Tampere University

DIANA CAVONIUS-RINTAHAKA

Dialogical Family Guidance in Families with a Child with Neurodevelopmental Disorders

Implementation and Outcomes

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Finalizing this doctoral dissertation has been a trip that took over ten years, but the trip from recognizing that something must be done to increase dialogue between professionals and families has been much longer. Apart from the final year, I have been working consistently within child psychiatry. This may be one reason for the long time this PhD has taken. However, the families that I encounter in therapy have reminded me of the importance to continue to deliver a more dialogical way of working in the clinical setting.

The research communities have been far away from my ordinary life, with Gothenburg University, Sweden, being my main research base since 2012. Their international researchers and 'knowledge from the top of the world' has been present and available to me for many years, which makes me feel both grateful and privileged, and has given me a worldwide perspective during this research project.

I have been fortunate to have included Tampere university in my research from the beginning of my journey, and it became my headquarter from 2020, with Gothenburg University still following. Tampere university has given me the opportunity to strengthen both the sense and science of nursing in this research. The identity of being a nurse, and being proud of it, makes this research even more important and serves to remind us of the grassroots importance in both professionally and private life of respectful communication and dialogue between people.

The knowledge that has been gathered, used and implemented in clinical practice makes this finalized dissertation especially precious, and the research is already benefiting families that have a child with neurodevelopmental disorders and verifies that the ten-year effort has not been in vain. On the contrary, it shows that this research was both essential and necessary.

I want to thank all the families who have taken part in this study for sharing their experiences and the wisdom from their ordinary lives. Without them, we would not have this knowledge, nor this research. Thanks also goes to Helsinki University Hospital (HUH), to the administrators who believed in this intervention and for affirming the importance of this study. Also, thanks go to all the professionals who have attended the DFG training process and proceeded to deliver it to families, and for being patient with the study protocol procedure and delivering the questionnaires to the parents involved.

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On a winter day, January 14th, 2022
Diana Cavonius-Rintahaka

ABSTRACT

The purpose of this study is to develop and implement a family intervention, Dialogical Family Guidance (DFG) and to evaluate the outcomes of the intervention regarding family functioning, health, and social support in families with a child with neurodevelopmental (neuropsychiatric) disorder (NDD). FAFHES-instrument (Family functioning, family health, and social support) was modified and tested in the study. Furthermore, parents` hopes and expectations regarding the support they receive from health care professionals are described.

The study aims to increase the knowledge and understanding concerning family functioning, health, and their experiences of received social support of families with a child with NDD. The summary of this dissertation integrates and synthesises findings from the three research publications included in this submission, including a *Pilot study*, *DFG development- and implementation study*, and a *Randomized clinical study*.

Data was collected in the *Pilot study* (2012-2014) using the modified FAFHES instrument. The participants included in the Pilot study (n=29) were families that had a child between 4-16 years old with NDD and who had a new referral to the Helsinki University Hospital (HUH) neurocognitive/neuropsychiatric unit. The modified FAFHES was found to be suitable for purpose. The data collected in the Pilot study was analyzed using statistical methods and open-ended questions were analyzed using inductive content analysis. The results of the Pilot study show a positive correlation between family functioning and family health. At baseline, there were no differences between mothers` and fathers` experiences regarding family functioning, health, or social support. No significant change was reported during the three-month follow up regarding family functioning, health or social support.

DFG development and implementation study included data collected from DFG training participants during 2015-2019 using a tailored questionnaire, on the last day of a three-day DFG training session. Twenty-six professionals (n=26) taking part in the DFG training programme filled the questionnaire. The data was analyzed by using statistical methods and open-ended comments were reported as a summary. Professionals reported high levels of satisfaction in the DFG training, and positively anticipated DFG being able to offer new ways to support families.

A modified FAFHES instrument and a tailored DFG instrument were used for data collection in the *Randomized clinical study* (2016-2018). Participants included in the Randomized clinical study (n=50) were families that had a child between 4-16 years old with NDD and who had a new referral to HUH neuropsychiatric unit. Randomization was achieved in the Randomized clinical study by placing alternate families into an intervention group (n=23) that received the DFG intervention immediately as well as ordinary clinical treatment, or a comparison group (n=19) that received only the ordinary clinical treatment. Parent questionnaires were completed by families taking part in the study before and immediately after they had received the DFG family intervention (intervention group). The DFG family intervention included six meetings within a three-month period. Parents in the comparison group filled out the FAFHES questionnaire twice, as baseline and three-month follow-up responses. The FAFHES and DFG questionnaires were analyzed by using statistical methods and the open-ended questions were analyzed by inductive content analysis.

