appointments with the patient relating to pregnancy than appointments not related to pregnancy. Participants also thought that they had either the same or more influence over the patient’s decisions about pregnancy than they had over decisions that were not related to pregnancy. Both spouses/partners and non-spouses/partners showed a trend of feeling that they had either the same level or more influence over decisions related to the pregnancy than those not related to the pregnancy. There was no significant difference in the level of influence reported by spouses as compared to participants in all other relationship categories ($p = 0.068$).

Figure 2 shows a comparison between the reported levels of influence over pregnancy-related decisions with the participant’s attendance at pregnancy-related doctor’s appointments. Those who think they have a higher level of influence over pregnancy-related decisions were likely to attend more appointments. Conversely, those who reported that they had little to no influence over the patient’s decisions about the pregnancy report going to fewer appointments.

Figure 2. Attendance at pregnancy-related physician appointments compared to reported level of influence over pregnancy-related decisions



Discussion

It is well-documented that decisions about prenatal testing are influenced by factors other than the decision-making skills of the patient alone (Lawson & Pierson 2007; Pergament & Pergament, 2012; Wohlgemuth & Lawson, 2010). Although it is known that support people influence prenatal testing decisions, there can be great variation in the level of influence (Santalahti et al., 1998; Sjogren & Uddenberg, 1998). Our data supports this premise and found that the support people attending prenatal genetic counseling sessions, whether spouses/partners or other relationship types, expect to be involved in the education, discussion, and decision-making aspects of the genetic counseling session.

As expected, most support persons were spouses/partners and attended both the genetic counseling and ultrasound portions of the appointment. Proportions of the types of support people brought to the counseling sessions in our data appeared to be similar to those proportions in the existing prenatal database. Although not specifically analyzed, the proportions of each indication represented in the study population anecdotally correspond well to the general indications for prenatal genetic counseling.

Overall, participant knowledge of patient indications for the genetic counseling session was poor. Across all of the screening and testing options, only a small percentage of participants marked the options that were actually offered to the patient during the genetic counseling session. A previous study reported that 83.8% of patients correctly identified an indication for which they were referred (Czerwinski et al., 2010). In contrast, only 33.5% of the support persons in this study were able

to correctly identify the patient's indication. Despite their understanding of why they were referred, many women are not fully informed of the possible reproductive choices and testing options available to them (Li, Karlberk & Norem, 2008; Marteau & Dormandy, 2001; McCoyd, 2013; Pergament & Pergament, 2012). If we extrapolate our findings that support persons are less informed about indications than the patients, we would expect that support persons would be less knowledgeable about genetic testing options for the pregnancy. In our study, only 17.7% of support persons were able to correctly identify at least one testing option that would be offered to the patient. Genetic counselors can incorporate this information to be more cognizant of the gap in knowledge that may exist between the patient and the support person. It is critical to assess not only what the patient understands about the reasons for the appointment and screening/testing options, but to also consider the knowledge of the support person(s) during the session. The influence of an under- or misinformed support person may negatively impact the decision-making process for the patients.

The majority of participants in this study did expect to be involved in discussions about screening and testing options for the pregnancy and anticipated helping the patient make a decision during the genetic counseling appointment. Though genetic counselors at present may not ask a support person how frequently he or she attends pregnancy-related appointments with the patient, our data suggests that asking this question could provide the counselor a general idea about how much influence the support person thinks they have over the patient's decisions.

We were unable to survey the patients themselves with similar questions due to clinic flow and time limitations. Comparing the patient's knowledge and the level of influence that they believe the support person has with the support person's knowledge and perception of their level of influence is important. Previous studies conclude that women in a prenatal setting want their support person(s) to be involved in the decision-making process (Nuccio et al., 2010). Our data demonstrates that the support people attending prenatal genetic counseling appointments want to be involved in discussions about screening and testing options. Additionally, support people on the whole believe that they have a higher level of influence over the patient's pregnancy-related decisions than decisions not related to pregnancy. However, as discussed previously, their incoming knowledge of what will be discussed during the session is poor. Genetic counselors should acknowledge that educating support people about indications and screening/testing options can be just as important as the patient's own understanding and these individuals should be actively engaged in the genetic counseling sessions.

