

primary studies - published, non RCT

Cystic fibrosis newborn screening: impact on reproductive behavior and implications for genetic counseling.

Code: PM9651412

Year: 1998 **Date:** 2020

Author: Mischler EH

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

non-randomized trial

Participants

154 Patients with Cystic Fibrosis (CF) followed by the CF clinic of the Bambino Gesù Hospital in Rome. Two groups of patients were recruited, homogeneous for age, sex, BMI, FEV1, prevalence of CF-related Diabetes and CF-related Hepatopathy, access to new therapies with modulators

Interventions

Home care through a telemonitoring system. 1) an IN group (N = 44) followed through a home telemonitoring system, 2) an OUT control group (N = 110) followed according to the standards of care.

Outcome measures

Pulmonary colonization of the lungs, number and type of hospital admissions, respiratory function, BMI.

Main results

The OUT group had a statistically significant increase in the prevalence of *Pseudomonas Aeruginosa* infections during the observation period. Furthermore, a significant decrease in lung function assessed through FEV1 was also observed in the OUT group.

Authors' conclusions

Adolescent and adult patients belonging to the CF center who are not followed through the dedicated home telemonitoring service show, in the three-year period 2017-19, an increase in *Pseudomonas Aeruginosa* infections and a greater decrease in respiratory function. The use of telemedicine in CF is therefore an effective system not only in monitoring the disease but also as a treatment strategy, in the context of an evolving multidisciplinary model. As advantages, telemedicine can reduce the number of *Pseudomonas Aeruginosa* lung infections and the greater stability of respiratory function over time.

<http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/549/CN-00153549/frame.html>

See also

Pediatrics. 1998 Jul;102(1 Pt 1):44-52.

Keywords

Adult; Caregivers; Home; Home Care Services; Lung Transplantation; non pharmacological intervention - psycho-soc-edu-org; non pharmacological intervention - surg; telemedicine; transplantation; Depression; Mental Disease-Psychiatric Conditions; Organization;