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How do patient perceived determinants influence the decision-making process to accept or decline preimplantation genetic screening?

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Objective: Identify the determinants that influence the patient's decision-making process when deciding to accept or decline preimplantation genetic screening (PGS) in a given IVF cycle.

Design: Pilot, retrospective, cross-sectional study that used a questionnaire containing a combination of quantitative and qualitative items.

Setting: Private practice IVF clinic.

Patient(s): Patients and partners initiating an IVF treatment cycle, both autologous and donor, between October 2012 and January 2015.

Intervention(s): None.

Main Outcome Measure(s): Identification of patient perceived determinants and the importance of each on the decision to accept or decline PGS.

Result(s): Responses from the questionnaire (N = 117) were returned, and of these, 60% accepted PGS. The female response rate was 75% (N = 88) and the male response rate was 25% (N = 29). Ninety-eight percent were Christian (N = 112) and 88% college educated (N = 102) with 39% (N = 40) having some postgraduate education. Sixty-eight percent (N = 79) had no knowledge of PGS before the IVF cycle; however, after provider education, 92% (N = 108) correctly identified that PGS was elective and 93% (N = 109) reported sufficient knowledge to make an informed decision to accept or decline PGS. The additional cost of screening, the provider information and influence, and social support or acceptance from partner, family, and/or friends, were the three statistically significant variables affecting the decision.

Conclusion(s): This is the first study, to the authors' knowledge, to identify and assess the determinants of the patient decision-making process when presented with the choice of PGS. Several factors contribute to the patient-perceived determinants when choosing to accept or decline PGS, including cost, religious and ethical beliefs and values, social and family support, provider influences, and the past reproductive experience of the patient. (Fertil Steril® 2016;105: 188–93. ©2016 by American Society for Reproductive Medicine.)

Key Words: Patient decision-making, shared decision-making, preimplantation genetic screening, in vitro fertilization

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Preimplantation genetic screening (PGS) has been used for more than 15 years as an option to improve the reproductive outcome of patients (1). Since the first successful IVF birth in 1978, numerous developments and advancements have occurred, including the upsurge of genomics, which has experienced rapid growth during the past two decades (2). Advances in PGS allow for comprehensive chromosomal screening of embryos created from IVF. Patient and clinic requests for PGS are now in demand worldwide (3) and the availability of PGS has presented both patients and providers with the decision to use PGS as adjuvant therapy within IVF treatment cycles.

The first live births from PGS were published in 1995 and PGS is now one of the most frequently used alternatives to morphological selection alone when preparing an embryo for transfer (4). The thought process behind the use of PGS is conceived on the well-known fact that human embryos are frequently abnormal (aneuploid) and these embryos do not produce successful outcomes. The addition of PGS to aid in the selection of an embryo with the greatest potential for success seems reasonable in an attempt to improve IVF success and shorten the interval to a live birth. The European Society of Human Reproduction and Embryology (ESHRE) reported 61% of all preimplantation genetic testing involved PGS during the past 10 years (5). Despite the lack of randomized controlled trials demonstrating benefits of PGS and the lack of support from many professional societies, PGS is increasingly utilized (6). Many clinics continue to routinely expand the offering and broad use of PGS to all IVF patients (5).

There is ongoing controversy as to who benefits most from the utilization of PGS and to which population PGS should be offered. Even at the time of publication, the debate surrounding the appropriate patient for PGS remained unclear (5). Patients and providers are faced with making decisions with each IVF cycle regarding the utilization of PGS; therefore, leaving the decision to perform PGS a clinic-, provider-, or patient-elected choice. Meldrum (7) reported that each IVF program would ultimately decide, in conjunction with the patient's choice for screening, to the use of PGS in any given IVF cycle. Unfortunately, the science examining how couples become aware of and decide when to use genomic biotechnology lags behind the genomic advances, leaving the patient with little or no decision-making support (8).

A shared decision-making model between patient and provider is necessary in the treatment of the patient undergoing IVF (9). Patients desire to be partners in their health care decisions and treatment options. However, there is a lack of information from providers and patients to optimize patient engagement. Using the theoretical framework of the shared decision-making model, provider and patient make treatment decisions collaboratively, based on the best available evidence and the patient's values, beliefs, and preferences (9). The objective of this study was to identify the patient-perceived determinants contributing to the decision-making process for the utilization of PGS.

MATERIALS AND METHODS
The Institutional Review Board at The University of Alabama at Birmingham granted approval for the study. The setting for the study was a private practice infertility clinic and the desired population was patients and partners who elected IVF therapy (regardless of infertility diagnosis) between the dates of October 2012 and January 2015. The population consisted of female and male partners with a minimum age of 21 years. Once deemed eligible, the study population was notified of an invitation by e-mail to participate in the study.

The study tool was a questionnaire consisting of 30 questions (25 quantitative, nominal, and ordinal questions and 5 qualitative questions) developed for the population of interest and based on four categories that were internally and externally identified as determinants of this study. These determinants included the following: *What was the patient's knowledge base regarding the risks, alternatives, benefits of PGS? What was the source of PGS information and how did this influence the patient(s) decision? What were the attitudes and motivations (i.e., costs, social, religious, ethical, or family acceptance and support) that influenced the patient to elect or decline PGS? How did the patient's prior reproductive history or experiences affect the decision?* The last category focused on the qualitative component of the questionnaire, allowing respondents to provide additional information regarding feelings or thoughts toward PGS and how the choice affected their IVF experience. A questionnaire was created because no existing standardized instruments that were validated could be identified to study this population. A similar questionnaire previously used to study the decision-making process for preimplantation genetic diagnosis was identified in the literature (8) and served as a resource in the development of the instrument used in the present study.

A process map was used to determine eligibility into the study (Fig. 1). A total of 266 invitations were e-mailed, 133 to the female patient and 133 to the male partner. The questionnaire was open and available for voluntary participation for a specified time period. Participant consent was implied by the completion of the questionnaire. Anonymity of results was maintained to decrease social desirability bias. No personal identifiers were collected from the participants. A reminder e-mail was delivered to those who had not returned the questionnaire at 1 week and 2 weeks after the initial invitation was delivered. The study was closed to participation after 3 weeks. The data were collected and stored through Survey Monkey, a leading provider of web-based survey solutions. Data were analyzed using SAS (SAS Institute). In the preliminary univariate analysis, differences in group responses (accepted PGS vs. declined PGS) were analyzed using χ^2 tests, with an alpha level of 0.05 to determine statistical significance. In the subsequent multivariate analysis, a multivariate logistic regression model was used to estimate the independent influence of the six main explanatory variables (cost, religious beliefs, social acceptance, provider explanation, information about discarding abnormal embryos, and information about freezing embryos) and to adjust for gender, race, and education.

RESULTS
Invitations were sent individually to 133 patients and their respective partner (N = 266). Seven e-mails were