



Symposium 6 - 2018 Nordic Implementation Conference

Implementation of a manual-based intervention to promote health in siblings of children with chronic disorders

Presenters: Krister Fjermestad, Yngvild Bjartveit Haugeland (Department of Psychology, University of Oslo), Christoffer Hals and Torun Marie Vatne (FRAMBU resource centre for rare disorders, Norway)

Overview

This symposium comprises four presentations, which all relate to various implementation aspects of an ongoing research trial for siblings and parents of children with chronic disorders.

Siblings are at increased risk of mental health problems due to facing multiple burdens. Limited services are offered for this group, and when offered, interventions are often group-based and provided by practitioners with limited formal training.

We represent a research consortium responsible for having developed and tested a manual-based sibling and parent group intervention.

- Presentation 1 (Vatne, PhD) provides an overview of the project to date.
- Presentation 2 (Haugeland, PhD) provides results from an open trial of the intervention with 99 families.
- Presentation 3 (Hals, MSc) provides details from an e-learning program to train practitioners in developing the intervention.
- Presentation 4 (Fjermestad, PhD) provides plans to expand the project to a large randomized controlled trial.

The presentations will be followed by a discussion of implementation challenges in the project, chaired by Mossige (Professor).

Details are provided below.



Presentation 1: The development of a parent-child intervention for siblings of children with chronic disorders (Torun Marie Vatne)

Background

Despite the documented elevated risk for psychological maladjustment among siblings of children with chronic disorders, few preventive interventions are provided. Occasionally, support groups are provided, but the interventions are not evidence based and are often led by personnel with little or no formal education in leading child groups.

Project aim

To develop a group intervention for siblings and parents of children with a chronic disorder, establish an evidence-base for the intervention, and develop tailored training schemes for group leaders.

Project methods

We describe the development of a group intervention for siblings and parents of children with a chronic disorder in a five-stage process; (1) reviewing literature about siblings of children with chronic disorders, (2) reviewing research on sibling interventions, (3) an exploratory study with 56 siblings aged 8-16 years, (4) six expert workshops and (5) pilot testing of intervention with 99 families.

Project results

The process resulted in a five session intervention with the aim of increasing quality of the parent-sibling communication. The intervention comprises three modules: (1) Introduction module with information and relationship building. (2) Knowledge module about siblings' need for knowledge about the disorder. (3) Emotion module about the challenges experienced by siblings. The intervention comprises parallel separate parent-child groups and joint parent-child sessions. A descriptive manual for group leaders, tutoring videos, folders for siblings/ parents and evaluation forms were developed.

Preliminary or final conclusion / discussion

We have developed a knowledge based intervention with the potential to prevent psychological maladjustment in a vulnerable group of children. The intervention received positive evaluations from children and parents involved in the developmental process and are currently being evaluated in an open trial with 99 children.



Presentation 2: An integrated support group intervention for siblings and parents of children with chronic disorders (Yngvild Bjartveit Haukeland)

Background

Chronic health conditions in children affect family communication and are associated with an elevated risk for psychological difficulties in healthy siblings. Parental support and sibling diagnostic knowledge are among the factors associated with sibling mental health. Effective interventions may enhance the outcome for siblings. However, no evidence based intervention for siblings exist.

Project aim

Based on family system theory and previous research, a manual of a five-session parent-sibling support group program was developed. The aims of the intervention were to strengthen parent-sibling communication about diagnosis and the emotional experiences of siblings, and through this improve sibling adjustment. The current study aimed to evaluate the components of the intervention in an open trial, to give directions for further sibling intervention research in a randomized controlled design.

Project methods

The current study explored an integrated parent-sibling intervention in a pre-test-post-test design. The sample consisted of 99 siblings aged 8-16 years ($M = 11.5$ years; 54.5% girls) of children with different chronic disorders, and their parents. Twenty-two support groups were conducted, and outcome measures were assessed at baseline, three months after the intervention and at six months' follow-up. Both sibling and parent reports were gathered, and user satisfaction was registered at the end of intervention. All group sessions were video recorded and manual fidelity was assessed.

Project results

Longitudinal data was analysed through growth curve modelling and revealed that from pre- to post-test measurement, sibling adjustment improved, sibling diagnostic knowledge increased, and parent-sibling communication was strengthened. Both siblings and parents reported high satisfaction after participation in the intervention, indicating high approval of the usefulness of the intervention components.

