KNOWLEDGE AND EXPECTATIONS OF SUPPORT PEOPLE IN PRENATAL GENETIC COUNSELING SESSIONS

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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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