Cochrane Database of Systematic Reviews - - Cochrane Review

Interventions for promoting participation in shared decision-making for children and adolescents with cystic fibrosis

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

Randomised controlled trials (RCTs) and cluster RCTs; cross-over trials not included.

Participants

Children and adolescents diagnosed with CF clinically with or without any concomitant disease or disorder and aged between four and 18 years.

Interventions

Interventions for promoting shared decision-making (SDM) in children or adolescents which are aimed at children or adolescents, their parents or healthcare professionals, or any combinations of these groups (a one-to-one basis, a group basis, discussion sessions, role play sessions, blended learning sessions, online learning sessions and the use of hard-copy information resources such as leaflets or workbooks; interventions may be delivered by professionals or parents or both), compared with usual care or to alternative SDM promotion strategies for the same group of people

Outcome measures

Primary outcomes 1. Presence of shared decision-making measured by the change in score of any validated tool (the Observing Patient Involvement 12-item (OPTION) Scale; the Observer-based Measure Observer 5-item (OPTION) Scale;. decision-making instrument facilitation antecedents;. decision process (e.g. the Rochester Participatory Decision-making Scale 2. Quality of life (QoL) as measured by the Cystic Fibrosis Questionnaire-Revised (CFQ-R) 3. Adverse effect such as longer consultation time, increased frequency of hospital admissions, longer hospital stay, increased costs or unanticipated adverse effects as reported by study authors

Main results

No eligible RCTs were identified for inclusion in this systematic review.

Authors' conclusions

We were unable to identify RCTs with evidence which would support healthcare policyâ€•making and practice related to implementation of shared decisionâ€•making for children and adolescents (aged between four and 18 years) with CF). We hope that having identified this gap in research, awareness will increase amongst researchers of the need to design highâ€•quality shared decisionâ€•making interventions for young people with CF, perhaps adapted from existing models for adults, and to test these interventions and children's preferences in RCTs. It is also important to target health professionals with evidenceâ€•based education programmes on shared decisionâ€•making and a need for international consensus on addressing the variability in education programmes.

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See also

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Keywords

Behavioural interventions; non pharmacological intervention - psyco-soc-edu-org; Training;