



# A Qualitative Study of Men's Experience of Being a Father in Families with Childhood Disability

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## Abstract

Fathers in families with childhood disability have an important role in fostering coping and resilience in children. Insight into men's thoughts about fathering is necessary to provide family-centered interventions. The purpose of this study was to explore men's experience of being a father in families with childhood disability. Qualitative interviews were conducted with seven fathers in families with childhood disability. Content analysis was applied to analyze the data. The participants described their thoughts about children's needs; mastery, secure attachment, clear boundaries, positive emotions, and role models. Creating a father-child unity, being active, playful, fearless, and sometimes restraint was described as fathering behaviors aiming to meet these needs. However, personal, family, and social factors were described as influencing fathers' behaviors. Fathers' psychological wellbeing was described to be affected by the childhood disability to different degrees, and emotional triggers related to the disability were described. Participants described using a variety of emotion regulation strategies, but somewhat restraint support seeking behavior. We conclude that the health and social welfare system should involve fathers in the provision of services to children, empower them in their role as fathers, and provide support tailored to their needs.

**Keywords** Fathering · Fathers experiences · Childhood disability

Fathers in the twenty-first century are more involved in child rearing compared to their ancestors (Cabrera et al., 2000). Families have gone from being generational to nuclear, leaving parents with a higher caretaking burden (Boström & Broberg, 2014;

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Williams, 2008). In Western societies, political guidelines facilitate more equal gender roles in parenting (Brandth & Kvande, 2009). However, gender inequality in regard to access to long-term employment and income, may force parents into traditional roles (Williams, 2008). Fathers report to experience a tension between being “the breadwinner” and being more involved in parenting (Shave & Laschewicz, 2016).

The current study explores men’s experience of being a father in families with childhood disability. By childhood disability, we mean impairment or delay of physical, intellectual, or psychological functioning that are innate or appear between the age of 0 to 18 years. Applying a relational understanding of disability (Shakespeare, 2004), disability is not solely the medical diagnosis of the child. Disability is also created or maintained when the child and the other family members, with their unique traits and contributions, interact, and when the family meet the demands of the society. Consequently, the term “families with childhood disability” will be used throughout this paper. Fathering in these families is a topic that has received little scientific attention (Bogossian et al., 2019).

For families with childhood disability, there has been a movement from institutionalized care towards emphasizing children’s right to grow up in the family home (Rosenthal, 2018). Parents in these families are described to have multiple roles of being therapists (working to improve functioning), lawyers (advocating for needs), and administrators (ensuring system cooperation) for their children (Gundersen, 2012). Parents of children with a disability report higher caretaking burdens compared to parents with typically developing (TD) children only (Gerstein et al., 2009).

In response to the high caretaking demands, parents in families with childhood disability are found to take more traditional parental roles. For example, mothers tend to work part time or stay at home to meet the care needs of the child (Tøssebro & Paulsen, 2014). Health and social services are also reported to reinforce this pattern. Health care personnel tend to primarily involve mothers and provide fathers with less medical information and support (Doherty & Dimond, 2018; Feenstra et al., 2018; O’Halloran et al., 2013).

Although the research basis is scarce, previous studies have provided valuable insights into the experience of fathers in families with childhood disability. Parents in families with childhood disability have a higher risk for depression, anxiety, and stress compared to parents of TD children (Oelofsen & Richardson, 2006; Risdal & Singer, 2004). However, the risk of negative psychological sequelae is lower for fathers compared to mothers (Hastings et al., 2005; Pinquart, 2018). This leaves a (possibly false) impression of fathers as more resilient than mothers. More knowledge about fathers’ experiences may provide insight into the cause of this divergence between parents.

Fathers have described the process of receiving a diagnosis for the child as a period of uncertainty about the future and the child’s prognosis (Meadan et al., 2015; O’Halloran et al., 2013). Further, fathers have described to cope with this uncertainty and inform their fathering behavior through seeking information about the diagnosis (Huang et al., 2012; Meadan et al., 2015). A self-expectation to be “strong and silent” has been reported by fathers (Swallow et al., 2012). Compared to mothers, fathers report to use less problem focused coping strategies, and seek less

social support when they experience negative emotional reactions (Chesler & Parry, 2001; Gray, 2003).

Studies on parents in families with childhood disability are disproportionately mother-focused. When fathers are included, studies often aim to compare fathers' experiences to those of the mothers rather than exploring fathers' unique experiences (Bogossian et al., 2019). Research has shown that the experiences of mothers and fathers tend to be qualitatively different (e.g., Gray, 2003; Pelchat et al., 2009). This indicates that the paternal perspective should be explored independently for mothers and fathers (Thackeray & Eatough, 2018). A scoping review called for more research on fathers' behavioral involvement with children in families with childhood disability (Bogossian et al., 2019). Paternal involvement has so far been limited to assessment of frequency and manner of interaction, and the quality of involvement has solely been evaluated with mothers as informants (Bragiel & Kaniok, 2011; Simmerman et al., 2001). Less knowledge exists about how fathers understand their own parenting behavior (Bogossian et al., 2019).