The Randomized clinical study demonstrated that social support increased more in the intervention group than in comparison group. Managing in daily life and the relationship between parents were associated with family functioning and family health. However, while the experience of family health increased to some degree after DFG, family functioning did not. Parents reported high degrees of satisfaction and experienced the DFG intervention as empowering and needed. Importantly, DFG helped them to manage better in daily life with their child with NDD.

This dissertation concludes that the DFG intervention provides strength to the entire family and improved positive experiences of received social support for all family members. Furthermore, DFG offer support to both parenthood and the relationship between parents, along with providing an opportunity for all family members to discuss their concerns and to be heard.

Keywords: Child, Dialogical Family Guidance, Family, Family health, Family functioning, Social support, Implementation, Intervention, Neurodevelopmental disorders,

TIIVISTELMÄ

Tutkimuksen tarkoituksena on kehittää ja implementoida Dialoginen perheohjausmalli (DFG) sekä arvioida sen vaikuttavuutta perheen toimivuuteen, terveyteen ja sosiaaliseen tukeen perheissä, joiden lapsella on neurokehityksellinen (neuropsykiatrinen) oireyhtymä. Tutkimuksessa modifioitiin ja esitestattiin FAFHES-mittari (Family Functioning, Health and Social support). Lisäksi tutkimuksessa kuvataan vanhempien toiveita ja odotuksia terveydenhuollon henkilökunnalta saadusta tuesta.

Tutkimuksen tavoitteena on tiedon ja ymmärryksen lisääminen neuropsykiatrisesti oireilevien lasten perheen toimivuudesta, terveydestä ja sosiaalisesta tuesta. Tämän väitöskirjan yhteenveto-osassa integroidaan osajulkaisujen I-III (*Pilottitutkimus, DFG kehittämis- ja implementointitutkimus, Satunnaistettu kliininen tutkimus*) tulokset käyttämällä synteesiä.

Pilottitutkimuksen aineisto kerättiin (2012–2014) käyttäen modifioitua FAFHES mittaria. Osallistujat Pilottitutkimuksessa (n=29) olivat perheitä, joilla oli 4–16-vuotias neurokehityksellisen oireyhtymän omaava lapsi ja uusi lähete Helsingin Yliopistolliseen sairaalaan neurokognitiivisiin / neuropsykiatrisiin yksiköihin. Pilottitutkimuksessa modifioitu FAFHES mittari osoittautui tarkoitukseen soveltuvaksi. FAFHES-mittarissa oleva aineisto analysoitiin tilastollisia menetelmiä käyttäen ja avoimet kysymykset sisällönanalyysiä käyttäen. Pilottitutkimuksessa tulokset osoittivat positiivisen korrelaation perheen toimivuuden ja perheen terveyden välillä. Alkumittauksessa isien ja äitien kokemusten välillä ei ollut eroja perheen toimivuudessa, perheen terveydessä eikä sosiaalisessa tuessa. Perheen toimivuudessa, terveydessä ja sosiaalisessa tuessa tulokset säilyivät muuttumattomina kolmen kuukauden seurannan aikana.

DFG kehittämis- ja implementointitutkimus sisälsi DFG-koulutuksia, joista aineisto kerättiin (2015–2019) kolmepäiväisen koulutuksen viimeisenä päivänä siihen tarkoitukseen kehitetyn kyselylomakkeen avulla. DFG-koulutustutkimukseen liittyvään kyselyyn vastasi kaksikymmentäkuusi (n=26) koulutukseen osallistunutta terveydenhuollon ammattilaista. Aineisto analysoitiin tilastollisin menetelmin ja avoimet kommentit on raportoitu yhteenvetona. DFG-koulutustutkimukseen osallistuneet olivat hyvin tyytyväisiä ja kokivat DFG koulutuksen antaneen hyvän kokemuksen ja uusia perheen tukemiskeinoja.

