What challenges do siblings of children with chronic disorders express to their parents? A thematic analysis of 73 sibling-parent dialogues

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ABSTRACT

Purpose: The study explored challenges experienced by siblings of children with chronic disorders, as expressed by siblings in parent-child dialogues.

Design and methods: Seventy-three parent-child dialogues (*M duration* = 28.6 min) were analyzed using qualitative thematic analysis. The dialogues took place within the SIBS group intervention for siblings and parents of children with chronic disorders. The siblings (aged 8 to 14 years) had brothers and sisters with autism spectrum disorders, ADHD, rare disorders, cerebral palsy, or severe mental health disorders. The data are from session 5 in the SIBS intervention, in which the siblings are to express their wishes about family-related challenges (e.g., desired changes) to their parents. The parents are encouraged to listen, explore, and validate the child's perspective before discussing solutions.

Results: Most of the family-oriented challenges the siblings expressed were related to the diagnosis of the brother or sister with a disorder. Four main themes were identified: (1) Family life (e.g., limitations in family activities); (2) The diagnosis (e.g., concerns about the future); (3) Violence; and (4) Important relationships.

Conclusion: The siblings experienced challenges and difficult emotions in interactional processes in which the diagnosis affected family life and relationships. The study adds a new dimension to the field by identifying siblings' expressed challenges based on parent-child dialogues.

Practice implications: Identified themes can guide how parents should meet and address siblings' needs, how health care providers inform and support parents in doing so, and emphasize the relevance of interventions targeting family-level risk and resilience factors.

Up to 17% of children have a sibling with a chronic disorder (herein, siblings) (McKenzie Smith et al., 2018). The extra care burdens related to chronic childhood disorders affect the entire family, including healthy siblings. Multiple authors of meta-analyses have demonstrated that siblings face a slightly elevated risk of impaired mental health compared to controls (Pinquart, 2022; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002; Vermaes et al., 2012). Research has shown that the chronic disorder alone does not explain the variations in mental health outcomes, instead, the risk is mediated by complex risk and resilience pathways (Incledon et al., 2015; Tudor et al., 2017; Wolff et al., 2022). One of the identified risk factors is poor family communication (Fredriksen et al., 2023; Murphy et al., 2017). Poor quality of parent-child communication, such as less open and warm

communication, is associated with negative outcomes in children's mental and physical health, and the use of ineffective coping strategies (Afifi et al., 2011; Almas et al., 2011; Demidenko et al., 2014; Finan et al., 2018). Further, researchers demonstrated that families with a child with a chronic disorder exhibit communication styles characterized by reduced warmth and structure compared to controls (Murphy et al., 2017). Correspondingly, siblings have identified honest and open family communication as unmet needs across qualitative studies (Wilkins & Woodgate, 2005).

Siblings of children with chronic disorders may have needs of effective parent-child communication regarding the diagnosis (information needs) and their own emotional experiences (emotional support) (Jaaniste et al., 2020). Qualitative research can enhance the understanding of siblings' own-reported needs and subjects they may find helpful to talk about within the family. Qualitative syntheses investigated the experiences of siblings of children with different types of chronic disorders (for example, cancer, diabetes, Down syndrome, and autism spectrum disorders (ASD)) (Deavin et al., 2018; Leedham et al., 2020;

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Mandleco & Webb, 2015; Wilkins & Woodgate, 2005). Recurring themes across the qualitative literature are the diagnosis' impact on family dynamics, routines, and relationships (Deavin et al., 2018; Leedham et al., 2020; Mandleco & Webb, 2015; Wilkins & Woodgate, 2005). The changes within the family can be experienced as challenging due to differential treatment between children in the family, decreased parental tolerance, disruptions in everyday routines due to the diagnosis, and extended caregiving needs (Havermans et al., 2015; Wilkins & Woodgate, 2005). Beyond the difficult experiences, some siblings reported experiencing gains and positive life experiences, such as increased family closeness due to the diagnosis (Mandleco & Webb, 2015).