Limitations

The most significant limitation of our study was the disagreement between the indication that the participant chose and the indication selected by the genetic counselor. Similarly, the options for testing that the participant expected to be discussed did not match up exactly with testing options that the genetic counselor could select. This discrepancy partially occurred as a result of using patient-friendly language for participants in the descriptions of indications and testing options and

made data analysis difficult. Data analysis of participant's knowledge about abnormal ultrasound was particularly affected by participants choosing the option for their appointment being "to have an ultrasound". Patients referred for all indications generally have an ultrasound after the genetic counseling session with the exception of preconception cases. Therefore, even if the patient's indication was not "abnormal ultrasound", the participant would have been correct by choosing the response indicating that the patient would have an ultrasound at her appointment.

Also of note, a large number of participants skipped a question asking if they had helped the patient make a decision about testing prior to the appointment. This was most likely a result of the location of the question on the page that made the answer options less obvious than they were for the rest of the questions on the survey.

Finally, although we had a large number of participants who identified themselves as the spouse/partner of the patient, our sample sizes for all other relationship groups were too small for use in stratifying the data by each relationship. Larger sample size in a future study may be more helpful in determining if incoming knowledge about indications and testing options is different for each of the relationship categories. In addition, about half of participants stated that the patient had already made a decision about testing before attending the appointment. Future studies may want to explore more specifically what decisions were made before the genetic counseling appointment, especially given the percentage of support people who said that they helped make that decision and the limited knowledge they may have about the testing options prior to the appointment.

Although the above limitations exist, this study was able to describe the types of support people that prenatal genetic counseling patients bring with them into the counseling session and included responses from over 250 participants. We have identified a gap in incoming knowledge that may exist between the patient and support person(s), which is important for the genetic counselor to address during the session. Finally, the findings from this study can be used in future studies to compare the level of influence the patients report that their support people have over their decisions to the perceived levels of influence described here.

Conclusion

In conclusion, this study aimed to determine who prenatal patients bring with them as support persons to genetic counseling appointments, what those support persons knew about the reasons for the appointment, and what their expectations were regarding involvement in the decision-making process. The vast majority (79.4%) of support persons were spouses/partners of the patient. In general, support persons were not knowledgeable about the reasons the patient was being seen by a genetic counselor and knew even less about the screening and testing options that would be discussed. However, the study found that support persons do expect to be involved in discussions and decision-making about screening/testing options and that they tend to feel that they have more of an influence over the patient's pregnancy-related decisions than those not related to her pregnancy. The lack of knowledge about indications and genetic screening/testing options coupled with the desire to be involved in and influence decisions made about testing options

reinforces the importance of ensuring that the support person(s) brought to a prenatal genetic counseling session is appropriately included in the discussion. Since the support person(s) could potentially negatively impact the patient's decision-making process if they do not fully understand both the indication for genetic counseling and the testing options, their comprehension is essential for a truly informed decision.

Appendix A: Letter of invitation

Dear Participant:

My name is Michelle McDougale and I am a graduate student at the University of Texas Health Science Center at Houston. For my final project, I am trying to determine what support people of our prenatal patients know about the appointment before the patient is seen by a genetic counselor and/or doctor. Because you are here today with a patient who is scheduled for a genetic counseling appointment and/or ultrasound, I am inviting you to participate in this research study by completing the attached brief survey.

The following questionnaire will require approximately five (5) minutes to complete. There is no compensation for responding nor is there any known risk. We are not collecting any specific identifying information from you with this survey. In order to ensure that all information will remain confidential, please ***do not*** include your name or the name of the patient you are here with today. If you choose to participate in this project, please answer all questions as honestly as possible and return the completed questionnaire when the patient returns her intake paperwork to the front desk at the clinic. Participation is voluntary and you may choose not to participate, to stop the survey at any time, or to skip any questions you do not want to answer.

