Preconceptions of Conception: The reported expectations and experiences of individuals pursuing preimplantation genetic diagnosis

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OBJECTIVE: This study aimed to explore attitudes and experiences of patients who have pursued preimplantation genetic diagnosis (PGD). First hand descriptions of these experiences have been relatively unexplored in the literature. This information has important implications for counseling patients pursuing this emerging technique. METHODS: A qualitative, semi-structured interview format was utilized to ascertain 1) expectations prior to PGD 2) experiences with PGD 3) outcome of PGD and 4) personal impact of PGD. PARTICIPANTS: The study population consisted of individuals who had pursued PGD in the past five years through the Fertility Center of New England. Participants were selected irrespective of the stage of PGD treatment, treatment outcome or treatment termination. RESULTS: Five content areas were identified with three to five themes described within each content area. Content areas were assigned to categorize themes based on informational content. Themes focused more specifically on opinions or specific topics within each content area. Content areas included 1) Practical Issues and Concerns, 2) Personal Relationships, 3) The Power of Knowledge, 4) Personal Identity, and 5) Reflecting with Experience. Themes included cost and insurance coverage, isolation and guilt, changing relationship roles, the desire for more information, having options to choose from, feeling thankful/grateful/lucky, coping with stress and the desire to pass on knowledge. CONCLUSIONS: Participants conveyed a wide range of knowledge and experience. Overall, participants felt that more explanation and support were necessary from their medical providers. Suggestions for providers and patients are made based on study findings.