Parent-child conversations about shared emotional events are important for developing self-awareness, strengthening the bond between the child and others, and teaching children how to cope and regulate emotional experiences (Fivush et al., 2003; Wang & Fivush, 2005). Siblings' emotional experiences examined in qualitative studies are pointing to topics that may be beneficial for parents to explore and help the siblings to cope with. Intense and difficult emotional experiences identified across the qualitative literature include feelings of sadness, loneliness, rejection, anxiety, anger, jealousy, and guilt (Wilkins & Woodgate, 2005). In studies with siblings of children with ASD, informants identified strong negative feelings related to impact of behaviors such as disruptive behavior (Leedham et al., 2020; Mandleco & Webb, 2015). Nevertheless, siblings have reported to cope with difficult emotions on their own instead of sharing with others including their parents (Haukeland et al., 2015). Additionally, as indicated by Hanvey et al. (2022), siblings expressed a perception of being invisible to others, notably their parents, leading them to keep feelings of guilt and self-blame to themselves. Such isolation is reported across the literature, representing generalized feelings of loneliness in this population (Deavin et al., 2018).

Children's self-disclosure in parent-child conversations, involving the expression of thoughts, experiences, and emotions to others (Derlega et al., 1993) may depend on various factors. These factors comprise the child's developmental stage, parenting style, and parents' communication skills, including parents' comfort and confidence in discussing sensitive topics (Almas et al., 2011; Hernandez & Ebersole, 2022; Smetana et al., 2006; Tilton-Weaver et al., 2010). For example, researchers indicate that parents gravitate towards simple and surface-level conversations and avoid more comprehensive (that is, open, honest, and detailed) dialogues for different reasons: (1) parents perceive to lack information and worry about how to best support the children, (2) due to own emotional experiences such as discomfort and uncertainty, and (3) cultural barriers (Holman, 2021; Holman et al., 2023). In turn, such parental factors impact what children share with their parents.

Consistent with this, research suggests that adolescents are more inclined to be open with parents perceived as reacting appropriately, exhibiting warmth, responsiveness, understanding of their feelings, and acceptance (Smetana et al., 2006; Soenens et al., 2006; Tilton-Weaver et al., 2010). Correspondingly, Almas et al. (2011) found that authoritative parenting styles displayed by mothers predicted higher levels of self-disclosure in children, which in turn predicted children's use of positive coping strategies when dealing with stress (for example, problem-solving and seeking social support). Parents of children with chronic disorders experience a wide range of potential care burdens, including financial burdens, strenuous involvement in medical treatment and hospital stays, and difficult emotions such as continuous worrying (Carpentier et al., 2006; Lawoko & Soares, 2006; Pinquart, 2019). The parents must balance daily requirements and caregiving for the child with a chronic disorder, along with balancing a healthy environment for the other family members (Carpentier et al., 2006). Exposure to such stressors may negatively impact parental functioning and communication patterns (Murphy et al., 2017).

Considering the potential impact of family-level factors on parent-sibling communication, exploring siblings' disclosures in parent-child dialogues represents a unique opportunity to help move the field forward. This understanding can inform interventions addressing family-level risk and resilience factors and guide how healthcare professionals can support parents in providing information and support on relevant topics to siblings.

Method

Aims

The aim of the study is to conduct a qualitative analysis of siblings' challenges and emotional experiences as they are expressed in parent-sibling dialogues.

Design

The current study applies a qualitaitve research design examining 73 audiotaped parent-sibling dialogues. The dialogues took place in the context of a manual-based group intervention for siblings and parents of children with chronic disorders. The qualiative data are drawn from "Intervention for siblings and parents of children with neurodevelopmental disorders – A randomized controlled trial (SIBS-RCT)", an ongoing RCT comparing the SIBS group intervention to a 12-week waitlist. The inclusion criteria in the SIBS-RCT are: 1) Being the sibling of a child diagnosed with a chronic disorder who is aged 0 to 18 years and who receives specialist and/or municipal health services. The following chronic disorders are included: neurodevelopmental disorders, congenital heart disease, cancer, diabetes, and eating disorders. 2) Sibling age 8–16 years, and 3) One parent able to attend the intervention. The exclusion criteria for siblings are: 1) Being enrolled as primary patients in specialist mental health services; and 2) Being diagnosed with any of the inclusion disorders (see Fjermestad et al. (2020), for the full study protocol).

