Cochrane Review

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

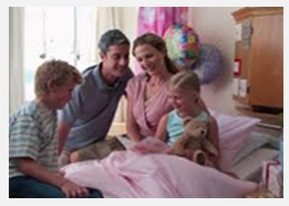
Helen Malone, School of Nursing & Midwifery, Trinity College Dublin, The University of Dublin. (hmalone@tcd.ie)
Susan Biggar, Consumer Partnerships, Health Issues Centre, Melbourne, Australia.
Sheila Javadpour, Respiratory Medicine Department, Our Lady's Children's Hospital, Dublin.
Zai Edworthy, Psychology Department, Temple Street Children's University Hospital, Dublin.
Greg Sheaf, The Library of Trinity College Dublin, The University of Dublin.
Imelda Coyne, School of Nursing & Midwifery, Trinity College Dublin, The University of Dublin. (Supervisor)

Background and context

Cystic fibrosis (CF) is a genetic condition with significant variations in incidence, morbidity and mortality worldwide. The Republic of Ireland has the highest prevalence of CF in the world. Treatment improvements mean that children and adults with CF are living longer. As a result, long term management issues have become more relevant. Paediatric shared decision-making (SDM) helps children and young adults to express preferences in healthcare decisions that affect them. Children and young adults involved in healthcare decisions about their healthcare report less anxiety and increased satisfaction with care. We wanted to find out if there were techniques for helping children and young people with CF to take part in decisions about their healthcare

Methods

This was a Cochrane Systematic Review. Electronic database searches included: PubMed, CINAHL Complete (EBSCO), Embase (Elsevier), PsycINFO (EBSCO), WHO (ICTRP), ASSIA (ProQuest), ERIC (ProQuest), ClinicalTrials.gov and grey literature searches. The primary outcome was presence of shared decision-making for children and adolescents with CF aged four- 18 years.



Results

A total of 3,028 records were retrieved from the database and grey literature searches. Unfortunately no studies were eligible for inclusion in the review**.**

Discussion

We found no evidence from randomised controlled trials (RCTs) regarding shared decision-making for children and adolescents with cystic fibrosis. However, the literature suggested a number of factors as impacting on the likelihood of paediatric shared decision-making being successful, some of which include: simple jargon free language, checking the young person's understanding of information, providing time and opportunity to express preferences.

Conclusions

This Cochrane review has identified a lack of RCTs on interventions that promote participation in SDM for children and adolescents with CF aged between four and 18 years. For children and adolescents with CF (4-18 years) there is a need for high-quality SDM interventions that are tested using RCTs.

References
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IMDF 2014 Informed Medical Decision Foundation: what is shared decision-making? http://informedmedicaldecisions.org/what-is-shared-decision-making

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