Satunnaistetun kliinisen tutkimuksen aineisto perustuu modifioidun FAFHES-mittarin ja DFG intervention vaikuttavuusarviointiin (2016–2018). Osallistujat olivat perheitä (n=50), joilla oli 4–16-vuotias neurokehityksellisen oireyhtymän omaava lapsi ja uusi lähete Helsingin Yliopistolliseen sairaalaan neuropsykiatriseen avohoitoyksikköön. Satunnaistetussa kliinisessä tutkimuksessa perheet (n=50) satunnaistettiin siten, että joka toinen perhe sijoitettiin interventioryhmään (n=23) ja joka toinen perhe sijoitettiin vertailuryhmään (n=19). Interventioryhmä aloitti samanaikaisesti DFG:n yksikön tavanomaisen hoidon lisäksi. Vertailuryhmä osallistui vain yksikön tavanomaiseen hoitoon. Vanhemmat täyttivät kyselylomakkeet ennen DFG:tä (interventioryhmä) ja heti sen jälkeen. DFG sisälsi kuusi tapaamista, jotka toteutettiin kolmen kuukauden aikana. Vertailuryhmään osallistuneet vanhemmat täyttivät FAFHES-lomakkeen lähtötasomittauksena ja kolmen kuukauden seuranta-ajankohtana. FAFHES- ja DFG-mittarissa oleva aineisto analysoitiin tilastollisia menetelmiä käyttäen ja avoimet kysymykset sisällönanalyysiä käyttäen.

Satunnaistettu kliininen tutkimus osoitti, että vanhempien kokema sosiaalinen tuki lisääntyi interventioryhmässä enemmän kuin seurantaryhmässä. Arjessa selviytyminen ja vanhempien välinen suhde olivat yhteydessä perheen toimivuuteen ja perheen terveyteen. Myös perheen kokemus perheen terveyden lisääntymisestä kasvoi hiukan DFG-intervention jälkeen, mutta perheen kokema toimivuus ei. Vanhemmat olivat hyvin tyytyväisiä ja kokivat DFG-intervention voimaannuttavana ja tarpeellisena. DFG auttoi heitä selviytymään arjessa aiempaa paremmin neuropsykiatrisesti oireilevan lapsensa kanssa.

Tämän väitöskirjan johtopäätöksenä voidaan todeta, että DFG toimii koko perhettä vahvistavana ja näin lisää perheiden myönteistä kokemusta saadusta sosiaalisesta tuesta. DFG tuo neuropsykiatrisesti oireilevien lasten perheille tukea vanhemmuuteen ja parisuhteeseen sekä lisää kaikkien perheenjäsenten mahdollisuutta keskustella huolista kuulluksi tulemisen lisäksi.

Avainsanat: Dialoginen perheohjaus, Implementaatio, Interventio, Lapsi, Neuropsykiatriset häiriöt, Perhe, Perheen terveys, Perheen toimivuus, Perheen tuki,

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ABBREVIATIONS

NDD	Neurodevelopmental Disorder
DFG	Dialogical Family Guidance
ADHD	Attention Deficit Hyperactivity Disorder
AS(D)	Autism Spectrum (Disorder)
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
HUH	Helsinki University Hospital
FAFHES	Family Functioning, Health, and Social support
ESSENCE	Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations

ORIGINAL PUBLICATIONS

Publication I Cavonius-Rintahaka D., Aho AL., Voutilainen A., Billstedt E., Gillberg C. 2019. Health, functionality, and social support in families with a child with neurodevelopmental disorder – a pilot study. Neuropsychiatric Disease and Treatment 15, 1151-1161. doi:10.2147/ndt.s195722.

Publication II Cavonius-Rintahaka D., Aho AL., Billstedt E., Gillberg C. 2020. Dialogical Family Guidance (DFG) – Development and implementation of an intervention for families with a child with neurodevelopmental disorders. Nursing Open 8, 17-28. doi:10.1002/nop2.627.

