

primary studies - published RCT

A pilot study of aerosolized amiloride for the treatment of lung disease in cystic fibrosis.

Code: PM2157983

Year: 1990 **Date:** 1995

Author: Knowles MR

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

Pragmatic randomised trial at an Hospital antenatal clinic serving a regional population.

Participants

2002 women (couples) attending for booking antenatal visit at less than 17 weeks' gestation with no family history of cystic fibrosis.

Interventions

Offering counselling and carrier testing for cystic fibrosis, either to women in the first instance (stepwise) or to couples (couple screening).

Outcome measures

Uptake rates; anxiety; knowledge of cystic fibrosis and carrier status (both partners); attitudes to health, pregnancy, the baby, and screening (both partners); and uptake of carrier testing by relatives.

Main results

Uptake of screening was the same for both approaches (90%). After delivery most women remembered test results and their meaning, but 53/253 (21%) of those with negative results of couple testing had forgotten that repeat testing would be advisable if they had a pregnancy with a new partner. With stepwise screening women identified as carriers had high levels of anxiety when results were received (mean anxiety score 52.3). This dissipated with a reassuring partner's result (carriers' mean anxiety score 36.1) to levels similar to those receiving negative results from couple screening. Of those receiving negative results, women who had stepwise screening were significantly less anxious than those who had couple screening (mean score with result 32.1 v 35.4, 95% confidence interval for difference -4.7 to -2.1).

Authors' conclusions

Couple screening allows carriers to avoid transient high levels of anxiety, but is associated with more anxiety and false reassurance among most screenees who will test negative. Stepwise screening gives carriers and their relatives genetic information and is, in our opinion, the better method.

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See also

N Engl J Med. 1990 Apr 26;322(17):1189-94.

Keywords

Antenatal; Family Therapy; Counseling; Genetic Testing; Heterozygote Detection; Hospitalization; Hospital care; non pharmacological intervention - diagn; non pharmacological intervention - psycho-soc-edu-org; pharmacological_intervention; Pregnancy; Prenatal Diagnosis; screening; carrier status; Genetic Predisposition to Disease; Psychoeducation; Systemic interventions; diagnostic procedures; Organization; non pharmacological intervention - genetic& reprod;