primary studies - published, non RCT

Population-based genetic screening for cystic fibrosis: attitudes and outcomes.

Code: PM20090299 **Year:** 2010 **Date:** 2010 **Author:** Ioannou L

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

non randomised trial

Participants

Between January 2006 and June 2008 all carriers (n = 79) and a randomly selected cohort of non-carriers (n = 162) were invited to participate.

Interventions

A purpose-designed questionnaire

Outcome measures

knowledge, recollection and meaning of carrier status, reasons for having screening, anxiety and communication of results to family members. participants' attitude towards carrier screening for CF was generally very positive.

Main results

47 carriers (62%) and 65 non-carriers (41%) returned the questionnaire. Most participants were female (97%) aged 35-39 (46%). The main reasons for choosing screening were the perception of CF as a severe condition and a doctor's recommendation. All carriers correctly recalled their carrier status and the risk of having a child with CF, while 3 non-carriers (4.7%) were unsure of their carrier status and 12 (22%) incorrectly recalled their residual risk. Carriers answered the knowledge questions correctly more often than non-carriers. There was no difference in anxiety between carriers and non-carriers. The majority of carriers informed relatives of their increased risk of being a carrier.

Authors' conclusions

Participants' attitude towards carrier screening for CF was generally very positive. Our model of screening could be applied on a larger scale.

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See also

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Keywords

Adult; Antenatal; Family Therapy; Counseling; Genetic Predisposition to Disease; Genetic Screening; Genetic Testing; Heterozygote; Heterozygote Detection; non pharmacological intervention - diagn; non pharmacological intervention - genetic& reprod; non pharmacological intervention - psyco-soc-edu-org; pharmacological_intervention; Pregnancy; screening; carrier status; Psychoeducation; Systemic interventions; diagnostic procedures;