Publication III Cavonius-Rintahaka, D., Roos, M., Billstedt, E., Gillberg, C., Aho, AL. 2021. Randomized Clinical Trial Comparing Dialogical Family Guidance with Ordinary Clinical Treatment for Families with a Child with Neurodevelopmental Disorders. Advances in Neurodevelopmental Disorders. Open Access. https://doi.org/10.1007/s41252-021-00230-w

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When referred to publications in this dissertation, the following terms are used: Publication I, Publication II, and Publication III.

1 INTRODUCTION

When looking backwards, I understand that this study already had its starting point at the 1980`s, although I did not realize it at the time. Over the years, when working with children with special needs, I have been in a privileged position having an opportunity to listen to these families` life stories, including their experiences regarding health care and the professionals involved. Although, every family story is unique, there seemed to be many common issues. Especially, the opportunity to voice their concerns as parents, as individuals, and as a couple appeared to be an important issue, but one that was too often overlooked. Without pointing to any special diagnostic label, dialogue encourages parents to express genuine worries, and leaves a space for mutual conversation (Seikkula & Trimble, 2005). Still, it is crucial to pay attention to parents' mental health when developing interventions aiming to improve health and functioning for all family members. To achieve this, we need dialogue between professionals and parents.

Both professionals and families of children with neurodevelopmental disorders (NDD) benefit from knowledge regarding family aspects associated with this heterogeneous disorder. The first notable factor is the strong degree of heritability, meaning that when there is a child with NDD, it also appears more frequently in adults and other children in the family, than in the population in general (Archer et al., 2011; Faraone & Larsson, 2019; Jones et al., 2021; Morris-Rosendahl & Crocq, 2020; Thapar & Rutter, 2021).

Another factor worth noticing is that although symptoms reduce over time, approximately half of children with NDDs will have lifelong symptoms affecting them across their lifespan. Along with the common comorbidities, there is also a risk of antisocial behavior, additional psychiatric disorders, difficulties to manage in school or work, and risks for accidents and various addictions (Anker et al., 2021; Faraone et al., 2015; Jones et al., 2021; Retz et al., 2021).

There have been tremendous advances within NDD regarding the available non-pharmacological treatment options to improve functioning or to manage symptoms at an individual and parental level. There are for example individual and group-based parenting interventions, classroom-based interventions, and a range of child psychological therapy approaches which are widely covered in published research reports (see e.g. Retz et al., 2021; Tarver et al., 2014a). A systematic review by Goode at al. (2018) reports the common use of parent programmes and different intervention approaches, but also a remarkable lack of knowledge regarding how effective non-pharmacological treatments are. Research evidence indicates a need for family-centred care based on a critical approach to improve health care quality. However, it is extremely demanding to support people with NDD both as a parent in the family, and also from the perspective of professionals who are exposed to the parental stress and burnout.

Psychological factors have an impact on human interactions, which also affects the quality of any given interventions. Contemporary studies report the importance to increase the quality of life and understanding of both families who cope with a child with NDD, and also the professionals working with them. Especially, training and involvement in the planning of services can increase professionals` willingness to receive and use novel practices, raise wellbeing, and affiliate a stress prevention approach (Leoni et al., 2020; Park et al., 2018).

Despite extensive advances in understanding the complexity of NDDs, there is an urgent need to develop more family-focused interventions. Studies highlight parents` stress levels, the demands seen in family dynamics, and dysfunctional family functioning as risk factors, and as aspects to be given notice when building up interventions for this target group (Duarte et al., 2005; Factor et al., 2019; Falk et al., 2014). A common understanding is that having a child with NDD in the family may have various impacts regarding family members, although there is an uneven distribution between individual versus family studies (Cavonius-Rintahaka et al., 2019; 2020; Dykens, 2015; Factor et al., 2019).

However, given our knowledge of hereditary risks and NDDs being life-long conditions with comorbidities, it is important to include parents and siblings of children with NDDs in interventions. Parents can bring knowledge regarding family functioning, family health and challenges within the family unit, and factors like competence, confidence, and self-efficacy regarding parenthood are elements that need attention when developing and delivering interventions. Especially, these factors can affect the health and development of children (Vance & Brandon, 2017). Accordingly, this study concentrates on the parental perspective, and parents` opinions, emotions and experiences of the health and functioning of their family.

