

primary studies - published, non RCT

Initiating transitional care for adolescents with cystic fibrosis at the age of 12 is both feasible and promising.

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

Single centre, non-randomised and non-controlled prospective study

Participants

Patients aged 12 to 18 at baseline, at the cystic fibrosis centre at Copenhagen University Hospital Rigshospitalet from 2010-2011

Interventions

Prospective programme assessing patients aged 12 to 18 at baseline and after 12 months.

Outcome measures

Changes implemented included staff training on communication, a more youth friendly feel to the outpatient clinic, the introduction of youth consultations partly alone with the adolescent, and a parents' evening focusing on cystic fibrosis in adolescence. Lung function and body mass index (BMI) were measured monthly and adolescents were assessed for their readiness for transition and quality of life at baseline and 12 months.

Main results

We found that 40 (98%) of the eligible patients participated and youth consultations were successfully implemented with no dropouts. The readiness checklist score increased significantly over the one-year study period, indicating increased readiness for transfer and self-care. Overall quality of life, lung function and BMI remained stable during the study period.

Authors' conclusions

A well structured transition programme for cystic fibrosis patients as young as 12 years of age proved to be both feasible and sustainable.

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See also

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Keywords

Adolescent; Adult; Caregivers; Child; non pharmacological intervention - psycosoceduorg; Self-Management; Behavioural interventions; training;