primary studies - published RCT

Teaching about cystic fibrosis carrier screening by using written and video information.

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

RCT

Participants

Subjects in group I (n = 238) were (1) individuals in steady relationships and their partners, (2) > or = 18 years old, and (3) not pregnant. . Subjects in group II (n = 108) were parents seeking well child care in a university clinic.

Interventions

Participants were randomized to receive written or video materials. All received a brief questionnaire. Those who accepted free screening and were not demonstrable carriers were sent a letter explaining their results and another questionnaire

Outcome measures

The main outcome measures were ability to answer questions correctly about (1) health status of CF carriers and people with CF, (2) the possibility of false-negative results, and (3) for those who had screening, the implications of their own results.

Main results

Written and video materials were equally effective in conveying information. Prior to screening, subjects answered an average of 86% of questions correctly. Subjects with less formal education answered fewer questions correctly; 60% of those with less than a high school education had adequate knowledge of the health consequences of having CF or being a carrier, compared with > or = 94% of college graduates. Performance improved after screening. Where neither partner was a demonstrable carrier, 88% knew their own and their partner's test results, and 90% indicated that their risk of having a child with CF was not zero.

Authors' conclusions

Written and video educational materials can be used without face-to-face counseling to inform most people about carrier screening and their test results. These materials may be less effective for those with lower educational backgrounds.

http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/107/CN-00116107/frame.html

See also

Am J Hum Genet. 1995 Jul;57(1):171-81.

Keywords

Adult; Genetic Testing; Heterozygote Detection; information; non pharmacological intervention - diagn; non pharmacological intervention - psyco-soc-edu-org; pharmacological_intervention; Prenatal Diagnosis; screening; training; carrier status; Genetic Predisposition to Disease; diagnostic procedures; Psychoeducation; non pharmacological intervention - genetic& reprod;