SIBS is a five-session, manual-based intervention program targeting siblings and their parents. The intervention aims to support parent-child communication through 1) parallel groups for siblings and parents with a shared focus, 2) siblings prepare topics they want to talk with their parents about, 3) the topics prepared by siblings are used in the parent group for discussion, 4) parents are trained to talk with the siblings about the diagnosis and challenges, and 5) parent-child dialogues as part of the intervention, under supervision of a group leader (Vatne et al., 2019). The data in the current study were collected from session 5 in the intervention (see Fig. 1). In session 4, both parents and siblings are being prepared for session 5. The siblings talk about challenges and emotions related to their family situation in sibling groups. They write down challenges they want to discuss with their parents in session 5. Thereby, the siblings are encouraged and supported in expressing their experiences and emotions before the conversation with their parent. Parents are trained to listen, explore, and validate the siblings' challenges in parallel parent groups. In session 5, parents and siblings talk about challenges the siblings have written down. Each sibling-parent dyad is seated separately from the other participants, and during the conversation brief input is provided by a group leader who supervises the parent in communication techniques.

Data collection

The SIBS-RCT was conducted across eight sites in Norway, including five hospital sites and three municipal health services, covering rural and urban areas. Participants were invited via letters, phone, or personal communication at the different sites (Fjermestad et al., 2020). The dialogues analyzed in the current study took place and were recorded between December 2019 and June 2021.
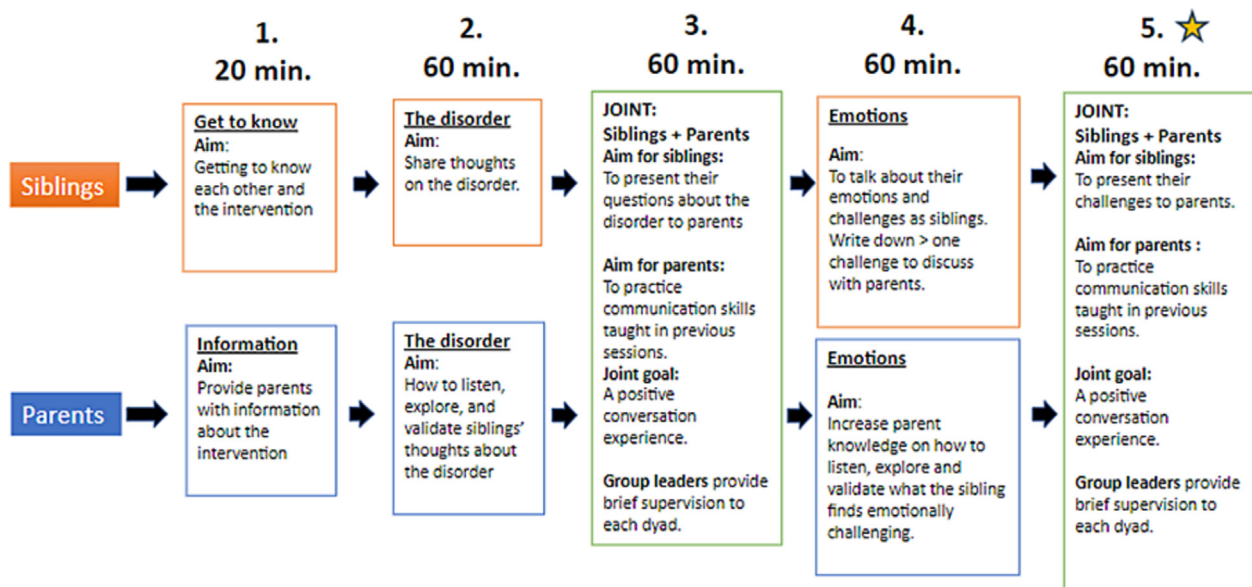
Fig. 1. Overview of the SIBS intervention. Adapted with permission from Vatne et al. (2019) and Fjermestad et al. (2020).

Data analysis

The dialogues were analyzed qualitatively in an inductive and iterative way using thematic analysis based on the research question: What challenges are identified in parent-sibling conversations? Due to the qualitative nature of the study, a priori hypotheses are not presented. Because of the commonalities in family-level challenges across disorders, a broad transdiagnostic perspective can enhance the understanding of the impact on families and improve care (McKenzie Smith et al., 2018). Therefore, a transdiagnostic perspective was applied when examining siblings' experiences. Inductive thematic analysis is a flexible qualitative method suitable to identify themes and patterns derived from the data. It can be used with large sample sizes (up to 100) when analyzing data where the researcher has not been directly involved in data collection (Clarke & Braun, 2013). Therefore, thematic analysis was considered suitable.