Richer insight into fathers' experiences may advance the development of theories on parenting in families with childhood disability and provide directions for future research. Further, more knowledge about fathers' perspectives may inform the design of family-centered intervention programs, which are recommended for childhood disability (e.g., Mas et al., 2019). This may be of particular importance as fathers' psychological state has been found to affect fathers' parenting more than mothers' psychological state affect mothers' parenting (Bögels et al., 2008). Further, self-reported psychological adjustment among TD children in families of childhood disability, has been found related to father-reported mental health but not to mother-reported mental health (Fredriksen et al., 2021).

The purpose of the current study was to explore fathers' experiences to gain a deeper understanding of how men experience being a father in families with childhood disability. We aimed to answer the following research questions: 1) How do fathers in families with childhood disability describe their fathering behavior? 2) What factors do fathers perceive to impact on their behavior as fathers in families with childhood disability? 3) What do fathers in families with childhood disability experience as sources of emotional stress, and how do they cope with the associated emotions? These questions were explored openly using a qualitative approach, as recommended when multifaceted social phenomena is to be described from the participants' point of view (Brinkmann & Kvale, 2015).

## Methods

### Sample

A sample of seven fathers from families with childhood disability participated. Participants were aged between 35 and 55 years and lived in urban areas in Norway. All lived with a female partner; five with the biological mother of the child with a disability. Six were biological fathers of the child with disability and one was an adoptive father. All participants also had TD children. The mean number of children

per participant was three (range 2–5). Four participants were employed, one was a student and two were on long term sick leave. The children were from primary school age to in their early twenties and had different disabilities. Five children had an intellectual disability diagnosis; three with co-morbid conduct disorders. Two children had a diagnosis of progressive nature, one with physical manifestations, the other with both intellectual and physical manifestations. The oldest child with a disability lived in residential care, whereas the others lived at home.

## Procedures

As preliminary results from an open trial of an intervention aiming to improve family communication in families with childhood disability (Haukeland et al., 2020) indicated a unique psychological profile and a unique contribution of fathers we decided to take a closer look at their experiences. The study was approved by the regional committee for research ethics. Participants were recruited by convenience sampling. A study information letter with an informed consent form was sent to 19 fathers who lived within one-hour drive from Oslo, and who had previously participated in the open intervention trial (Haukeland et al., 2020). Consenting participants were contacted by phone and place and time for the interview was scheduled. Face to face interviews were conducted and audiotaped by the second author, an advanced psychology student. The interviews were conducted at the participants' choice of localization (four at the participants' home, one at the participant's workplace, one at a competence center, and one secluded in a local park). The interviews lasted from 76 to 196 min. The interviews were transcribed verbatim by the second author.

## Data Collection

Data were collected through individual in-depth semi-structured interviews based on an interview guide. The interview guide was developed based on empirical and clinical knowledge about fathers in families with childhood disability, and a focus group with fathers from families with childhood disability. A first draft of the interview guide was also reviewed by three fathers who had previously been involved in the development of a manualized intervention for TD siblings (Vatne et al., 2019). We asked these fathers for their opinion about relevance, comprehensibility, and respectfulness of the questions. Based on their feedback, the final interview guide was completed.

The interview comprised questions about two main areas, the first about fathering in general, the second about fathering in relation to the child with a disability. For the specific questions, see Table 1. The interview guide also contained prompts to enhance the depth and specificity of the participants' answers and descriptions. The interviewer aimed to keep the structure of the interview as open as possible and enable the participants to bring up own topics and nuances as this may increase the accuracy and credibility of the answers (Brinkmann & Kvale, 2015; Malterud, 2011).

**Table 1** Questions in the Interview Guide

Domain	Probe questions
General father role	<p>What is typical for you as a father?</p> <p>How are mothers and fathers different from each other?</p> <p>When do you find being a father challenging?</p> <p>With whom can you share your challenges?</p>
Being the father of a child with a disability	<p>How are you affected by having a child with a disability?</p> <p>What do you find challenging with being the father of a child with a disability?</p> <p>What is positive with being the father of a child with a disability?</p> <p>How are you met as a father by the healthcare system?</p> <p>Fathers of children with a disability have been found to have a better psychological health compared to mothers. What are your reflections about that?</p>

## Data Analysis

Data were analyzed using conventional content analysis (CCA). This is an inductive qualitative method that involves subjective interpretation and identification of topics in a text through systematic classification and coding processes (Hsieh & Shannon, 2005). In CCA, categories are derived directly from the text rather than from existing theory and empirical basis (Kondracki et al., 2002). The data were analyzed following the recommendations of Hsieh and Shannon (2005). First, transcripts were read as a book, capturing an overall impression of the content. Second, the text was closely reviewed and sentences that seemed to capture important themes were highlighted. Third, excerpts of the transcripts were sent to the first author, an experienced clinician who works with families with childhood disability. The coder (second author) and the expert (first author) coded the excerpts individually and then met for comparison and discussion of themes identified. Based on this discussion, ten tentative categories were developed. Fourth, all data were reviewed in depth and coded based on the ten categories, and in this process several additional categories were identified. The coder discussed the codes consecutively with the expert throughout the coding process. This team developed a hierarchy of codes in which the initial codes were organized under main categories. Fifth, the main categories and the subcategories were defined and illustrative examples from the interview text transcripts identified.

