**Introduction**

- The family health history is a valuable source of information for stratifying risk and understanding patterns of health and disease in families.
- Family health history reflects complex interactions of genetic and environmental factors that influence health and illness.
- Usefulness of traditional family health history, which focuses on the genetically related family, has not been established for nontraditional families.
- A significant proportion of contemporary American families are nontraditional families, including families formed by adoption, foster, and step relationships; single parent families; and same sex couples with and without children.
- The family health history management and communication needs of these families are largely unexplored.

**Objectives**

1. Understand experiences and perceptions of parents who adopted a child with Fragile X Syndrome (FXS), an X-linked genetically mediated syndrome, related to receiving the child’s diagnosis.
2. Explore the usefulness of available family health history applications to stimulate conversation about family health history with research participants from nontraditional families.

**Materials and Methods**

- Questionnaire completed by adoptive parents of children with FXS in a large national study.
- Telephone interview of adoptive parents of children with FXS.
- Family health history for child with FXS completed by adoptive parent using My Family Health Portrait, a web-based consumer health application.

**Themes related to sharing genetic family health history information**

- Telling the birth family about the diagnosis.
- Encountering problems in contacting the birth family.

**Preliminary Results**

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<tr>
<td>Telephone Interview</td>
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</tr>
<tr>
<td>Family Health History Completed</td>
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</table>

**Themes related to traditional family health history**

- Feeling not welcomed, not valid, not real.
- Valuing social connections in the family.
- Completing it is easy but time consuming.

**Observations about methodology**

**Conclusions**

- Adoptive families of children with FXS are interested in communicating with birth families about genetic diagnoses for birth family’s family health history.
- Support for communicating this information among adoptive and birth families is needed.
- Traditional family health history applications may not be appropriate or meaningful for nontraditional families.
- Family health history applications based on an inclusive definition of family, not limited to the genetic family, may be more suitable for use by nontraditional families.

**References**


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**Family Health History for Nontraditional Families: Preliminary Findings**

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