The dialogues were transcribed verbatim. Fifty-five dialogues were transcribed by the first author, and 18 dialogues were transcribed by a research assistant in the project group. These were both advanced clinical psychology students at the time. During the transcription, the dialogues were de-identified by removing or changing personal information (for example, name of participants, family members and friends, and names of places). The transcribed text material was analyzed using the following steps: 1) Get familiar with the data, 2) Generate initial codes, 3–5) Search for, review, and name themes (Braun & Clarke, 2006). This was a reflexive process, moving between phases and reviewing themes and codes.

Initially, the first author read through all the transcribed text material, and the third author (a clinical psychology professor with 16+ years of experience in qualitative and quantitative research) read approximately 15%. Initial codes were independently written down by the first and the third author, and thereafter compared and discussed. It was agreed that the point of data saturation was reached, indicating that ample data had been included. Broader coherent themes were developed by the first author through repeated reading and reviewing, and through discussions with the third author. Thereafter, the second author (a clinical psychologist and university lecturer (PhD) with 15 years of qualitative research experience) contributed in reviewing and re-organizing the themes. During the entire process, including initial reading, transcription, initial coding and searching for themes,

ideas, thoughts and reflections were written down, reflecting the continuous and iterative process that this form of thematic analysis represents.

The data were coded using the NVivo-12 software. Text material considered not relevant for the research question was not coded since the aim was to identify themes in the text material related to the siblings' perspectives. Themes were not constructed to be mutually exclusive, meaning that segments of the dialogues could be coded into several themes.

Ethical considerations

Parents provided written informed consent to participate, and parental permission on behalf of children under 12 years. Children aged above 12 years assented to study participation. The SIBS-RCT is approved by The Regional Committee for Medical and Health Research Ethics South East (#12890). Although the main aim of the SIBS-RCT was to examine the effect of the intervention, the approved project protocol and the information letter to parents and siblings also described the aim of documenting siblings' experiences and using the audiotaped data for qualitative analyses. The audio was recorded using a recording app in which the audio files are automatically transferred to a secure access database approved by the relevant data protection agency.

Results

The 73 parent-child dialogues had an avareage duration of 28.6 min. Two of the participating children were from the same family, and both attended with their mother but in different groups. This means the 73 dialogues represent 72 unique families, including 73 children and 72 parents. The participating siblings' mean age was 10.2 years ($SD \pm$ 1.6; $range = 8{-}14$; 59% girls; 41% boys). Each sibling was in a dialogue with one of their parents (74% mothers; 26% fathers). The average number of children in the family was 2.6 children ($SD \pm 0.8$; $range = 2{-}5$). Parents' mean age was 41.3 years ($SD \pm 5.8$; $range = 30{-}58$). The disorders represented in the sample were autism spectrum disorder (34%), attention deficit hyperactivity disorder (ADHD; 27%), rare disorders including 22q11.2 deletion syndrome, Angelman syndrome, and Kleefstra syndrome (20%), cerebral palsy (7%), Down syndrome (7%), and other mental disorders (5%).

The authors identified a structure of four main themes with corresponding subthemes when analyzing the challenges expressed by siblings in the dialogues.

Theme 1: family life

This theme captures the siblings' reflections on family life and is sorted into three subthemes.

Parenting and family rules: This subtheme entails experiences of injustice/unfairness related to unequal treatment between children in the family. The participants explained how their parents had different rules and expectations for them compared to their brother/sister with a disorder. For example, one participant said: *"[brother with disorder] always gets what he wants […]. He has all his outbursts, then he's allowed in the end […]. That's unfair, I would never be allowed, but because of his diagnosis he's more entitled to do whatever he wants."*

Family dynamics: This subtheme encompasses the viewpoints and thoughts of participants concerning communication between family members and the power balance within the family. In the conversations, siblings brought up the high frequency of arguments and shouting between family members. They talked about how both their parents and their brother/sister with a disorder often raised their voices: *"In the mornings there is loud crying from [brother with disorder] and shouting from dad. It's like a chemical reaction."* Descriptions of withdrawal from family conflicts were recurring in the dialogues. For example, participants would go to their room or hide when conflicts got out of control.

Family activities: The participants talked about activities that were impossible or difficult due to disorder-related issues. The participants explained that the family rarely can go on vacations or sleep anywhere but home, go to the movies, or go out to for meals. They also explained how family members may need to separate to make activities possible. For example, one participant explained: *"I wish the entire family could travel more places, not just stay at home. Because of [sister with disorder] we must split the family in two."* Importantly, participants also expressed hope for more family activities, dwelled on positive memories of activities, and talked about the many adjustments that were made to find appropriate activities.