## Trustworthiness

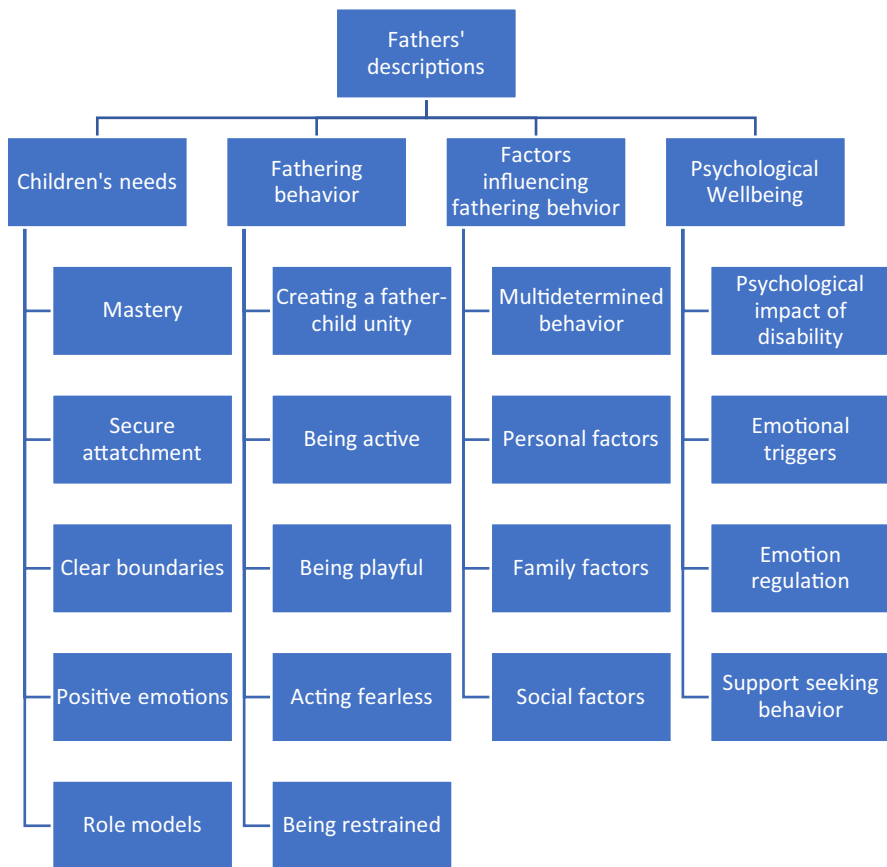
We sought to ensure trustworthiness of the results in several ways. First, through the involvement of fathers in families with childhood disability in the development of the interview guide. Second, the coder shared reflections and discussed with an expert throughout the coding process. Finally, we asked the participants to review the results and provide feedback about whether the categories identified reflected their experience, and if there were any important topics from their interview they felt were left out.

## Results

The participants' experiences of being a father in families of children with disabilities were categorized into four main categories: (1) Children's needs in the father-child relationship, (2) fathering behavior perceived to meet children's needs, (3) factors perceived to influence father behaviors, and (4) psychological wellbeing among fathers. See Fig. 1 for details of main categories and subcategories.

### Children's Needs in the Father-Child Relationship

This category concerns the participants' descriptions of their children's developmental needs in interaction with the father. The same basic needs were described for the children with a disability and the TD children.



**Fig. 1** Main Categories with Subcategories

## Mastery

Participants described their children's need for experiencing mastery, meaningful activities, and autonomy in the father-child relationship. One father described how he actively created a space for his child to experience mastery: *"I have always tried to make the children join me when I do gardening (...). I think it's good that they get to do practical chores with me, it's a way of learning (...). She [child with a disability] wasn't actually much of a help, but she joined me, and she felt that she did something important with her spade and everything. I think that for her, the feeling of being useful is really important"*.

## Secure Attachment

Participants described their children's need for safety and attachment in the father-child relation, such as knowing that they had a "safe harbor" to return to: *"I have some chicks here who are about to leave the nest. So I am kind of in the phase where (...) don't know, I am concerned about making the road back home as short as possible. Yes "out, spread your wings, and if you get hurt, return home"'*.

## Clear Boundaries

A need for fathers to establish clear and predictable boundaries in the relationship, particularly for the child with a disability, but also for the TD children, was described by the participants: *"I think all children like strict rules. Clear set of rules, clear boundaries. I remember a childhood friend of mine, who I always envied. He had no rules, could stay out as long as he liked. Later he actually said "no, I felt envious of you. You had somebody who cared"'*.

