

# Parental expectations and satisfaction with service from a referral to genetic counseling and a genetic evaluation: a study of Hispanic parents

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The Hispanic community is the largest and fastest-growing minority group in the United States (Gonzalez Burchard, 2005). This increase is reflected in the growing number of patients of Hispanic origin receiving medical care from certain medical centers or hospitals. In the American healthcare system, Hispanic patients can have access to several medical specialties, including genetics. A very limited number of studies have focused on a family's expectations from a referral to genetics. For this study, two questionnaires were administered to the participants, one before and one after they met with the genetic counselor and geneticist at the Pediatric Genetics Clinic at Boston Medical Center (BMC). The purpose of the first questionnaire was to determine what parents understand about why their child was referred for genetic evaluation and which questions they were hoping to have answered, if they have any background knowledge of genetics, and their understanding of the potential role of genetics in their child's diagnosis. The second questionnaire was administered after the genetic evaluation and its purpose was to assess participant satisfaction with the information received. Furthermore, participants were asked about their interest in an informational pamphlet on what to expect from a referral to genetics, and what information they think should be included in this pamphlet. A total of 14 Hispanic participants were enrolled in the study: 9 parents of returning patients and 5 parents of new patients. Comparative studies were performed to compare expectations and satisfaction between parents of returning patients and parents of new patients, and no significant differences were found between these two groups. The study population demonstrated to have little knowledge about genetics and understanding about this referral. In addition, their expectations from the referral to genetics were frequently left unfulfilled. A significant correlation was found between meeting participant expectations and satisfaction with the session. The interest in information pamphlets was 91.6% among participants, and an information pamphlet on what to expect from a referral to genetics was created at the end of the study.