
primary studies - published, non RCT

Inconclusive cystic fibrosis neonatal screening results: long-term psychosocial effects on parents.

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Author: Perobelli S

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

Prospective study

Participants

Parents of 11 children with Ambiguous Diagnosis (group AD) were compared with parents of 11 children diagnosed with CF through neonatal screening [group Cystic Fibrosis Diagnosis (CFD)] and with parents of 11 Healthy Control children (group HC) matched for gender and age.

Interventions

Newborn Screening

Outcome measures

The emotional reaction to the inconclusive result; parents' anxiety about their child's health, long-term emotional distress, parent/child relationship

Main results

The emotional reaction to the inconclusive result was less pronounced in AD than in CFD ($p = 0.003$), and AD parents considered their infants as healthy as controls. Parents' anxiety about their child's health is stronger in CFD than in AD (p

Authors' conclusions

Inconclusive neonatal screening results appear to be understood and associated with lower anxiety levels than CF diagnosis. Concern about the child's health is similar to healthy controls and lower than in parents of CF children.

<http://dx.doi.org/10.1111/j.1651-2227.2009.01485.x>

See also

Acta Paediatr. 2009 Dec;98(12):1927-34. Epub 2009 Aug 18.

Keywords

Neonatal Screening; non pharmacological intervention - diagn; screening; diagnostic procedures;