## Positive Emotions

Participants described the importance of children feeling positive emotions and joy in the father-child relation. Laughter was regarded as a good indication of joy, particularly in children with a disability who did not have verbal language: *"I have found myself almost manic about making my son laugh. But his laughter .... It's a good sound, it assures you that he is ok"*.

## Role Models

Children's need for the fathers to be role models was also described by the participants. One father described being aware of practicing as one preaches: *"... the strangest thing I see is when parents ride a bike without a helmet and then tell then children to 'put your helmet on'. It's like, 'do it yourself"'*.

## Fathering Behavior Perceived to Meet the Children's Needs

This category concerns the participants descriptions of their behavioral involvement as fathers and their thoughts about how this behavior met children's needs.

### Creating a Father-Child Unity

Participants described creating a unity with their children as a prerequisite to meet the children's needs. However, the development of such a unity was perceived in different ways. Some described the unity with their child as predefined and symbiotic. Others described unity as something they actively worked to achieve, but which they believed fell more natural and instinctive for mothers. One participant had the following advice to other fathers of children with a disability on how to build a relation to the child: *"Engage. Get to know your child (...) If you establish a good report with your child the child will get attached to you as well"*.

### Being Active

Descriptions of being active included organizing and taking part in activities with the children, for example as a coach or an organizer of children's sports, through paying interest in the children's hobbies and joining their leisure activities: *"We share good moments, my son [with a disability] and I, when we go to concerts and have a good time just the two of us... My youngest daughter (TD child), she practices cross country skiing and she is actually quite talented. This winter I tried to spend some time with her, go skiing with her. We had some long trips, I think she likes that I spend the time"*. Being involved in patient organizations or sports associations was also described as a way of being engaged in the children's lives.

Active fathering behavior was perceived as means to both strengthening the father-child unity, and to foster mastery by teaching children, particularly the child with a disability, practical skills.

### Being Playful

Participants described a strive to be a "a playful father" through various strategies, including playing with the child, telling jokes, using humor and play in the child rearing, and adjusting to the level of their child during play: *"It's important to adjust to their level too, without feeling stupid. Like yesterday...(at bowling) I had to join them so that the youngest was allowed in, but it resulted in me joining them and having so much fun!"*.

Playful behavior was perceived as a way of evoking positive emotions in the relation, but also as a way of stimulating child development and mastery through interaction: *"I believe that the way I challenge the kids is by making it into some kind of play. A game or a puzzle (...) I have joked and had fun with these kids since they were really, really tiny. In a way we became best friends and playmates, and sometimes, a toy myself"*.



## Acting Fearless

Participants described how they tried to make new activities less scary, but also to challenge their children: *“The children need to become tough, not porcelain figures. So... when my daughter (child with a disability) was younger, I tossed her into the water even though she could not swim. She just ‘blub blub blub’, disappeared into the water. Then I just picked her up and she was brilliantly happy every time. (...) It has ensured she is not afraid of the water, even though she is not a good swimmer, and I think it is a great advantage for her”*.

Acting fearless was described as fathering behavior where a secure attachment between the father and the child allowed them to act as role models and push limits. The importance of not becoming overprotective but let the children master new skills by trying and failing was highlighted: *‘To paint a (laughs) strong picture: ‘My son should be able to break a leg’*”. This was described as of particular importance when interacting with the child a disability.

## Being Restrained

Participants also described actively limiting their involvement in their children’s lives, including interacting when needed, but not initiating activities to a large degree: *“Like, I don’t dig into, I don’t try to take up too much space in the life of these children and.... Yes, that’s them and that’s me. (...) Still, they know that they can come to me”*.

As for the previous category (concerning children’s needs), being restrained was described to be based on a perception of a secure attachment between the father and the child, which was seen as a way of fostering mastery.

## Factors Perceived to Influence Father Behaviors

This category concerns participants’ perceptions of possible direct and indirect influences on their fathering behavior.

## Multidetermined Behavior

Participants expressed multifactorial views when describing factors influencing their fathering behavior: Evolution, genetics, gender roles, social environment, support systems for persons with disabilities in the community, the family situation, and the diagnosis of the child with disability: *“There are cultural differences in what is expected of men and women (...). Strict demands that you put on yourself. (...) The roles we are taught, but also what’s in your DNA make us behave differently. (...) You watch what other fathers have done for decades, and what your neighbors do. It makes up your role models and expectations.”*

## Personal Factors

Participants described their attribution of control over own fathering behavior, varying from expressing that “it all depends on me” to experience being controlled by external factors. A gradual change of an initial internal locus of control when entering fatherhood was also described: *«I believe it's a lot up to me (...) it's kind of a feeling of defeat when you need help (...) I just really believed that it was all up to me, but then life experiences sort of indicated that there are so many things outside that affect you as well, right?»*.

