The development of a joint parent-child intervention for siblings of children with chronic disorders

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Sammendrag

Juni 2017 ble det vedtatt en endring i helsepersonelloven som innebærer at helsepersonell plikter å identifisere og adressere behov for støtte blant søsken til barn med kroniske helsetilstander. Denne artikkelen beskriver utviklingen av en manualbasert intervensjon for søsken.

Med sikte på å utvikle en erfarings- og kunnskapsbasert intervensjon inneholdt utviklingsprosessen litteratur- og internett søk, en deskriptiv studie av støttegrupper for søsken med 80 deltakende barn, workshops med tjenesteyter- og brukermedvirkning og pilottesting av intervensjonen med 68 barn og deres foreldre.

Resultatet ble en integrert søskens og foreldre-intervensjon (SIBS) med fokus på å styrke kommunikasjonen om diagnosen til det affiserte barnet og relaterte søskenutfordringer. SIBS intervensjonen inneholder fem økter; tre separate barne- og foreldregruppe-økter og to økter hvor foreldre og barn samtaler i par under veiledning. SIBS mottok positive evalueringer av deltakende foreldre og barn.
Vi presenterer preliminærv evidens for at den intensive og fokuserte SIBS intervenjonsen kan identifisere og adressere behov blant søsken til barn med kroniske tilstander. SIBS kan i fremtiden bli implementert i kommunehelsetjenesten i tråd med Helsepersonellens nye krav.

Nøkkelord: kroniske tilstander, foreldre-barn kommunikasjon, søsken, gruppeintervensjon, forebygging

Abstract
As of June 2017, Norwegian health personnel are required by law to identify and address the needs of siblings of children with chronic health disorders. This paper describes the development of a manual-based intervention for siblings.

To create a knowledge- and evidence-based intervention, the developmental process involved literature and internet searches, a descriptive study of sibling support groups with 80 participating children, workshops with practitioner and user participation, and the piloting of the intervention with 68 children and their parents.

The result was an integrated parent and sibling intervention (SIBS) focusing on strengthening communication about the diagnosis of the affected child and the challenges of siblings. The SIBS intervention comprises five sessions: three separate sibling and parent group sessions, and two sessions where the sibling and the parent talk in pairs with supervision. The SIBS intervention received positive evaluations from children and parents.

We offer preliminary evidence that the intensive and focused SIBS intervention may identify and address the needs of siblings of children with chronic disorders. The SIBS intervention may be implemented in future municipal health care given recent legislation requirements.

Keywords: chronic disorders, parent-child communication, siblings, group intervention, prevention

Introduction

Up to 15% of Norwegian children have a chronic physical or mental disorder that affects their everyday functioning (Grøholdt & Nordhagen. 2002; The Norwegian Directorate for Children, Youth and Family Affairs, 2017). These children often have healthy siblings. Sibling relationships normally last longer than any other relationships in life. Sibling relations may have profound effects upon children’s cognitive, emotional and social development, and represent a potential buffer against everyday stress and difficult life events (Brody, 1998; Gass, Jenkins, & Dunn, 2007). Children report that warmth, conflicts, mutuality, power negotiations, and differential parental treatment affect their evaluations of the quality of sibling relations (Furman & Buhrmester, 1985; Buhrmester & Furman, 1990). Based on research regarding the implications on life in families
of children with a chronic disorder (CD) (Grue, 2011), there is reason to believe that a CD may affect the sibling relation and lives of healthy siblings.

The Norwegian Law for Health Personnel (Helsepersonelloven) was changed in 2009 requiring health personnel to safeguard the need for information and necessary follow-up of children as next-of-kin. A major fault of the law was the exclusive focus on children as next-of-kin to adults affected by illness or disability. However, in June 2017 the law was changed to also include siblings (§ 10a). Thus, health care providers are currently in need of knowledge about how to provide support to siblings when required.

One potential way of addressing the needs of siblings is to arrange support groups. Groups of likeminded individuals may provide support by sharing feelings and listening to problems without offering criticism or suggestions (Forssyth, 1999). For some vulnerable groups of children, nationally recommended group interventions exist and are offered by local health care providers in Norwegian municipalities (e.g. ‘SMIL’, groups for children of adults with psychological difficulties, and ‘PIS’, groups for children with divorced parents; see www.ungsinn.no). The purpose of support groups is for children to experience support, gain attention, and better cope with difficulties. To the best of our knowledge, there exists no national initiative to coordinate such groups for siblings of children with chronic disorders.

