Perceptions of genetic counseling and testing in the Haitian patient population

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I. Introduction

Prenatal genetic counseling in South Florida allows for interaction with patients from diverse areas including the Caribbean, Central and South America. Understanding of how a patient's cultural background influences their attitudes towards genetic counseling and testing is required. Haitian patients have a distinct culture and set of beliefs which are necessary to acknowledge in order to effectively engage the community (Meade, Menard, Thervil, & Rivera, 2009). The purpose of this study was to analyze how Haitian prenatal patients perceived genetic counseling and testing and measure satisfaction with the services provided.

II. Methods

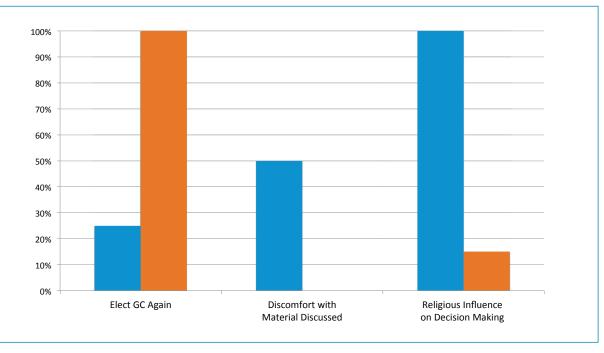
Eleven self-identified Haitian participants consented to participate. Participants were interviewed via telephone using an interview guide composed of 10 close-ended and 5 open-ended questions. A Haitian Creole interpreter was utilized as necessary.

III. Results

100% of patients said the genetic counselor helped them understand genetic testing and risks; none reported concerns with the testing plan they and their genetic counselor created. 72% of patients were less anxious after speaking with the genetic counselors. Of patients who spoke Creole as their primary language, 75% reported they would not choose to have genetic counseling again because they found it unnecessary. 100% of Creole speaking patients sited a belief that God would protect their baby from harm, including genetic diagnoses. One English speaking patient referenced strong religious beliefs, but said she was too anxious during her counseling to reflect on them. 50% of Creole speaking patients said they were uncomfortable with the discussion of prenatal diagnostic testing. Conversely, none of the English speaking patients identified a discomfort with the material discussed, and all said they would elect genetic counseling again in a future pregnancy.

Figure 1. Differences in Perceptions Between English and Creole Speakers

Creole SpeakingEnglish Speaking



IV. Discussion

Genetic counseling was found to be beneficial for and appreciated by the Haitian patient population, even when no prior concerns about their genetic risk existed. Even the patients who were not interested in future counseling, expressed satisfaction with the genetic counseling session. One such patient said, "I refused genetic counseling with my first baby because I know my babies will be fine. I do not worry about them. [However] I was very pleased that she helped me understand the testing and what would happen

with the baby if anything was wrong." However, perceptions of genetic risks and testing were stratified by the primary language identified by the patient. Creole speaking patients were more likely to rely on their religious beliefs than those risks identified by the genetic counselor, and unlikely to be interested in future genetic counseling. Said one such patient, "I don't believe in what they told me. They told me that my age puts me at risk but I don't believe God would do that."

IV. Conclusions

Overall, this data may indicate that those patients who speak Creole as a primary language identified more with their Haitian culture; additional considerations should be made to acknowledge their preexisting beliefs when counseling about risk and testing options.

V. References

- 1. NSGC Code of Ethics. (2017, April). Retrieved March 9, 2020, from https://www.nsqc.org/p/cm/ld/fid=12.
- 2. Thompson S, Noblin SJ, Lemons J, et al. Perceptions of Latinas on the Traditional Prenatal Genetic Counseling Model. *J Genet Couns*. 2015 Aug; 24(4):675-82.
- 3. Definition of Genetic Counseling Services. (2020). Retrieved from https://www.nsgc.org/p/cm/ld/fid=187.
- 4. Buchanan AH, Datta SK, Skinner CS, et al. Randomized Trial of Telegenetics vs. In-Person Cancer Genetic Counseling: Cost, Patient Satisfaction and Attendance. *J Genet Couns*. 2015 Dec; 24(6), 961–970.
- 5. Desrosiers A, St. Fleurose S. Treating Haitian patients: Key cultural aspects. Am J Psychother. 2002; 56(4):508–521.
- 6. Meade CD, Menard J, Thervil C, Rivera M. Addressing Cancer Disparities Through Community Engagement: Improving Breast Health Among Haitian Women. Oncol Nurs Forum. 2009 Nov; 36(6):716-22.

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