

primary studies - published RCT

Psychosocial and educational outcomes associated with home- and clinic-based pretest education and cystic fibrosis carrier testing among a population of at-risk relatives.

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

Parallel RCT

Participants

Sample agreeing to participate was N = 299 Subsequently unable to collect some data on 68 participants whilst waiting for test results. 1st, 2nd & 3rd degree relatives of people with CF treated at one of the University of North Carolina Hospitals. Participants randomised on basis of family membership of index CF patient. 11 excluded. Population of interest N = 514

Interventions

Two approaches to CF gene pre-test education and carrier testing. Families then randomly allocated to the 2 treatment arms prior to relatives of CF index patient being approached for participation in the study. 30 minute education session & saliva sample. 1. Genetic clinic education and testing (N = 70) 2. Home-based education and testing (N = 171) CF carrier pamphlet received in mail & kit for providing a buccal cell sample for mail return. Both groups received a toll-free telephone number for any questions.

Outcome measures

State Trait Anxiety Inventory (STAI). Positive and Negative Affect Scale (PANAS). Survey - Satisfaction of education and testing Assessments at three time points: 1. baseline - telephone interview 2. waiting for test results - mailed questionnaire 3. immediately after test results - mailed questionnaire. Results of the test were normally reported about 4 weeks from the date of supply of the saliva sample. Ad hoc knowledge test measure delivered before test results received.

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See also

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Keywords

Home; non pharmacological intervention - psyco-soc-edu-org; Psychoeducation; carrier status; Genetic Predisposition to Disease;