

*"The doctor needs to talk to me,
because I'm the one that deals with it
and I know what happens"*

Shared Decision-Making - An Evidence-Based Approach for
Supporting Children, Parents and Practitioners to Manage
Chronic Conditions

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Abstract

UK government policy urges healthcare practitioners to involve patients, including child patients, in decision-making. To date, there has been no assessment of the evidence regarding the efficacy and the acceptability of such approaches when used with children. This thesis reports the development, testing and consequent refinement of a theory-based model of shared decision-making (SDM) for use with children with chronic conditions. A multi-method approach was used to explore its composition comprehensively and to assess the evidence base.

SDM involves patients and carers in the process of making healthcare decisions; drawing on both clinicians' expertise, and patients' and carers' experience and values. Four distinct elements were identified in the development of a theoretical model:

- a. recognising and understanding that *patients' experiences and values* play a part in managing chronic conditions
- b. facilitating active *involvement in consultations* of patients, carers and practitioners
- c. *making mutual decisions* about treatments and management regimes agreed by practitioners, patients and families
- d. fostering a sense of *trust and partnership* between practitioners and families.

Qualitative evidence collected via in-depth interviews and a systematic synthesis of qualitative research reveals that, although minor amendments are necessary, the structure of the four-component model is valid. The strong qualitative evidence base reveals children and parents perceive SDM to improve

their experience of chronic conditions, their experience of working with practitioners, and their ability to manage their condition.

A systematic synthesis of research measuring the effects of SDM-type interventions reveals a more limited evidence base. Evidence from four sound trials suggests that each individual SDM component can improve the health of children with chronic conditions, address their social concerns in relation to their condition and improve practitioner-patient relationships. Further trials research is needed, however, to determine the efficacy of SDM as a holistic and theoretically embedded intervention.