Frambu Resource Centre for rare disorders is a national competence unit for rare disorders in Norway. Frambu offers information services to families affected by rare neurodevelopmental disorders caused by chromosomal abnormalities, microdeletions, copy number variations or single gene mutations, or progressive neuromuscular or metabolic disorders. At Frambu, groups for siblings have been conducted for decades. Methods used have varied from open conversations, pen-and-paper tasks, applied theatre groups, lecture-based sessions and creative art groups (Vatne, Andersen & Haug, 2013). The topics of the sessions have varied. In some groups, topics have been initiated by children; in others, topics have been pre-defined and introduced by the group leader.

In 2011, the group leaders (psychologists and education specialists) reviewed and evaluated the methods used at Frambu and identified a need to develop a standardised protocol based upon the existing knowledge base. Consequently, psychologists from Frambu and the Department of Psychology, University of Oslo, initiated the study “Preventing Mental Health Problems in Siblings of Children with Neurodevelopmental Disorders” (short title SIBS) with the aim of
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developing an intervention for siblings of children with chronic disorders based on current knowledge and clinical experience.

Method
The SIBS intervention was developed in a two-stage process: 1) The establishment of a knowledge base and 2) The development and pilot-testing of the intervention. These stages are described below.

Establishing a knowledge base
To gather knowledge about the wellbeing of siblings, and to inform the focus of the SIBS intervention, we conducted literature searches published before 2013 in the bases PsychInfo and Medline. Search terms were siblings/children as next of kin AND children with disability/illness/disease/disorders. All abstracts were reviewed, and relevant papers selected for close reading.

To gather information about existing group interventions for siblings in Norway, we conducted internet searches and contacted institutions. The information about existing interventions was discussed in project group meetings, and aspects relevant for the development of the SIBS Intervention were documented. Knowledge about international interventions was gathered through searches in the bases PsychInfo and Medline on research published before 2013. Search terms were siblings/children as next of kin AND children with disability/illness/disease/disorders AND intervention/support group/group therapy/camps. All abstracts were reviewed by the group and relevant papers selected for close reading. Similar internet searches were conducted to identify international resource sites targeting this population. Aspects relevant for the development of the SIBS intervention were documented.

Given that (a) the literature reviewed about sibling wellbeing was primarily quantitative and/or based on parent report; (b) the disorders in focus were not rare; and (c) the literature about interventions focused on effects and not the processes of interventions, we found it necessary to fill in the gaps and conduct a descriptive study. Participants in this study were 80 siblings aged four to 18 years old of children with rare chronic disorders who were recruited as part of residential family courses at Frambu. The support group sessions were conducted in the spring of 2012, and all sessions were videotaped. Content analysis, communication analysis, and descriptive statistical analysis were conducted to describe (a) the diagnosis knowledge and misunderstandings of siblings; (b) the emotional experiences of siblings; and (c) the communication in support
groups. The results guided the development of the SIBS intervention. For more information about the aims and methods of the study, see Vatne, Helmen, Bahr, Kanavin and Nyhus (2015), Hukeland, Fjermestad, Mossige and Vatne (2015), and Vatne and Zahl (2017).

Developing and piloting the intervention
The development of the intervention was conducted in a manner that ensured that research findings, user participation and the experience of practitioners were all incorporated. This was done by arranging workshops and conducting pilot testing of manual drafts. Delegates from two patient associations (The Norwegian Association for Children with Congenital Heart Disease (FFHB) and the Norwegian Patient Organisation for Autism Spectrum Disorders (Autisme-foreningen)), and from four resource centres for rare disorders (Centre for Rare Disorders, The National Autism Unit at Oslo University Hospital, TRS Sunnaas Hospital, and Frambu) were invited to discuss topics related to the development of the intervention, to review drafts of the intervention manual and to test out parts of the intervention through role-plays. The delegates were adult siblings of people with chronic disorders, psychologists, education specialists, social workers, and nurses.

The delegates met for six three-hour workshops. The topics of the workshops were: 1) Discussion and definition of group objective, aim, and working manner; 2) Presentation of the various methods delegates applied in their work with siblings; 3) How to create a supportive and well-functioning sibling group; 4) Difficult situations in group sessions and how to handle these; 5) Review of the intervention manual, role play and feedback; 6) Presentation of the product and future research plans. Important topics discussed during the workshops were consecutively incorporated in the intervention manual and workbooks in weekly meetings in the project group.

