primary studies - published, non RCT

Parent Experience With False-Positive Newborn Screening Results for Cystic Fibrosis.

Code: PM27485696 **Year:** 2016 **Date:** 2016 **Author:** Hayeems RZ

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

mixed-methods cohort design

Participants

Authors obtained prospective self-report data from mothers of infants with False Positive CF NBS results 2 to 3 months after confirmatory testing at Ontario's largest follow-up center, and from a randomly selected control sample of mothers of screen negative infants from the same region. Mothers completed a questionnaire assessing experience and psychosocial response. A sample of mothers of FP infants completed qualitative interviews.

Interventions

newborn bloodspot screening (NBS)

Outcome measures

Mothers experience and psychosocial response.

Main results

One hundred thirty-four mothers of FP infants (response rate, 55%) and 411 controls (response rate, 47%) completed questionnaires; 54 mothers of FP infants were interviewed. Selected psychosocial response measures did not detect psychosocial distress in newborns or 1 year later (P > .05). Mothers recalled distress during notification of the positive result and in the follow-up testing period related to fear of chronic illness, but valued the screening system of care in mitigating concerns.

Authors' conclusions

Although immediate distress was reported among mothers of FP infants, selected psychometric tools did not detect these concerns. The NBS center from which mothers were recruited minimizes delay between notification and confirmatory testing and ensures trained professionals are communicating results and facilitating follow-up. These factors may explain the presence of minimal psychosocial burden. The screening system reflected herein may be a model for NBS programs working to minimize FP-related psychosocial harm.

http://dx.doi.org/10.1542/peds.2016-1052

See also

Pediatrics. 2016 Aug 2. pii: e20161052.

Keywords

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