Theme 2: the diagnosis

This theme revolves around the siblings' reflections on the diagnosis of their brother/sister. The theme is sorted into three subthemes.

Diagnosis-related characteristics and behaviors: This subtheme contains the participants' perceptions of frequent interrupting and bothersome behavior exhibited by their brother/sister. This included how their brother/sister easily became upset and angry, and how they lacked the ability to regulate strong emotions. For example: *"I wish [brother with disorder] didn't have the diagnosis. Then there would be fewer arguments and fewer things would be destroyed. If he didn't have it, he could still have arguments and destroy things, but not as often, as he would not get so easily upset. He gets angry so easily."* Participants also described difficulties in dealing with such outbursts, and how it made them both scared, angry, and sad. They also described feelings of embarrassment when the outbursts happened in front of others, for example friends or neighbors.

Medical treatment: This subtheme captures medical treatment of the diagnosis, hospital stays, and concerns about how much time parents had to spend away from the home due to medical treatment. For example, one participant explained: *"I dread to think about you [parents and sister with disorder] going to the hospital. I wish dad didn't have to join you at the hospital […]. Or I want to join you."*

The future: This subtheme encompasses the participants' various worries expressed about the future, for example if their sibling could die, get hurt, hurt someone else, or not manage life as an adult. The worries affected siblings in their everyday life. One participant described worries about her sister's condition getting worse in time and

explained how such thoughts affected her: *"I get so stressed […]. I'm stressing so much, I'm totally unable to pay attention [at school]."*

Theme 3: violence

The violence-related issues that came up in the conversations varied in severity and mutuality. Participants talked about being exposed to violence in the form of hitting, kicking, pulling hair, and being pushed. In the extreme end of the scale, participants expressed fear of violence with fatal consequences. Other participants described the unpredictability of violent outbursts and the fear associated with this. For example, one participant explained: *"I get a little afraid. Afraid that she might hit me several times and tell me many bad words."*

Theme 4: important relationships

This theme encompasses the participants' perspectives on important relationships in their lives, and how relationships are affected by their family situation. The theme is sorted into three subthemes.

The sibling relationship: This subtheme entails both positive and negative aspects of the sibling relationship. The participants described a lack of closeness in relation to their brother/sister with a disorder. The lack of closeness was related to challenging communication and how their sibling is difficult to understand or get to know. The participants also described longing for more closeness with the brother or sister with a disorder, role asymmetry in the relationship, and about wishes for a "normal" relation. The participants described that they feel responsible for their brother/sister with a disorder and take the role of caregivers, and the effect this have on them. For example, one participant explained: *"I feel like I'm responsible for him [brother with disorder] […]. That it's only me who is responsible."* Further, they described love and care for their brother/sister with a disorder.

The relationship to parents: This subtheme captures dimensions of the siblings' relationship to parents. Participants reflected upon parents' time and availability, including both physical presence/availability and perceived emotional availability. Some participants experienced their parents as changed, tired, and irritated due to the difficult family situation. For example, one participant explained: *"Sometimes I'm wondering if you're [parents] tired of her [sister with disorder]. When she comes home, I've asked you if something's wrong […]. You look really tired, and you also seem to be angry or sad. You look a bit different."* Others talked about their parent's perceived availability not explicitly related to the child with a disorder, and they expressed how their parents use their spare time on activities such as renovation, hobbies, or work, instead of spending time with the family.

Relationships to significant others: This subtheme covers dimensions of the siblings' relationship to others. The participants emphasized positive functions of relationships to for example grandparents and teachers. Such relations were also mentioned related to how to cope and deal with challenges and difficult emotions. For example, grandparents were mentioned related to what may help support themselves and the family: *"I wish grandma could move in with us. [Brother with disorder] is calmer around her, and grandma is able to calm him down even when he has exploded."*

See Table 1 for an overview of the identified themes and exemplar quotes.

Discussion

This study extends the existing body of knowledge about sibling experiences by providing insight into what siblings share with their parents and can be used to guide interventions. Four themes were identified: Family life, The diagnosis, Violence, and Important relationships. One prominent aspect concerning family life was the siblings' experiences of unequal treatment between children in the family. The differential treatment may be a consequence of the diagnosis, and

Table 1
Main- and Subthemes of Identified Challenges with Exemplar Quotes.