Participants described how experiences with their own male caregivers could form an ideal for them and inspire their fathering. This is one example: *“I don't have a close relationship to my own dad. But then you find substitutes. For me it was my best friend's father, you must find some male ideal. Maybe you have several impressions [of men] that you put together and make an illusion of 'this is how my father should have been. What would he have thought?' So, your store this in your subconsciousness and you are kind of formed by this”*.

Participants described how they evaluated their fathering behavior according to their ideals. Not living up to own ideals could serve as a motivator for change. For example, negative experiences with parenting practices in their own childhood could cause a counter reaction when finding their own role as a father: *“Some of my boundary setting and parenting is probably about inheritance. And I also consciously try to distance myself from this inheritance (...) I have been thinking 'this did not do me any good', and I have tried to act differently”*.

Participants also described how some of their own personality traits were not in accord with their parenting ideal and the work put in to not transferring these traits to the children. One father described: *“As they grow older you face yourself to a larger and larger degree. And it's maybe the parts of me that I do not like I notice most (...). Both me and my father we are both critical by nature... We easily say something critical. It can be a bit too much. I try to be gentler in the way I speak”*.

## Family Factors

Perceived traits of the individual children were described as influencing fathering behavior, both in terms of intensity and form. Fathering was tailored to the needs of the individual child. The TD child was sometimes experienced as needing less intensive fathering compared to the child with a disability: *“I am like more limited when it comes to the other two [TD children]. I do not mobilize as quickly and it takes more before I use my energy and effort on their needs. I am not that attentive to their needs... like more superficial. Looking for something that confirms that they are ok rather than looking for challenges and needs for attention.”* Participants also described how they felt the need to more actively ensure that the needs of the child with a disability were met, that realistic goals for the father-child interaction were set and evaluated and adjusted when needed.

Mothers' behaviors were also described as influencing fathering behavior, sometimes forcing participants into an unwanted role: *“I have often heard my partner say [to a child] 'if you don't do as I tell you your father will come and...!' You become a*

*powerful threat, and I don't like that. I don't want to be the d\*\*\* who's strict? Am I supposed to be the troll? Why does she want to put me in that role?"*

## Social Factors

The social welfare system and health care system were factors described by the participants as affecting fathering behavior. The participants described not to been given the same opportunities as the mothers, e.g. by not being shown the same understanding by employers, or by not being involved by the health care system: *"They [health professionals] always turn to the mother when they talk. Like, if I am to say anything, I have to go through her, like she has to say it (...). In that way I feel like I am put on the sideline. I have to channel it through the mother. Correspondence is fully targeted towards the mother. It's really rare, I have almost never experienced being the recipient. It's never in my name. It has never ever happened, and we are talking about a lot of envelopes"*.

## Psychological Wellbeing Among Fathers

This category concerns participants' emotional experiences as fathers in a family with childhood disability.

### Psychological Impact of Being a Father in a Family with Childhood Disability

Childhood disability was described as potentially affecting participants' psychological wellbeing, but to different degrees. The participants expressed how the emotional life had become expanded in both positive and negative directions: *«With my son [child with a disability] I feel like my emotional life has become wider. That is, the downs are deeper and the difficult thoughts heavier, but the ups are higher"*.

Some described periods of great emotional suffering and periods where sick leave was necessary due to emotional distress. *"The last time I was really down, I remember I was trying to tie the shoelaces of my son [child with a disability], and I could not do it (...) and I fell apart and broke down (...) And I was thinking, 'here is a dad who cannot even tie a shoelace without having a breakdown'. (...) It feels wrong, I wish my sons [the TD children] could see a dad who coped better with his own life"*. Others described being minimally affected, like the father who stated: *«I am more upset on behalf of others than on own behalf. I am not often upset or sad. If I am sad it's for a short period, so there are no major depressions here (laughs)"*.

One of the participants, whose son had a progressive life-shortening diagnosis, described a continuous grief: *«The loss and the deep grief are there all the time. When we take family photos like all other families. The family around the dinner table, 'click'; the children playing soccer in the garden, 'click'; children taking a bath in the bathtub, 'click'; opening presents on Christmas eve, 'click'. All the normal family pictures (...) But there in the background, always present; the Grim Reaper. He is in that chair, all the others are smiling around the dinner table, but he is there, all the time. That's maybe the hardest part."*

The participants described having a lot of worries. In periods with a lot of worry and emotional suffering some participants experienced that their ability to perform the desired fathering behavior decreased, as evident in this quote: *“I am a good dad, in the large picture I have been a great dad, but sometimes it falls apart and the feeling of powerlessness is overwhelming. And the sorrow makes me act so childish, instead of being angry with myself I get angry with my son [child with a disability]. I have yelled out at him and made him cry, like he is responsible for anything (...). And when I come to myself I say ‘I am sorry son, I love you’, and his lips are trembling when he says, ‘I know’, then I feel so, so small “.*

Participants described prioritizing their own mental health in everyday life as important: *“If you don’t prioritize yourself there are a lot of consequences. For many others beside myself (...) To continue to be able to work, to relate to the two other [TD] children, to be a husband, and especially to be the father of the one that has a lot of needs. The preconditions for this disappear if I run empty.”*

