

Parents 'avoid pregnancy' rather than face testing choices

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Parents of children with genetic conditions may avoid the need to choose whether to undergo pre-natal testing or to abort future pregnancies by simply avoiding subsequent pregnancy altogether, a study has found.

Parents are 'choosing not to choose', researcher Dr Susan Kelly, who is based at the Egenis research centre at the University of Exeter, suggests, in a 'reflection of deep-seated ambivalence' about the options and the limitations of new reproductive technologies.

According to 'Choosing not to choose: reproductive responses of parents of children with genetic conditions or impairments' published in the journal *Sociology of Health and Illness*, more than two-thirds of parents in the USA-based study chose not to have any more children rather than accepting tests to identify or avoid the birth of an affected child. Of the parents who did have further children, a majority chose not to make use of prenatal screening or testing.

"Prenatal testing procedures (to detect genetic conditions or fetal anomalies) were perceived by many parents as presenting rather than resolving risks," says Dr Kelly. "Many parents rejected the possibility of being confronted with the choice of termination or continuation of an affected pregnancy."

The parents studied had children who were clients of a state-wide rural genetic outreach programme in the USA. A majority of parents still of childbearing age chose to avoid future pregnancies, or to decline prenatal

testing for subsequent pregnancies. "These decisions do not reflect simple rejection of medical intervention, opposition to abortion, and/or affirmation of a positive parenting experience with an affected child," says Dr Kelly. "Rather, choosing to avoid the condition of choice appears to be a strategy of responsible parenting that emerges from ambivalence towards the options presented by reproductive technologies."

"The choices associated with prenatal screening and genetic testing practices ... were for most parents shaped by a heightened sense of the risks inherent in reproduction and of the limits of medicine's ability to predict and control them," says Dr Kelly.

"Faced with this set of choices, many parents chose to avoid future reproduction. Many parents did not perceive the information they understood to be available from prenatal testing to be useful or relevant to their sense of responsibility and control. Experiencing the birth of an affected child for some parents exposed the limitations of medical knowledge and practice, and placed medicine alongside other forms of interpretation and evidence. Interventions such as genetic testing for many were associated with uncertainty and a loss of control for parents as responsible caretakers and decision makers."

More information: The paper 'Choosing not to choose: reproductive responses of parents of children with genetic conditions or impairments' is published in the journal *Sociology of Health and Illness* volume 31 no.1 January 2009 pp81-97, print ISSN 0141-9889, online ISSN 1467-9566. The paper can be accessed at: www3.interscience.wiley.com/journal/121575270/abstract .

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