Family Life

Parenting and Family Rules
  I would never be allowed, but because of his diagnosis he's more entitled to do whatever he wants
  I wish there were more consequences. Because if you don't learn how to behave, you become horrible

Family Dynamics
  I haven't really noticed that I'm always in the background. Because he has always been the main focus, and I've become so used to it so I don't think about it anymore
  I don't like that there are ongoing arguments all the time. I get so tired because of the non-stop arguing

Family Activities
  If we go out, something always goes wrong and she starts to scream, and then we can't go
  It's not that we don't have fun together, it's just that we can't do anything together

The Diagnosis

Characteristics and Behaviors
  Suddenly, he might scream out loud
  If he got well, it would be easier to deal with him. And he wouldn't be so scared

Medical treatment of the Diagnosis
  Why can't he just take lots of medicine? Why doesn't that help?
  I don't know if I want her to start on medication. If she loses her personality, I don't want her to

The Future
  I don't think he will ever manage life on his own
  I'm scared that she has to go to prison if she doesn't get better, or that she will run away

Violence
  Yesterday, I said something I think she misunderstood. Then she started to hit me several times. Also, she can suddenly hit me for no reason
  I get a little afraid. Afraid that he might hit me and tell me many bad words

Important relationships

The Sibling Relationship
  When she gets angry, I get afraid of her. At the same time, I'm afraid that she could get hurt
  I want to spend more time with him. But it's difficult

The Relationship to Parents
  We can't talk until she's gone to bed, but then you're tired. And when you're tired, it's difficult to talk with you
  I want him to be more out of the house, so that me and you [father], or me and mum, could have some time to ourselves

Relationships to Significant Others
  I tell grandma more things than I tell mum
  Yes, it helps [to be together with a friend]. Then I focus on something completely else

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several participants explicitly stated this. The finding is aligned with existing qualitative literature (Chan & Goh, 2014; Haukeland et al., 2015; Wilkins & Woodgate, 2005). Given that differential parental treatment is associated with an increased risk of developing internalizing and externalizing problems (Buist et al., 2013), it may be advantageous that siblings and parents are given the opportunity to discuss this matter.

It should be noted that conflicts and disagreements about family decision-making and rule construction are typical for families, particularly in the transition to the teenage years and throughout the teenage phase (Sorkhabi, 2010). Negotiation with parents may be an expression of healthy developmental trajectories, such as the development of autonomy. Without undermining the siblings' expressed challenges, they should also be understood in the context of normal child development, with experiences and challenges that occur regardless of the presence of a chronic childhood disorder in the family.

Further, the findings imply that the siblings experienced communication in the family as challenging, with high levels of conflicts. This finding also aligns with previous literature (Murphy et al., 2017). The siblings described that they are not necessarily involved in the conflicts, and they could withdraw or hide when other family members were having loud arguments. Such scenes from family life capture the potential invisibility of these siblings. Siblings as *"glass children"* (Hanvey et al., 2022) can be an illustrating metaphor, emphasizing how siblings may become hidden family members. Initiating parent-sibling conversations about this topic may strengthen parents' understanding of how siblings experience conflicts within the family, even those not directly involving them. In turn, parents can become more aware of the emotional support siblings require, especially in situations where siblings may be easily overlooked or unnoticed.

Another important finding concerned the siblings' experiences of limitations in everyday life, especially concerning family activities. Previous qualitative study authors reported that siblings express a need to spend time outside the family with friends and like-minded individuals, especially in studies of adolescent siblings (Angell et al., 2012; Corsano et al., 2017; Gorjy et al., 2017). These themes are not necessarily contradicting and siblings may need both more family time and more support to engage in activities outside the family. Supporting siblings to maintain their interests was identified as a protective factor across studies, as it helps to keep the siblings' lives close to normal (Bellin et al., 2008; Murray, 2002; Velleman et al., 2016). However, the findings imply that the siblings were more focused on activities with the family, including both parents and the child with a chronic disorder.

