primary studies - published, non RCT

Implications of carrier identification in newborn screening for cystic fibrosis.

Code: PM14602692 **Year:** 2003 **Date:** 2003 **Author:** Parsons EP

Study design (if review, criteria of inclusion for studies)

Prospective study

Participants

Study: (a) families of an affected infant identified by screening (n = 9); (b) families of a carrier infant identified by screening (n = 10). Control: group of mothers from the general population (n = 82).

Interventions

carrier screening

Outcome measures

Questionnaires and semistructured interviews. MAIN OUTCOME MEASURES: Attitude to screening, assessments of the mother/baby relationship, anxiety, wellbeing.

Main results

All families were in favour of screening, with no evidence that the mother/baby relationship, anxiety or wellbeing had been adversely affected. Parents, however, did identify problems in terms of the service delivery protocol and genetic counselling practice.

Authors' conclusions

Six months after disclosure, carrier identification was not perceived by parents to be problematic.

See also

Arch Dis Child Fetal Neonatal Ed. 2003 Nov;88(6):F467-71.

Keywords

Heterozygote Detection; Neonatal Screening; Newborn; non pharmacological intervention - diagn; non pharmacological intervention - psyco-soc-edu-org; screening; carrier status; Genetic Predisposition to Disease; Psychoeducation; diagnostic procedures; non pharmacological intervention - genetic& reprod;