primary studies - published, non RCT

The uptake and acceptability to patients of cystic fibrosis carrier testing offered in pregnancy by the GP.

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

women accepting were alternately allocated to either couple testing (with full disclosure) or stepwise testing. Setting - Eight general practices in the north west region with a combined patient list size of 42,000.

Participants

623 pregnant women below 14 weeks' gestation

Interventions

cystic fibrosis (CF) carrier testing offered to women at the first antenatal booking appointment by their general practitioner.

Outcome measures

Main outcome measures - (1) Acceptance of the offer of CF carrier testing. (2) Acceptability of the test to women following screening, evaluated through (i) postal questionnaire, (ii) semistructured interview.

Main results

Five hundred and twenty-nine (84.9%) women accepted the test; the level of uptake varied across the eight practices (range 11-99%). In 26/249 (10%) couple tests no paternal sample was provided. When asked what had influenced their decision to be tested, 59/377 (16%) women did not refer to CF in their answers and six (2%) said that they did not feel they could refuse the test. After receiving their results, 368/379 (97%) women felt that they had made the right decision to be tested, but two carriers and three non-carriers had felt unhappy about testing. Couple testing with full disclosure was associated with lower anxiety levels two weeks after receiving the result for the pregnancy than stepwise testing and 82/278 (29%) non-carriers believed that they had no residual risk in relation to CF.

Authors' conclusions

The response from women accepting CF carrier testing was largely positive but a minority of women expressed concern about the test and the way it was offered and a substantial proportion of women were falsely reassured by their ('negative') result. Higher levels of acceptance tended to occur in the practices which offered the test there and then rather than giving couples more time to decide about testing. Some women appeared to have accepted the test because of a belief in the importance of testing in pregnancy rather than because of the disease in question.

http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/486/CN-00334486/frame.html

See also

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Keywords

Adolescent; Adult; Heterozygote Detection; non pharmacological intervention - diagn; Pregnancy; screening; diagnostic procedures;