The siblings expressed a diverse set of challenges related to the diagnosis, and difficult behavior characteristics of their brother/sister impacted the siblings negatively. For example, when the siblings witnessed outbursts and the destruction of objects or property, they expressed that this made them both sad and scared. Additionally, they felt embarrassed when outbursts and improper behavior occurred in the presence of others. Studies of siblings of children with ASD have reported similar findings, including a high frequency of destructive and disruptive behavior, which is experienced as both stressful and shameful (Angell et al., 2012; Mascha & Boucher, 2006; Moyson & Roeyers, 2011). This theme is less prominent in studies of children with chronic physical disorders (Deavin et al., 2018; Wilkins & Woodgate, 2005).

Further, the wide range of worries concerning the future was closely connected to the sibling relationship. Worries about the future may also be interpreted as worries concerning the development of the disorder and future healthcare provision. This theme is prominent across the qualitative literature with siblings as informants (Malcolm et al., 2014; Moyson & Roeyers, 2011; Velleman et al., 2016). The siblings in the current sample were all under the age of 14 years, however, they voiced comparable concerns about the future akin to those expressed by adult siblings in relation to the development of the diagnosis. These concerns encompass worries about their brother/sister's ability to navigate adult life and potential progression of the condition (Noonan et al., 2018). Therefore, the onset of worries about the future seems to start

at a young age and the worries may not be unfounded in the light of research on adult siblings.

An important finding was that the participants experienced sibling violence as particularly difficult in everyday life. Research on sibling violence in general is scarce, despite being the most frequent type of family violence (Elliott et al., 2020; Perkins & Grossman, 2020). Instead, sibling violence has often been dismissed or marginalized as harmless and normal sibling behavior in both research and in societal discourse (Elliott et al., 2020; Khan & Rogers, 2015; Phillips et al., 2009). The interpretation of violence as normal sibling rivalry may contribute to increased invisibility of sibling violence, which obscures the siblings' experiences, and hinders the establishment of interventions targeting this form of violence (Elliott et al., 2020).

Exposure to sibling violence in childhood has potentially long-term negative effects, such as difficulties in interpersonal relationships and impaired mental health in adulthood (Dantchev et al., 2018; King et al., 2018). This emphasizes the need to take these experiences seriously. Sibling violence may persist over several developmental stages throughout childhood and therefore affect the siblings' development (Phillips et al., 2009). Although the research is scarce, sibling violence seems to be more frequent in families with the presence of some types of chronic disorders (Leedham et al., 2020; Phillips et al., 2009). Enhancing openness and strengthening communication between siblings and parents may be important to prevent sibling violence and its negative consequences. When parents are made aware of the siblings' experiences related to violence, they are also enabled to act. They are the ones who are present in the siblings' everyday life, can set limits and boundaries, and help resolve conflicts between children in the family.

The relationships theme was divided into three subthemes. However, challenges related to one dyadic relationship can only be fully understood within the family context perspective, aligned with family systems theory (Minuchin, 1974). The family illness model, embedded in family systems theory, may be used as a framework when interpreting descriptions of relational experiences (Rolland, 1999, 2005). The disorder's impact on relationships can be understood as an interactional process. For example, characteristics of the diagnosis may lead to a lack of closeness in the sibling relationship (the brother/sister as difficult to understand or interact with), difficulties in the parent-sibling relationship (less time with the parents because they must engage in extended caregiving tasks or are emotionally unavailable due to stress), and increased closeness with the extended family (finding support in relationships with others such as grandparents). These different relational experiences impact each other. For example, some siblings attributed their parents' anger, sadness, or "appearing different", to the parental role of having a chronically ill child.

Limitations

The sample size in the current report is large for a qualitative study. The large sample size may have limited the in-depth understanding of the individual participants, and rather captured a broad impression of experiences across the data. A transdiagnostic perspective on siblings' experiences was applied which obscures potential diagnose-specific perspectives. Because of the commonalities in family-level challenges across disorders, a broad transdiagnostic perspective can enhance the understanding of the impact on families and improve care (McKenzie Smith et al., 2018). Thus, it is acknowledged that there are diagnosis-specific outcomes among siblings. Researchers including siblings of children with Down Syndrome in their samples found that these siblings, at the group-level, are at lower risk of developing impaired mental health compared to siblings of other disorders such as ASD (Heller & Arnold, 2010; Hodapp & Urbano, 2007; O'Neill & Murray, 2016).

Wider implementation of data triangulation could have enhanced the robustness of this study (Donkoh & Mensah, 2023). The limitations stem from the nature of the data: audio recordings of parent-child

dialogues without the researcher's direct observation. This restricts opportunities for triangulation, such as using observational notes. Moreover, the dialogues were transcribed verbatim and non-verbal cues like pauses and tone of voice were not included. Therefore, this study may have missed capturing emotions expressed through non-verbal cues.