### Emotional Triggers

Participants described various triggers for negative emotions in the relation with the child with a functional impairment or when the father-child unity met the demands of the surroundings. If the child with a disability behaved in an abnormal or challenging way in public places this could cause embarrassment. However, trying to restrain the child or deal with the situation could also be emotionally difficult: *“It’s difficult... It’s never ok to become physical with your children (...) If I do not hold him down and use force, he may destroy things (...) when he breaks stuff he becomes so sad, so, in a way I spare him the sorrows.”* Unwanted attention and reactions from others could also in turn trigger negative emotions such as anger: *“When adults are staring because she’s different, then... I find it so annoying and hurtful, on behalf of my daughter. That is, I do not think she notices, but I do, and I feel that people should behave”.*

Not being able to understand the child due to speech impairments could also trigger emotions: *«When he comes home from school, I often ask him about his day. And then he may try to tell me something and I do not understand (...) and then he just says ‘no’ and gives up explaining. That is really difficult. He really wants to share something with me, his father, and I do not understand (...) and he crumbles and gives up, and it’s all quiet.”*

Participants described how not being able to cope and behave according to their own or society’s parenting ideals could trigger shame and guilt. Sometimes this was related to how they dealt with aspects of the disability as evident in this quote: *«When it comes to him not knowing that he is going to die I often think that I am lying to him...I have never lied to him, but I have not told him the complete truth. I have had a pain of conscience related to that (...) but if I had told him (...) and he gets really sad and risks going into a lifelong depression its irreversible. And if he one day should blame me and say ‘why didn’t you say anything dad?’ at least I can say ‘I am sorry, I did my best...’.*

Shame and guilt were also expressed in relation to fathering the TD children as described in these two quotes: *“I spend most time with our son [child with a*

disability]. He needs a lot of one-to-one attention. Then the distance between me and my girls [TD children] have become larger compared to between my son and I, and that's a bit...(...) Then your six-year old [TD child] throw a comment like 'dad, you never put me to sleep (as mum does)' and I'm like 'but... he has an illness. Sorry!' It's difficult".

Participants described how the relation to the health and social welfare system caused stress: *"The biggest challenge is not the fact that the child is sick, it's the fight with the system (...). You get rejection by rejection. It seems like they reject your applications just to make you stop applying. And when you stop applying, they think 'ok, then there are no needs'. (...) all the applications and the fighting made me break down, I could not take it anymore and was on three weeks sick leave. (...) I did not have the strength to appeal"*. Many, unsuccessful meetings with the public welfare system were described as demanding energy and resources that the participants not necessarily had, and also as causing future meetings and applications for support to evoke anxiety.

Lack of trust in the system could also evoke fear for their children's future like one participant described it: *"Every time we hit a rough spot with some instance involved in his life it's like (...) it's the thought that he needs us to survive him, that's a basic worry. Because who is going to be there and take care of his needs when we are to old, sick or dead? (...) This is kind of an existential dimension of being the father of a child with a disability that is really heavy."* One father described having intrusive thoughts about the care provided to his son in the future: *"I read an article in the paper about a man named John who died alone at a nursing home, but suddenly I did not read 'John' but the name of my son! That is my fear, right? And when I read the article, that's enough for me to get a physical reaction."*

## Emotion Regulation

Participants described several strategies as means to regulate their own emotions, such as physical activity, distracting activities, and mental techniques. One participant described that he had a mental image that helped him deal with intrusive thoughts about this son's death: *"He (a psychologist) managed to paint a new picture of his deathbed (...) and it does not involve white coats (health care) surrounding him, but... his big brother and little brother is there. So when I managed to paint that picture, it was enough for my focus to change (...) So now I have a new picture that gives me a peace».*

Another participant described how practical chores helped him deal with frustration or give him time to think: *"I need to have some concrete chores. Clean out the closet, build a fence, move something – I prefer doing something physical, but sometimes PlayStation helps. Simply because you must pay attention, and you cannot think about all the difficult stuff."*

Doing something fun was described by one participant as a way of being distracted from the emotional pain related to his son's loss of function: *«I have delt with it [the emotions] by... or we have delt with it by thinking that once in a while we are going to have a really, really, really fun time. My son [child with a disability]*

*put it into these beautiful words: 'There is a sad tone playing inside me all the time, but sometimes I have so much fun that I cannot hear it'. And I think that is probably what I am doing as well".*

### **Support Seeking Behavior**

Even though participants described they were able to share their emotions with others, it became evident that they often held back. They described not wanting to seem weak or whining in the eyes of their partner or friends. Participants expressed a desire to not burden the family with their emotions, especially if the partner was stressed: *"I simply want to protect her (...) it's like if I fall apart, she has to hold the fort"*. Even when sharing difficult experiences with their partner, participants would often keep this from their friends. *"I do not want to be seen as the bad blister... like them ending up thinking "oh no, here he goes again, talking about that stuff again, I can't stand it"."*

