Emotional communication in support groups for siblings of children with disabilities

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Abstract

Objective: Support groups are often arranged for siblings of children with disabilities to prevent psychological maladjustment. This study describes how children express emotions in support groups and how group leaders and other children respond.

Method: Conversations in 17 group sessions for siblings aged 11 to 16 were coded with VR-CoDES to report frequency of emotional expressions and responses.

Results: Children expressed negative emotion during group sessions (n = 235), 59% as cues and 41% concerns. The immediate response was in 98% of the instances from the group leader. 38% of the responses focused on emotion, cognition or behavior.

Conclusion: Children express emotions, but seldom respond immediately to others’ emotional expressions in support groups. Group leaders should attend to emotion, cognition and behavior more frequently.

Practice implications: Group leaders may better fulfill the support potential of support groups through explicitly stating the role of participants, and by exploring emotional aspects.
1. Introduction

Growing up with a child with a disability is related to slightly increased risk of psychological difficulties and less resilience in healthy siblings [1]. Siblings report to have difficult emotional experiences and to try to cope without the support from others [2].

Research indicates that support groups may prevent psychological maladjustment in siblings [3]. Providing them with opportunities to share experience, express emotion, gain attention, and feel support are often described as the means to achieve this goal [e.g., 4].

Children often express emotion in subtle ways [5], and their ability to express emotions verbally is related to age [6] and gender [7]. Support groups have been found to provide possibilities to ventilate negative emotions (NE) [58], but there is little research on how children express NE in support groups.

Adult behavior may provide or reduce opportunities for further disclosure of children’s emotional experiences [6]. The importance of adult conversation partners’ paying attention to, adjust to and validate children’s emotions is well described in literature [9], but how group leaders (GL) respond when emotions are expressed during group sessions is unknown.

Pro social behavior (i.e., comforting, cooperative, helping, and sharing behavior) between children could be difficult for adults to observe as it may be subtle, and adult presence may reduce its frequency [10]. Healthy siblings have been described as more emphatic and caring compared to peers [11], but how they respond to NE of peers during support groups has not been investigated systematically.

This study aims to provide new knowledge about emotional communication in support groups for children and answer the following questions: 1) How frequent, and how explicit do
children express NE in support groups? 2) How do children and GL respond to expressions of negative emotions in support groups?

2. Methods
Siblings (aged 4-18 years) of children with a disability were recruited during family residential courses a Norwegian resource centre. IRB approval was obtained. Families were provided written and verbal information about the study. Consenting families completed a consent form and a demographic questionnaire. Of the 104 families approached 80 (77%) consented.

For the purpose of this study children aged 11 years or older (n=30) were selected to reduce developmental variation. The participants were 30 children, mean age 13.2 years (range 11.5-15.11), 80% girls, from families with 2 to 5 (mean 3) children. Many were older sibling to the affected child (63.3%). The diagnosis of the affected child was either of a cognitive (66.7%), somatic stable (6.7%) or somatic progressive nature (26.7%).

The children joined one of six groups matched on age (≤ 4 years age span) and diagnosis. Three open discussion sessions were arranged; 1) Siblings disorders, 2) Self perception and family relations, 3) Emotions. All group sessions were videotaped. The GLs (psychologists and education specialists) were instructed to explore experiences and stimulate spontaneous conversation. The children were informed that the purpose of the groups was to talk about the disorder and to share experiences and coping strategies being the sibling of a child with a rare disorder.

Two coders identified expressions of negative emotions and immediate responses by applying the Verona Definitions of Emotional Sequences - Cues and concerns (CC) and Provider response (P) [12,13] on video data. The unit of analysis was a communicative turn. Inter-rater reliability was satisfactory (87.2 %), Cohens Kappa was also calculated. For
definitions and IRR of cues, concerns and responses see Table 1. SPSS version 22 was applied for descriptive statistics.

3. Results

All participants expressed negative emotions during sessions. In total 235 expressions of negative emotion were identified, 59% as cues and 41% as concerns. The amount of NE expressed varied between participants. The frequency of cues ranged from 0 to 17 (M 4.58, SD 4.47). The frequency of concerns ranged from 0 to 7 (M 3.16, SD 1.68). No relations to child age or gender were found.