The intervention was pilot tested with nine sibling groups (age range seven to 18 years) conducted in four different settings: 1) During a family gathering arranged by FFHB with 18 children (three groups) and 12 parents (one group); 2) During a ‘sibling camp’ at Frambu with 36 children (four groups) and 34 parents (four groups); 3) During a residential family course at Frambu with four children (one group) and seven parents (one group); and 4) During a residential family course at Frambu with 10 children (two groups) and five parents (one group). Delegates from the workshop acted as group leaders in the pilot testing in order to gain personal experience. At the end of each pilot group,
participating children and parents were asked for verbal feedback and completed questionnaires developed to evaluate the content and form of the intervention.

Results
The needs of siblings and interventions targeting these needs
The review of literature on the needs and wellbeing of siblings of children with chronic disorders revealed several important topics that needed to be addressed by the SIBS intervention. Findings that especially informed the development are presented in Table 1. The essence of previous research findings on the lives, needs and wellbeing of siblings was also summed up in a national publication (Vatne, 2014).

The descriptive study at Frambu resulted in three publications focusing on diagnostic knowledge (Vatne, Helmen, Bahr, Kanavin, & Nyhus, 2015), emotional experiences (Hukeland, Fjermestad, Mossige and Vatne 2015) and communication in support groups (Vatne & Zahl, 2017) of healthy siblings. The main findings from these publications that are relevant for the development of the SIBS intervention is presented in Table 1.

The search for ongoing sibling interventions in Norway revealed that group interventions for siblings of children with chronic disorders were offered to siblings more sporadically by habilitation centres (e.g., at the Habilitation Centre in Østfold), resource centres (e.g., at Frambu), medical departments (e.g., Oslo University Hospital, Norwegian National Advisory Unit on Learning and Mastery in Health, 2015) and patient organisations (e.g., the Norwegian Cancer Society). However, the foci and therapeutic strategies of these support group interventions varied considerably. Several of the interventions lacked an evidence basis. Furthermore, none of the reviewed interventions took place as part of a scientific study, thus potential effects of the interventions were not evaluated. Noteworthy aspects of the Norwegian sibling interventions are summarised in Table 1.

International intervention studies targeting the population of healthy siblings were scarce. The studies identified in our literature review were promising; however, they had relied on small samples and did not include rare disorders. Based on the review of studies describing and evaluating sibling interventions, several important aspects for the development of a new intervention were noted by the project group. These are summarised in Table 1. An interesting finding of the review process was the studies showing the importance of involving parents in interventions that aimed to increase psychosocial
wellbeing among siblings of children with CD (i.e. Williams et al., 1997; Lobato & Kao, 2002). Incorporating a parental component in interventions with a group format, e.g. parallel sessions for parents, is found to enhance and lead to more long-lasting effects of the intervention (Mendlowitz et al., 1999).

After reviewing international websites, we became particularly interested in a Swedish project. The project involved providing groups for siblings and their parents in all habilitation units in Stockholm. After a study trip to Stockholm involving lectures, discussions and guided tours, the project group brought home important experiences that influenced the work with a new intervention. These aspects are summarised in Table 1.

Table 1. Important findings from the information gathering process

<table>
<thead>
<tr>
<th>Source</th>
<th>Aspects identified as relevant for new intervention</th>
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| Literature on needs of siblings | • Siblings often lack knowledge about the diagnosis (Lobato & Kao, 2002).  
• Siblings are at increased risk of psychological difficulties and are less resilient compared to peers (Vermaes et al., 2012).  
• Communication between siblings and parents is vulnerable (Mulroy, Robertson, Aiberti, Leonard & Bower, 2008).  
• Adjustment problems among siblings may be explained by:  
  – Lack of knowledge or inadequate communication between parents and children about siblings’ disorder (Carpenter & Levant, 1994)  
  – Lack of shared ways of perceiving and comprehending each other (Jakson, Bistra, Oostra & Bosma, 1998).  
  – A feeling of physical and/or emotional isolation from parents (Carpenter & Levant, 1994).  
  – Limited parental ability to offer siblings informative, emotional, and/or social support (Carpenter & Levant, 1994).  
• Parental awareness of siblings’ perceptions and attitudes towards the chronic disorder is a resilience factor in siblings’ adjustment (Taylor, Fuggle & Charman, 2001). |
The descriptive study

- Open exploration about children’s experiences in daily life is important to find out what they need of new information about the diagnosis (Vatne et al., 2015).
- It is important to explore what meaning children put into medical words (e.g. chromosomes or heredity) as use of correct words may conceal underlying misunderstandings (Vatne et al., 2015).
- Children have complex and often contradictory emotional experiences in relation to living with a disabled sibling and may need the help of adults to express, understand and cope with these emotions (Haukeland et al., 2015).
- Siblings often report trying to cope with their emotions on their own rather than seeking the support of parents (Haukeland et al., 2015).
- Children’s participation and expression of support in support groups seem dependent upon the communicative techniques used by the group leader (Vatne & Zahl, 2017).
- A child-focused style with open questions and probes is necessary to ensure that topics relevant for the participating siblings are addressed during support groups (Vatne & Zahl, 2017).