Participants described attending courses or patient organization gatherings where they met other parents in families with childhood disability as useful. In such settings, they were given information, learned about solutions to problems, built a network, and experienced social support. However, formal group settings could also be perceived as less useful than informal social gatherings: *"Like in a bar or something. Where you feel more comfortable, not like –'you cannot leave because now we are talking about this'. In the bar you can just 'I need to take a leak'. Because sometimes you get overloaded, and you are not supposed to cry because you are a man. And if you think that 'this is too much' you are allowed to just stand in the bar and talk about football."*

Seeking professional help was by participants described as positive and useful. *"...I went to a psychologist every second week and somehow got to ventilate a bit. It was quite alright, I got to whine a bit (laughs) and got kind of an acceptance for the difficult parts of being me (...) I miss it."*

## **Discussion**

The aim of this qualitative study was to describe men's experiences of being a father in families with childhood disability.

### **Fathering in Families with Childhood Disability**

Whereas the interview guide contained questions about being a father in general as well as more specific questions about being the father of a child with a disability, the participants did not make this distinction much when talking about children's needs. Children's basic needs were described as equal and the child's functioning was not taken much into account. One of the needs described was a need for a father-child unity. This is in line with previous research that indicates a unique contribution of fathers in the lives of children; in particular, they are important for children's

development of openness (Paquette, 2004). Further, fathers' psychological state has been found to be related to the state of their children (Bögels et al., 2008).

Participants described the father-child unity as something they had to work towards achieving, and which developed with time but in a slower pace compared to the mother-child relation. There may be several reasons behind this perception. In terms of biology, one reason may be that the biological prerequisites for the mother-child relation is stronger (Swain et al., 2014). Another potential explanation could be that the signals of children with a disability may be harder to read compared to those of TD children (Howe, 2006; Vandenberg, 2007). Generally, women have been found to be more sensitive to signals from infants than men (Hallers-Haalboom et al., 2017). As such, men may find it more difficult to tune in to children's signals. Physical symptoms, medical procedures, and abnormal stimulus interpretation or responses may also expose children with a disability to higher levels of stress compared to TD children (Spirito et al., 1994; Spratt et al., 2012). In such situations, children may need the calming and comforting behavior of a typical mother-child relationship more often compared to the exciting and surprising behavior of a typical father-child relationship, as described by Paquette (2004). In terms of sociology, another reason may be that mothers in Norway are the ones who stay at home for the majority of a child's first year while the father is working (Schou, 2017).

The participants described different kinds of fathering behaviors aimed at meeting the needs of their children, regardless of the disability. Some of the behaviors described by the participants, such as being active, being playful and being fearless, are fathering behaviors researchers have previously described to play an important part in child development. In a theoretical paper about the father-child relation, Paquette (2004) described how fathers tend to excite, surprise, and momentarily destabilize children during interaction. Further, fathers often encourage children to take risks in safe surroundings in order to develop the courage to be brave and stand up for themselves in more unfamiliar situations (Paquette, 2004). Children with a disability do experience more anxiety, experience less mastery, and have lower self-esteem compared to TD children (Dagnan & Sandhu, 1999; Green et al., 2015). In line with these findings, participants in the current study described that preparing the children for the "outside world" seemed to be a more explicit and conscious aim when interacting with the child with a disability compared to when interacting with their TD siblings.

Whereas the basic needs of children were described as equal regardless of the child's functioning, our participants described a need for a "higher dose" of fathering behaviors among children with a disability. The participants explicitly stated observing less needs from TD children and spending less time with them. This is an assumption that needs to be challenged as TD children in families of children with childhood disability have been found to hide their challenges and needs from their parents to not burden them (Haukeland et al., 2015). The needs of TD children in these families, especially the opportunities that a close relation to a father implies, require increased awareness as previous research indicates that the father-TD child relation may serve as a protective factor for sibling mental health (Fredriksen et al., 2021).

## Factors Affecting Fathering Behavior in Families of Childhood Disability

The participants' ways of fathering were described as conscious choices made based on personality, experiences, and memories of their own father figures. However, the participants also described how other factors shaped their fathering behavior and challenged their feeling of control. One of these factors was the mother's behaviors and traits. Mothers are found to be greatly affected when a child is diagnosed with a disability (Hastings et al., 2005; Pinguart, 2018). Mothers tend to worry more about the future (Bujnowska et al., 2019), experience higher levels of uncertainty (Stewart & Mishel, 2000), and use more problem focused strategies compared to fathers (Hastings et al., 2005). In light of these findings, we may interpret the participants' description of mothers trying to control their fathering behavior as mothers' effort to cope with anxiety. For example, when observing a challenge, mothers tend to seek advice or information, make up an opinion about the right way to deal with the problem, and then possibly try to make the father act according to her ideas.

In line with a previous study (Docherty & Dimond, 2018), participants in the current study reported that the health care system failed to involve them in the same manner as the mothers. Mothers tend to get the calls, the mails, and be the ones the system relies upon when caring for a child with a disability. It seems that there is a divergence between intention and practice and that measures must be taken to implement the rights of fathers in provision of care.