Thank you for taking the time to assist me with this project. The data collected will hopefully provide useful information that will help genetic counselors and doctors learn how to better include support people in the appointment. Completion and return of the questionnaire will indicate your willingness to participate in this study. If you require additional information or have questions, please contact me at the email address listed below.

Sincerely,

Michelle McDougale
Contact email address: Michelle.A.McDougale@uth.tmc.edu

Jennifer Czerwinski, MS, CGC



IRB NUMBER: HSC-MS-12-0388
IRB APPROVAL DATE: 7/5/2012

Appendix B: Survey

Please answer the questions below based on YOUR thoughts. The person that you came with today who has an appointment will be referred to as "the patient" on this survey. Please do not ask for or use help from anyone to answer these questions; there are no wrong answers. Thank you.

- 1) What is your Age: _____
- 2) What is your Gender: MALE FEMALE
- 3) What is your Race/Ethnicity?
- AMERICAN INDIAN
- ASIAN
- AFRICAN AMERICAN/BLACK
- AFRICAN
- HISPANIC OR LATINO
- HAWAIIAN/PACIFIC ISLANDER
- WHITE/CAUCASIAN
- MULTIRACIAL
- OTHER
- 4) What is your Education Level?
- SOME HIGH SCHOOL
- HIGH SCHOOL GRADUATE
- SOME COLLEGE
- TRADE/TECHNICAL/VOCATIONAL
- COLLEGE GRADUATE
- SOME POSTGRADUATE WORK
- POSTGRADUATE DEGREE
- OTHER
- 5) What is your Religion?
- PROTESTANT CHRISTIAN
- ROMAN CATHOLIC
- JEWISH
- MUSLIM
- HINDU
- BUDDHIST
- OTHER
- 6) What is your relationship to the patient: SPOUSE/PARTNER PARENT CHILD SIBLING FRIEND
- OTHER: _____
- 7) Why did you come with the patient to this appointment today? Check all that apply.
- ASKED BY PATIENT VOLUNTEERED TRANSPORTATION I DON'T KNOW
- OTHER (please explain): _____
- 8) During her current pregnancy, how often do you attend doctor's appointments with the patient?
- NEVER ALMOST NEVER SOMETIMES ALMOST ALWAYS ALWAYS
- ONLY WHEN THEY NEED A RIDE THE PATIENT IS NOT CURRENTLY PREGNANT
- OTHER (please explain): _____
- 9) How often do you attend doctor's appointments with the patient that are NOT related to her pregnancy?
- NEVER ALMOST NEVER SOMETIMES ALMOST ALWAYS ALWAYS
- ONLY WHEN THEY NEED A RIDE THE PATIENT IS NOT CURRENTLY PREGNANT
- OTHER (please explain): _____
- 10) Do you plan to go with the patient when she is called back for her counseling appointment and/or ultrasound?
- YES NO ONLY FOR COUNSELING ONLY FOR ULTRASOUND I DON'T KNOW
- 11) What is your understanding of the reason the patient is being seen today? Check all that apply.
- TO HAVE AN ULTRASOUND TO DISCUSS HER AGE TO DISCUSS THE RESULTS OF A BLOOD TEST
- TO DISCUSS THE FAMILY HISTORY OF A SPECIFIC CONDITION TO HAVE BLOODWORK DONE
- TO HAVE A CHORIONIC VILLUS SAMPLING (CVS) OR AMNIOCENTESIS/NEEDLE TEST I DON'T KNOW
- OTHER (please explain): _____

TURN OVER TO COMPLETE SURVEY

12) Do you think the patient will be making decisions about having testing during her appointment today?

YES NO I DON'T KNOW

If YES – About what? Check all that apply. ULTRASOUND BLOODWORK

CHORIONIC VILLUS SAMPLING (CVS) AMNIOCENTESIS/NEEDLE TEST I DON'T KNOW

OTHER: _____

13) Did you and the patient talk before her appointment today about why she is being seen and what may happen?