Preliminary or final conclusion / discussion

The present study suggests that an intervention directed at strengthening communication between parents and healthy siblings may be a useful way of intervening with siblings. Growth curve analyses reveal promising results indicating improved sibling adaptation and family communication, and suggest further investigation of the manual components within a controlled design.



Presentation 3: Implementing e-learning for intervention providers (Christoffer Hals)

Background

A group intervention for siblings and parents of children with chronic disorders (SIBS) was developed in 2012. SIBS showed to have promising effects on communication and child wellbeing in an open trial. Child group leaders often lack formal education in leading groups. For a planned RCT and future implementation of SIBS a learning package for practitioners needs to be developed.

Project aim

The aim is to develop a combined e-learning and practical course for group leaders in the SIBS intervention. The aim of the e-learning course is to establish a basic knowledge level that will maximize the learning outcomes from the practical course.

Project methods

The following methods will be implemented to support the project aim: 1) Conducting workshops to inform contents of the e-learning course. The workshops will be a collaboration between practitioners, siblings and parents of children with chronic disorders, and researchers; 2) Developing practical animations, illustrations, and videos for the e-learning course; and 3) Implement the e-learning course through an established open access online learning platform (www.sjelden.no), which is developed and operated by the Norwegian Advisory unit for Rare Disorders.

Project results

By May 2018 the program will have been developed and tested. Preliminary results will be presented at the conference, including video clips from the program. The e-learning course will comprise of 7 short modules. Each module should take 20 minutes to complete and comprises: a) introduction to the theme; b) interviews; c) case studies; d) discussions; and e) practical advice. The following media will be used: text, videos, animations, podcasts, pictures and gamification. The goal of this e-learning course is to prepare participants for the main course to be conducted in June 2018.

Preliminary or final conclusion / discussion

We have developed a knowledge based intervention with the potential to prevent psychological maladjustment in a vulnerable group of children. It is important to properly educate practitioners for future implementation and to conduct a randomized controlled trial. Development of a combined e-learning and practical course will potentially maximize learning outcome in participants.



Presentation 4: Plans for a multi-national RCT for families of children with chronic disorders (Krister Fjermestad)

Background

Sibling relations are challenged when one's brother or sister has neurodevelopmental disorder (ND), such as autism and intellectual disability. Siblings of children with ND are at risk of mental health problems and reduced quality of life due to multiple burdens. This means siblings need interventions. However, no evidence-based interventions for siblings exist. Therefore, we aim to develop one.

Project aim

Aim 1 is to improve functioning in siblings and parents of children with ND by evaluating the effectiveness of a manual-based group intervention for improving mental health and quality of life in siblings and parents in an RCT. Aim 2 is to advance knowledge about risk factors in families of children with ND. Aim 3 is to provide health care providers and authorities with the right tools to meet the health needs of siblings by advancing group leader skills that optimize outcomes of the intervention through offering training.

Project methods

SIBS is a group RCT. The control condition is 12-week waitlist. Planned sample size is 288 across 8 sites. Inclusion criteria are 1) Being the sibling of a child aged 0 to 18 years diagnosed with a ND enrolled in specialist services; 2) Age 12-16 years; 3) A parent able to attend. Exclusion criteria include the sibling having ND or severe conduct problems. Siblings and parents will be randomized in groups of 6. The intervention comprised 5 sessions delivered over 2 days. Outcomes include mental health, adjustment, and social support.

Project results

Outcomes will be measured from baseline to 3, 6, and 12 months follow-up. Based on results from a pilot study with > 100 families, we expect significant improvement on all relevant measures, and that the intervention group will outperform the waitlist. We will also examine predictors of change and symptom trajectories over time to provide the field with new insights into risk and protective factors for siblings and families of children with ND.

Preliminary or final conclusion / discussion

Issues to be discussed regarding the design are: How to ensure recruitment? What is the optimal control condition? Should inclusion and exclusion criteria be revised? How to ensure fidelity of intervention providers? What is the optimal level of training for intervention providers? How to enable electronic versions of measures? How to prevent dropout from follow-up measurement time points? This discussion will be based on intervention literature and experiences from our pilot trial.