primary studies - published, non RCT

Attitudes of parents of cystic fibrosis children towards neonatal screening and antenatal diagnosis.

Code: PM2289319 **Year:** 1990 **Date:** 1990 **Author:** al Jader LN

Participants

parents of CF babies diagnosed early following newborn screening (18 babies), and later on account of clinical criteria (11 babies). Families questioned were from Wales.

Interventions

detailed questionnaire

Outcome measures

parents' attitudes towards neonatal screening for cystic fibrosis (CF) and antenatal diagnosis by chorion villus biopsy (CVS)

Main results

Most parents supported screening: parents of 15/18 (83%) screened babies and 10/11 (91%) unscreened babies. Following antenatal diagnosis, 15/29 (52%) of families would abort a CF foetus. Neither standard of education nor social class correlated with attitudes to screening or antenatal diagnosis, although these factors were related to the parents' knowledge of CF in general. Several families emphasised the importance of minimal delay between the initial mention of the possibility of CF on IRT testing and confirmation (or otherwise) of the diagnosis. Four mothers acknowledge temporary rejection of their babies during the period of uncertainty or following the procedures of diagnosis, emphasising that neonatal screening for CF can have a psychological impact on the parent-child bonding.

Authors' conclusions

Although most families supported neonatal screening for CF, this study underlines some of the difficulties which may be encountered during the procedure of screening for CF by IRT.

http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/511/CN-00208511/frame.html

See also

Clinical Genetics YR: 1990 VL: 38 DE: RCT NO: 6

Keywords

Antenatal; Child; non pharmacological intervention - diagn; screening;