

## **An exploration of the approach to family planning among adult siblings of individuals with an undiagnosed condition**

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The goal of this study was to gain a general knowledge on the factors that impact the approach that adult siblings of individuals with an undiagnosed genetic condition take in family planning. The study explored the factors involved in the decision-making process in the context of an unknown recurrence risk. The study population was identified via support and advocacy groups and the National Society of Genetic Counselors email list. Respondents were interviewed using a semi-structured interview guide and responses were recorded and transcribed. Modified-grounded theory was used to analyze the themes that emerged from hand coding. Participants reported different family planning possibilities such as adoption, biological children, egg donor or surrogacy, and no children. Throughout the interviews the participants conveyed that their current decisions were subject to change. The participants also discussed the factors involved in their decision-making process. Uncovered salient themes included topics on information and control, family planning options, differing factors in the decision-making process, a reflection on participants' life experiences, and social support provided. This exploration established that the decision-making process is flexible and that the uncertainty in recurrence risk and adult siblings' caretaker status may play major roles on the decisions for planning a family. The research highlights that genetic counselors can provide guidance, acceptance, and support throughout the decision-making process.