

primary studies - published RCT

Assessment of Parental Understanding of Positive Newborn Screening Results and Carrier Status for Cystic Fibrosis with the use of a Short Educational Video.

Code: PM25236483 Year: 2015 Date: 2015 Author: Temme R

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

Randomized study

Participants

One hundred parents of infants identified as CF carriers through NBS

Interventions

parents were randomly assigned by household to either a genetic counseling only group or a genetic counseling and video group.

Outcome measures

All participants completed a knowledge-based questionnaire before, immediately after, and six weeks following genetic counseling. This included questions about resources accessed before and after the appointment.

Main results

Seventy-two percent of participants accessed resources on their own prior to genetic counseling; these participants scored significantly higher on the pre-counseling questionnaire (p = 0.03). Post-counseling knowledge scores for both groups significantly improved after genetic counseling (p

Authors' conclusions

This study demonstrates the effectiveness of an educational video and reinforces the importance of genetic counseling following positive NBS results for CF.

http://dx.doi.org/10.1007/s10897-014-9767-7

See also

J Genet Couns. 2015 Jun;24(3):473-81. doi: 10.1007/s10897-014-9767-7. Epub 2014 Sep 19.

Keywords

Adult; Caregivers; Child; non pharmacological intervention - psyco-soc-edu-org; Psychoeducation; training; Self-Management; Systemic interventions; Behavioural interventions; Cognitive analytic therapy; information; Counseling; Genetic Testing; Heterozygote Detection; screening; diagnostic procedures;