YES NO

14) Do you think the patient has already made a decision about what testing she will do today?

YES NO I DON'T KNOW I DON'T THINK THE PATIENT WILL BE MAKING DECISIONS ABOUT TESTING TODAY

If YES – Did you take part in making this decision with the patient? YES NO

15) Do you think the patient needs more information before she is able to make a decision about testing?

YES NO I DON'T KNOW I DON'T THINK THE PATIENT WILL BE MAKING DECISIONS ABOUT TESTING TODAY

16) Do you expect to help the patient make a decision today?

YES NO I DON'T KNOW I DON'T THINK THE PATIENT WILL BE MAKING DECISIONS ABOUT TESTING TODAY

17) How much influence do you think you have over the decisions the patient makes regarding her pregnancy?

NONE VERY LITTLE A LITTLE SOME A LOT VERY MUCH I MAKE DECISIONS FOR THIS PERSON

THE PATIENT IS NOT CURRENTLY PREGNANT

18) How much influence do you think you have over the decisions the patient makes NOT related to her pregnancy?

NONE VERY LITTLE A LITTLE SOME A LOT VERY MUCH I MAKE DECISIONS FOR THIS PERSON

THE PATIENT IS NOT CURRENTLY PREGNANT

19) How would you describe your role at this appointment? Check all that apply.

I AM ONLY HERE BECAUSE THE PATIENT ASKED ME TO BE HERE

I AM ONLY HERE BECAUSE THE PATIENT NEEDED A RIDE TO HER APPOINTMENT

I WANT TO HELP MAKE DECISIONS ABOUT THE PREGNANCY

I AM HERE TO SUPPORT WHATEVER DECISIONS THE PATIENT MAKES

I DON'T KNOW WHAT MY ROLE IS AT THIS APPOINTMENT

I DON'T HAVE A ROLE AT THIS APPOINTMENT

OTHER (please explain): _____

20) Do you want to be included in any discussion about screening or testing options for this pregnancy?

YES NO I DON'T KNOW THE PATIENT IS NOT CURRENTLY PREGNANT

21) How do you feel about testing for fetal abnormalities during pregnancy in general?

I AM STRONGLY AGAINST IT DEPENDS ON THE SITUATION I AM STRONGLY FOR IT I DON'T KNOW

FOR OFFICE USE ONLY

_____ of _____

Age of Patient: _____

Gestational Age: _____

Indication: AMA PosFTS PosTriple/Quad/Penta AbnlUS FH of _____ Other: _____

Testing Offered: FTS CVS Amnio NIPT

Testing Accepted: FTS CVS Amnio NIPT



IRB NUMBER: HSC-MS-12-0388
IRB APPROVAL DATE: 7/5/2012

Appendix B: Survey Distribution Dates

University of Texas Professional Building: August 22, 2012 – January 31, 2013

St. Joseph Medical Center: August 28, 2012 – January 31, 2013

Memorial Hermann Katy: August 29, 2013 – January 31, 2013

Memorial Hermann Memorial City: August 29, 2012 – January 31, 2013

Memorial Hermann Southwest: August 31, 2012 – January 31, 2013

Memorial Hermann Sugar Land: August 31, 2012 – January 31, 2013

Memorial Hermann Southeast: September 5, 2012 – January 31, 2013

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Michelle Annette McDougle was born in Dalton, Georgia on August 20, 1987, the daughter of Paula Darlene McDougle and Michael Anthony McDougle. After completing her work in the International Baccalaureate program at Northwest Whitfield County High School, Tunnel Hill, GA in 2005, she entered Brenau University Women's College in Gainesville, GA. She received the degree of Bachelor of Science with a major in Biology from Brenau in May, 2009. In August of 2011 she entered the University of Texas Health Science Center at Houston Graduate School of Biomedical Sciences.

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