Contextual factors are also important to consider when interpreting the findings. The conversations took place in an intervention program and in a clinical setting, for example at hospitals. The parents were trained to use specific communication techniques, the conversations were recorded, and a group leader listened to parts of the conversations. This may have contributed to adjustments in what the siblings shared with their parents and parental responses. In the SIBS intervention, siblings may be primed to talk about topics explicitly related to their family situation. Such priming may have prompted the siblings to overemphasize family challenges identified in this study. However, previous studies do not support this notion. For example, one study explored wishes created by siblings of children with chronic disorders compared to siblings of typically developing children and found that siblings of children with chronic disorders were more likely to make wishes related to their family compared with siblings of typically developing children (Shivers, 2019). This may reflect that the most prominent challenges in many siblings' lives are family-oriented.

Other potential factors influencing what the siblings chose to share with their parents, is social influence from other participants in session 4 in the intervention (the session prior to the dialogues analyzed in this study). Social influence occurs from a young age, and adolescents are especially susceptible to peer influence compared to other age groups (Large et al., 2019). However, social group processes in support groups can also strengthen the participants, helping them express difficult emotions and experiences (Evans et al., 2001; Vatne & Zahl, 2017). It is also important to consider the parental influences embedded within the current design. Siblings may have adjusted what they shared with their parents compared to what they would share with a researcher due to potential feelings of guilt or care-taking of parents. Further, themes and emotional expressions were influenced and possibly partly guided by the parents. This makes it challenging to separate the siblings' identified themes from parent-introduced experiences and challenges.

Implications for practice

The findings have implications for clinical practice. The themes identified can be used to guide how parents can meet and address siblings' needs, and how health care providers can inform and support parents in doing so. Since sibling violence seems to be hidden and marginalized as normal sibling rivalry in the societal discourse (Phillips et al., 2009), both parents and clinicians should address the subject directly and sensitively. Further, the findings indicate that parental involvement in sibling interventions is important. The challenges expressed in this study are predominantly related to the family system. Based on the family-oriented challenges reported in the current study, facilitating open communication and strengthening parent-sibling relationships may be particularly important in the context of chronic disorders. Concerning family systems theory, chronic disorders do not only affect the child, but the *family health* (Butcher, 1994). Chronic disorders impact the entire family in various ways throughout life, emphasizing the relevance of interventions targeting family-level risk and resilience factors.

Implications for research

The current study also has implications for research. Future research should investigate how parents' respond when siblings share difficult experiences and emotions. A prior quantitative study (using a different sample than the current study) found that parents to a low degree

validated siblings' expressions of emotions (Haukeland et al., 2022). Building on this, the current study found that siblings expressed emotionally demanding experiences to their parents, emphasizing the importance of thoughtful and sensitive appraisal of such expressions. When parents handle difficult experiences accurately and insightfully, it may foster a deeper understanding of appropriate coping strategies and emotion regulation in children (Waters et al., 2009), highlighting the importance of studying parental responses.

The theme structure in the current study may guide potentially relevant measures to include in quantitative studies. Across the quantitative research, sibling outcomes measured in clinical symptoms report small effect sizes (Pinquart, 2022; Vermaes et al., 2012). The findings in this study imply that other measures than clinical symptoms may provide a further understanding of siblings' functioning. There is a lack of children's involvement in both research and the development of intervention programs (Facca et al., 2020; Larsson et al., 2018). To guide quantitative studies towards siblings' own-reported experiences may create meaningful research results for siblings and their families. For example, it can be advantageous to include measures on relational experiences, and violence or trauma scales.

Conclusion

This study contributes to the evidence base of the impact of chronic childhood disorders on siblings. Importantly, it adds a new dimension by investigating the lived experiences of siblings in the format of parent-child dialogues. The findings imply that the siblings experience challenges and difficult emotions through interactional processes where aspects of the diagnosis impact family life and relationships.

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CRediT authorship contribution statement

Amalie Schumann: Writing – review & editing, Writing – original draft, Visualization, Methodology, Formal analysis, Data curation, Conceptualization. **Torun M. Vatne:** Writing – review & editing, Supervision, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Krister W. Fjermestad:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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