The immediate response to a child’s NE was almost always provided by the group leader (98%). Children responded immediately in only five instances (2%), two times to cues and three times to concerns.

When children expressed NEs responses of GL often provided space, e.g. by replying “what happened then?, “tell me more...” or through facilitating responses like “Yes…”, “aha..” (68%). GLs less often reduced space for further disclosure of the emotional experience, e.g. by replying “you should try not to think about it”, provide information, change topic, or turn towards another participant” (32%).

Of the responses providing space 56 % (representing 38 % of total responses) were explicitly focused on emotion, cognition or behavior of the child e.g. by stating “how does that make you feel?” or “What do you do when that happens?” (see table 1 for more examples from the study). The response pattern was similar for both cues and concerns. No relations to child age or gender were found.
4. Discussion and conclusions

4.1 Discussion
This study showed that children express negative emotions during support groups, which are in line with previous research [8]. However, where previous studies have found children to mainly express emotions in implicit ways [5] a high ratio of explicit concerns was observed in this study. The study did show individual variation in the amount of expressed emotions, but as age and gender could not explain this variation, it is possible that factors not included in this study were involved. The sample also included few boys.

Responses that increased the opportunity for the child to talk more about their emotional experience were frequent. In this way the GL’s acted in line with an aim of support groups; they made children share experiences [4]. However, the aims “to provide opportunity to ventilate emotion and provide support” [8] may not have been equally met as GL’s only focused on emotional, cognitive, or behavioral aspects about a third of the times children expressed emotion. More exploration of these aspects may increase children’s opportunities for learning from each other’s interpretations and coping with difficult experiences. Never the less, a trusting relation to the child should be established before confronting emotions (9). In this study, GL may have avoided excessive emotion focus due to few sessions and lack of a trusting relationship with the children.

Siblings have been described as highly empathic and caring compared to peers [11], but in this study they rarely responded immediately to others’ negative emotions. In line with the findings of Bergin et al [10] the participants may have perceived responding to distress as the GL’s responsibility and their own roles and desired behavior may not have been evident to them. The participants may also have showed support in ways that the adult researchers in this study have not yet been able to observe and understand [10]. Thus, future research should focus on children’s perception of supportive behavior in support groups.
4.2 Methodological discussion
Families self referred to the courses where the data of this study were gathered. This implies a possibility for sampling bias and generalization of the findings is therefore questionable.

4.3 Conclusion
Children express NE in groups. GLs often explore children’s experiences, but should pay more attention to emotional, cognitive and behavioral aspects. Children seldom respond to the emotional expressions of other group participants. Future research should focus on what children define as supportive behavior during support group sessions.

4.4 Practice implications
To fulfill the support potential of support groups GL should state the aim of and child role in the support group and make sure emotional, cognitive and behavioral aspects of experiences are explored.

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References


Table 1. Definitions, examples from study and IRR of NE and responses

<table>
<thead>
<tr>
<th>VR-Codes</th>
<th>Definition</th>
<th>Examples</th>
<th>Kappa</th>
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<tbody>
<tr>
<td>NE</td>
<td>Cues The emotion is not clearly verbalized or might be present</td>
<td>“In a way that’s the worst part”</td>
<td>.65</td>
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<tr>
<td></td>
<td></td>
<td>“It’s kind of unpleasant when people stare at him”</td>
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<td></td>
<td>Concern Clear verbalization of an unpleasant emotional state</td>
<td>“It is kind of sad”</td>
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<td></td>
<td>“It’s easy to get annoyed by him”</td>
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<tr>
<td>Response</td>
<td>Provide space Gives space for further disclosure of the NE expressed by the patient. Contextual aspects of the experience or emotional aspects (thoughts, feelings and behavior) may be explored.</td>
<td>“So when people stare you stare back, does that work for you” (explore emotion)</td>
<td>.65</td>
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<tr>
<td></td>
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<td>“Does that mean that you have to change school? (explore context)</td>
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<tr>
<td></td>
<td>Reduce space Reduces space for further disclosure of the experience.</td>
<td>“You don’t have to tell us more about it”</td>
<td>.50</td>
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<td></td>
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<td>“And what about you (another child) what do you think”</td>
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*No concerns were identified