Literature on effect of support groups

- Siblings have increased diagnostic knowledge after attending groups targeting this (Lobato & Kao, 2002; Granat et al., 2012).
- Psychological health of siblings may be improved through sharing experiences and providing support (Evans, Jones & Mansell, 2001; Incledon et al., 2013).
- Involving parents in the intervention may increase the effects on sibling knowledge and wellbeing of siblings (Williams et al 1997).

Norwegian Interventions

- Structured manual for group leaders seems useful (the Habilitation Centre in Østfold).
- Use of pen-and-pencil tasks and flip charts may increase child involvement in sessions (Vatne & Zahl, 2017).
- Conducting support groups during a short timeframe is feasible (the Norwegian Cancer Society).
The SIBS Intervention

The SIBS intervention was guided by the literature review, the descriptive study, and the interventions reviewed and was developed in a back-and-forth process between workshops, project group meetings and pilot testing. The resulting intervention aims to support the communication between children and parents by: (a) arranging parallel parent and child groups with a shared focus; (b) children preparing topics that they want to discuss with their parent; (c) topics and questions from the child group being brought into the parent group for discussion; (d) parents being lectured on how to talk with their children about potentially difficult topics; and (e) parents and children being provided with the possibility to talk about the topics in pairs under supervision of a group leader.

The preliminary intervention comprised: 1) an introduction module involving information to parents and a child group session with ‘get to know each other’ activities; 2) a knowledge module entailing a group session with children to assess their knowledge needs, a group session with parents featuring education on how to explore children’s thoughts, and a joint parent-child session where child and parent, under the supervision of group leaders, discuss topics related to diagnosis; 3) an emotion and coping module entailing a group session with children exploring their feelings, thoughts, and behaviours related to their siblings’ disorders, a parent session focusing on how to communicate with children in an emotionally supportive manner, and a joint session where child and parent, under supervision, work together with pen-and-paper tasks focused on exploring problems experienced by siblings. See Table 2 for a description of the intervention.
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Table 2. Overview of the intervention

<table>
<thead>
<tr>
<th>Sibling group</th>
<th>Parent group</th>
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<tbody>
<tr>
<td>Session 1 (20 mins) Introduction</td>
<td>Session 2 (60 mins) Knowledge module</td>
</tr>
<tr>
<td>Getting to know each other, explaining purpose, establishing rules incl. confidentiality</td>
<td>Exploration of children’s knowledge of their siblings’ disorder and identify needs for information. Develop questions for parents.</td>
</tr>
<tr>
<td>Session 3 (20–60 mins) Joint session</td>
<td>Session 4 (60 mins) Emotion and coping module</td>
</tr>
<tr>
<td>Parents and children in dyads discussing children’s question about the siblings’ disorder.</td>
<td>Exploration of children’s emotions and coping strategies. Chose personal challenges to present for parents.</td>
</tr>
<tr>
<td>Session 5 (20–60 mins) Joint session</td>
<td>Parents and children in dyads discussing children’s emotions and coping strategies in personally challenging situations.</td>
</tr>
</tbody>
</table>

A manual comprising instructions regarding the organisation, the equipment necessary, and the tasks to complete was developed. The manual also contained advice for group leaders regarding communication techniques and the means to cope with difficult situations that may arise during sessions. Child and parent folders were developed. The child folder consisted of tasks to fill in and show parents, while the parent folder consisted of written information about the topics of the session. In addition, the child folders contained an agreement about continuing to talk at home to be signed by the child and parent at the end of session five.
Results from the pilot testing of the intervention

All participants in the pilot testing (68 children and 57 parents) evaluated the intervention using a questionnaire. In general, the participants gave positive feedback regarding the topics and tasks in the intervention. Table 3 sums up the experience and evaluations of the children, parents and group leaders that informed further revision of the intervention.