## The Psychological Wellbeing of Fathers in Families with Childhood Disability

The reported psychological wellbeing of the participants varied, however their narratives involved strong negative emotions such as sadness, anxiety, shame, and sorrow. Research has described gender differences in the frequency, expression, and regulation of sadness. Men tend to cover up this emotion and are less effective in regulating sadness compared to women (Rivers et al., 2007; Timmers et al., 1998). We may assume that the lack of psychological stress in fathers could contribute to reduce the stress in the family system. However, there are higher levels of depression and anxiety among parents in families with childhood disability compared to other families (Oelofsen & Richardson, 2006; Risdal & Singer, 2004). Although the participants in this study described «being fearless» as an important fathering behavior, they also described much worry and fear for their children's wellbeing and future. We have reason to suspect that fathers' emotional suffering may go unnoticed. Not having their psychological needs met by health care providers or the social welfare system is in line with previous research on fathers in families with childhood disability (Docherty & Dimond, 2018).

To be the one to “hold the fort” in times of stress and to withhold own emotions, to not burden others, or to prevent appearing whining and ‘weak’, were all patterns reported by participants in the current study. This is line with previous research showing that fathers reported a self-expectation to be “strong and silent” (Swallow et al., 2012). Sadness, anxiety, and shame are emotions that socially signal



powerlessness. These emotions are expressed more equally by men and women in situations where displaying such emotions is regarded as culturally legitimate (Zammuner, 2000). The results of the current study may imply that the family is a context where some men experience that expressing sadness, anxiety, and shame is culturally inappropriate. Displaying such emotions is also perhaps in contrast to the behavior of the fathers' role models. Cultural norms may as such prevent the fathers from expressing emotions and seeking support. This is concerning, given that expressing emotions and seeking support have been found to be effective ways to regulate emotions such as sadness (Rivers et al., 2007).

Several factors were reported to trigger emotional reactions and reduce the psychological wellbeing of the participants in this study. Whereas some triggers were related to the disability, such as behavior problems, communication problems, and prognosis, it was evident that stress was also related to a perceived lack of societal support. The fathers described a need to be highly involved in the lives of their children due to the disability, but that societal factors challenged this. Long-lasting and frustrating application processes to enhance the economic situation of the family were described. We may speculate about whether this struggle is what forces fathers in families of childhood disability into more traditional parenting roles and into spending less time at home (Tøssebro & Paulsen, 2014). In line with previous research (Doherty & Dimond, 2018), the participants also described to be overlooked and not included as mothers by health care providers. By not being involved, father may miss out on opportunities to learn more about the child's disability. This may in turn make them less competent in meeting their children's needs, potentially leading to less coping experiences and lack of self-esteem as a father.

Lack of involvement with health care and men's tendency to hide emotional reactions may lead to fathers' potential support needs being overlooked by the health care and social welfare systems. Further, when offered, the support may not always be tailored for men's needs. Previous research has found that men do share their experiences in support groups, preferably with other men, when they expect to be understood and accepted (Chesler & Parry, 2001; Meadan et al., 2015). There may thus be a need for support groups for fathers only.

## Limitations

This study has limitations. First, the participants were recruited from an intervention study focusing on communication with siblings of the child with a disability. Participating in the intervention study may have affected their fathering experience. Second, the sample was small and heterogenous in terms of age and the nature of the disability of the affected child. Nuances related to specific disorders and age-related needs may therefore have been lost. Finally, for practical reasons, the sample was drawn from an urban area, and other themes may have emerged with a more geographically diverse sample.

## Directions for Future Research

Future research should aim to recruit more homogenous samples in terms of family situation, child age, and disability types, to be able to describe, in depth, the experiences of fathers in families of specific disabilities. Such descriptions may, to a larger degree than the results of this study, inform targeted family centered interventions. Further, future studies should focus on the relation and cooperation between mothers and fathers in families of childhood disability to better understand the dynamics of these families and how to promote resilience in parents as a couple.

## Implications for Practice

The results of the current study may have implications for the delivery of services and support to fathers in families with childhood disability. First, the health and social system may have a potential for increasing the involvement and interaction with fathers. Second, some fathers may need supervision in observing and interpreting signals and signs of children with a disability. Third, fathers should be empowered and reminded about their important role in the lives of TD children. Fourth, couple interventions and courses for families with childhood disabilities should focus on the unique contribution of the individual parent in family life and child rearing and aim to increase communication and mutual understanding. Finally, the health and social system should consider providing support groups for men only, and consider adapting the format to participant preferences, which could imply making the setting less formal.

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**Data Availability** Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

**Code Availability** N/A.

## Declarations

**Ethics Approval** This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Regional Committees for Medical and Health Research Ethics (14.02.19/#2013/2118).

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

**Consent for Publication** No copyrighted information included.

**Conflicts of Interest** The authors have no conflicts of interest to declare that are relevant to the content of this article.

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