

primary studies - published, non RCT

Proband and parent assistance in identifying relatives for cystic fibrosis carrier testing.

Code: PM8737645

Year: 1996 **Date:** 2017

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

This single-centre pilot study

Participants

Patients who were older than eight years of age

Interventions

Patients assigned to two groups: one without intervention (control group), and one with intervention. Each patient from the intervention group received Skype-based online video chats and WhatsApp messages from members of the multidisciplinary CF team.

Outcome measures

CF questionnaires, revised (CFQ-R) scores, knowledge and adherence based on CF My Way and patients satisfaction were evaluated before and after three months. Feasibility was assessed by session attendance, acceptability and satisfaction survey. Descriptive analysis and paired and non-paired t-tests were used as applicable.

Main results

Eighteen patients were recruited to this feasibility study (nine in each group). Each intervention group participant had between four and six Skype video chats and received 22-45 WhatsApp messages. In this small study, CFQ-R scores, knowledge, adherence and patient satisfaction were similar in both groups before and after the three-month intervention.

Authors' conclusions

A telehealth-based approach, using Skype video chats and WhatsApp messages, was feasible and acceptable in this pilot study. A larger and longer multi-centre study is warranted to examine the efficacy of these interventions to improve knowledge, adherence and communication.

<http://www.mrw.interscience.wiley.com/cochrane/clcentral/articles/935/CN-00451935/frame.html>

See also

American Journal of Medical Genetics YR: 1996 VL: 63 DE: RCT NO: 3

Keywords

Adult; Child; Adolescent; Caregivers; Home; Home Care Services; non pharmacological intervention - psycho-soc-edu-org; telemedicine; Organization;