Table 3. Evaluation by the children, parents and group leaders (GL) of the pilot interventions

<table>
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<tr>
<th>Source</th>
<th>Evaluation (open comments)</th>
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| Children | • Talk more, make everyone participate, but don’t put pressure on people to talk  
• Find out more about the diagnosis  
• Make children who disturb during sessions stop  
• Have a more positive focus  
• Less tasks involving writing |
| Parents | • Be more specific about the tasks  
• More time in general; specifically, have more time to talk with the children  
• More feedback to each family  
• More focus on communication techniques and more specific examples  
• Find out more about what happens in the child groups |
| GL | • Shorter sessions are needed  
• Sessions should preferably be separated by other activities  
• Maximum 6–7 children per group with an age span of maximum three years  
• The intervention is best suited for children 8 years or older  
• Only one parent should participate to even the power balance during joint sessions  
• Less tasks and topics should be addressed during each child session  
• More clear specification of mandatory and optional tasks in the manual  
• The parent folder should include more psychoeducation to read between sessions  
• The manual should include specific examples of effective communicative techniques  
• Standardised films are needed to exemplify efficient child-parent communication |

Note. GL = Group leaders.
Among the most influential feedback from parents was their wish to get more information about the child group sessions. As a result, we incorporated into the intervention that the group leader from the child group would present the chosen question from child group session 2, and challenge from child group session 4, for the parent group to provide more context and information about how the topic was discussed by the children.

All feedback regarding the content of sessions and folders from children, parents, and workshop participants was discussed and incorporated in the final version of the intervention manual, parent and child folder. The final intervention package consists of: a manual, a child folder, a parent folder, and four video examples of parents and children talking about disability and emotional experiences using the techniques taught in the intervention. More information is found on the project website (www.sibs.no).

Discussion
The current report describes the developmental process behind an intervention for siblings of children with chronic disorders and their parents. Based on this process, parent-child communication about the topics ‘diagnostic knowledge’ and ‘emotional challenges’ was selected as a target variable of the intervention. Strengthening parent-child communication, and thereby reducing emotional isolation and increasing knowledge is important for preventing psychological difficulties among siblings of children with chronic disorders (Carpenter & Levant, 1994; Lobato & Kao, 2002; Williams et al., 1997). The SIBS intervention received overall positive evaluations from both children and parents. However, there is a need to evaluate the effect. Thus, both a preliminary evaluation measuring pre- to six-month follow-up changes and a randomised controlled trial are the next planned steps of SIBS.

The process provided good input on how to arrange the intervention. One of the aspects that probably differentiates our intervention from previous support groups in Norway is the way parents are included. Previous studies describe how including parents may increase the effect of interventions (Mendlowitz et al., 1999; Sholten et al., 2013). As communication between siblings and parents has been found to be challenging (e.g., Mulroy, Robertson, Aiberti, Leonard & Bower, 2008), incorporating an element of parent-child communication training was found important. However, this expands the group leader role to also a communication trainer role. The descriptive study showed considerable variation in how child groups communicated and how group leaders moderated the
conversations (Vatne & Zahl, 2017). Thus, conducting the intervention requires formalised training of group leaders. SIBS is currently planning the development of an e-learning program in cooperation with Norwegian municipalities – for more information see www.sibs.no.

The SIBS intervention comprises only five sessions and was shown in the pilot to be possible to implement during weekend gatherings or five-day courses. However, it is also possible to provide this intervention over a larger timeframe. As the aim of this intervention is to support parent-child communication, some of the effects of the intervention may partly be expected to be attributed to increased communication in between sessions or at home in the aftermath of the intervention. If so, providing the intervention as e.g. two sessions per week in a two-week timeframe may even increase the potential effectiveness of the intervention. Future SIBS studies should evaluate the effect of the intervention across different time formats.

The SIBS intervention was developed in 2012 and consequently the knowledge base has since expanded. However, new knowledge strengthens the arguments on which the intervention is built: Siblings of children with chronic disorders are at risk of developing psychological difficulties (Tudor & Lerner, 2015) and have more difficulties expressing emotions than control (Long et al., 2013). Pediatric illness represents a risk of impaired family communication (Murphy, Murray, & Compas, 2017) and levels of sibling-parent emotional communication and emotional support from parents is found to predict wellbeing in siblings (Long et al., 2013; Incledon et al., 2015). Furthermore, research continues to document the importance of involving parents in interventions aimed at preventing psychological difficulties in children (i.e. Sholten et al., 2013).

We argue that delivering the SIBS intervention in Norwegian health care, involving parents and focusing on family communication, would be one of the ways to meet the legislation requirements of the 2017 amendment to the Law for Health Personnel. We aim to establish an evidence base for the intervention in co-operation with municipalities and specialist health services, and to continue our work to improve the lives of families living with chronic disorders in childhood.

Ethical considerations
The SIBS intervention was developed in cooperation with user organisations and pilot tested with families of children with CD to ensure that it safeguards respect for and integrity of the lives of those affected by CD.
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References


