

primary studies - published, non RCT

Cystic fibrosis newborn screening: impact on reproductive behavior and implications for genetic counseling.

Code: PM9651412

Year: 1998 **Date:** 1998

Author: Mischler EH

Participants

100 CF positive families (3 months after diagnosis); 71 CF positive families (1 year after diagnosis); 73 CF positive families (1994). 206 false positive IRT screening families (at sweat test); 109 false positive IRT/DNA screening families (at sweat test); 106 false positive IRT screening families (1 year later); 63 false positive IRT/DNA screening families (1 year later)

Interventions

questionnaire which was completed 3 months after diagnosis + the same questionnaire completed 1 year later

Outcome measures

Assessments of reproductive knowledge, attitudes, and behaviors of families of children diagnosed as having CF, of families of false positive CF NBS children

Main results

In families with a CF child, 95% initially understood that there was a 1 in 4 risk in subsequent pregnancies, and there was good retention of this information 1 year later. At the 1994 assessment, 52% of families had not yet conceived more children, but 74% of these already had children. In the couples in whom CF was diagnosed in the first child, 70% (95% confidence interval = 54% to 85%) conceived more children. There were 43 subsequent pregnancies in 31 families. Prenatal diagnosis was used by 26% of the families (8/31) for 21% of the pregnancies (9/43). There were 3 pregnancies with CF detected, all of which were carried to term. In the false-positive groups, >95% of families initially understood that their child definitely did not have CF. There was no difference between false-positive IRT and IRT/DNA groups, and the information was retained at 1 year. Follow-up assessment 1 year after negative sweat tests revealed that 7% of the IRT and 10% of the IRT/DNA families still thought about the results often or constantly. When asked whether the experience of screening affected feelings about having more children, an affirmative response was obtained in 4% of IRT families but in 17% of IRT/DNA families. One year later, more than half of the false-positive IRT/DNA families did not understand that they were at increased risk of having a child with CF.

Authors' conclusions

CF neonatal screening does not have a significant impact on the reproductive behavior of most families and that prenatal diagnosis is not used by the majority of CF families. IRT/DNA testing experiences seem to affect attitudes about having more children, and some parents are confused about the implications of the results, even with genetic counseling. However, persistent concerns about the sweat test result are limited. Questions raised by this study confirm the need for more research regarding the process of genetic counseling and its impact on reproductive attitudes and behavior in the newborn screening setting.

<http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/549/CN-00153549/frame.html>

See also

Pediatrics. 1998 Jul;102(1 Pt 1):44-52.

Keywords

Family Therapy; Counseling; Genetic Testing; Heterozygote Detection; Infant; Neonatal Screening; Newborn; non pharmacological intervention - diagn; non pharmacological intervention - psyc-soc-edu-org; pharmacological_intervention; Pregnancy; screening; Psychoeducation; Systemic interventions; diagnostic procedures;