The purpose of this study is to develop and implement a family intervention, DFG and to evaluate the outcomes of the intervention regarding family functioning, health, and social support in families with a child with NDDs. FAFHES instrument was modified and tested in this study. Furthermore, parents` hopes and expectations regarding the support they receive from health care professionals are described. Family intervention offering treatment to the entire family, dialogue inside the family and between family and professionals are discussed.

2 REVIEW OF THE LITERATURE

2.1 Neurodevelopmental disorders

NDDs are a group of disorders including neurological and psychiatric symptoms, also termed in literature and clinical settings as neuropsychiatric disorders. NDD disorders have an onset in early childhood and can include disorders affecting learning, language, intellectual capacity, motor development issues such as coordination, or appear as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), tic-disorder, obsessive compulsive disorder (OCD), or oppositional defiant disorder (ODD). Overlaps within these impairments are typical, as well as the presence of additional impairments seen as comorbidities (Antshel et al., 2016; Cohen et al., 1997; Morris-Rosendahl & Crocq, 2020; Thapar & Cooper, 2016; Thapar et al., 2017).

These impairments have a high degree of heritability and can be affected by a range of pre- and postnatal risks. Specifically, prenatal exposure to alcohol and smoking during pregnancy, a mothers young age, and stress are known to increase the risks of children developing ADHD (Faraone et al., 2015; Oerlemans et al., 2016), and more boys than girls are seen within the NDD umbrella (Lai et al., 2014).

Children with ASD have a 70% risk of comorbidities and a 41% risk having two or more comorbidities. Aggression, language or anxiety disorders, ODD symptoms, and for example sensory integration disorders can appear as comorbidities. Some conditions may not be identified at an early age but may become more visible and disturbing when the child gets older (Simonoff et al., 2008; Soke et al., 2018). Children with ASD can have, for example, psychiatric comorbidities that cause their main impairments. If NDD symptoms are identified, children are recommended to have neurodevelopmental, psychiatric, and cognitive assessments and monitoring on a regular basis, even though it may not be possible to reach a final clinical diagnosis at this stage (Posserud et al., 2018).

A concept used regarding cases of multiple NDD symptoms is ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations), highlighting the heterogenous symptoms and the profile of NDDs that also tend to change during childhood. ESSENCE represents those impairment symptoms of NDD appearing already before the age of three and up to five years of age. Furthermore, major difficulties seen in the ESSENCE domains before five years of age should be given attention, as they may predict NDD symptoms that appear later more clearly (Gillberg, 2010; Gillberg et al., 2014).

Treatment for NDDs is usually divided into pharmacological and non-pharmacological interventions. Early interventions are recommended to minimalize long-term and co-morbid outcomes. However, NDDs are affected by combinations of both genetic and environmental factors, meaning that other family members surrounding the child with NDD can have a significant impact on the outcomes of the child's treatment (Paidipati et al., 2020; Rutter, 2006; Rutter, 2010; Rutter et al., 2006; Tarver et al., 2015).

2.2 Family functioning and health in families with a child with NDD

Family functioning includes factors regarding family members` skills and abilities to maintain cohesion within the family, according to the relationships, roles, new routines, operating models, surviving problems, and strengthening communication between family members (Zhang, 2018). Discussions of family functioning can bring family members closer to each other, increasing their understanding of one another. Families may occasionally want and benefit from professional help that helps them to find the courage to open up and communicate their experiences of illness. This can affect family functioning in a positive direction (Ahlberg et al., 2020), and parents` psychosocial health and the family's abilities to function together in their daily life affect all the children, either with or without NDD (Barlow et al., 2014).

When raising a child with NDD, parents experience higher rates of stress and parental tiredness more often, compared to parents with children without disorders (Craig et al., 2016). Parental stress and tiredness can naturally have a negative effect on family functioning, as symptoms of family members are known to affect parents` perceptions of family functionality (Biederman et al., 2006; Herring et al., 2006; Williamson & Johnston, 2016). Accordingly, the relationship between parents, and between the rest of the family members are influenced by the nature of NDD symptoms appearing in the home environment (Craig et al., 2016; Duarte et al., 2005; Hartley et al., 2010; Hartley & Schultz, 2015). Studies report connections between quality of life, family functioning, typical child NDD symptoms, and parental stress levels (Craig et al., 2016; Falk et al., 2014). In particular, parents, who have children with ASD report decreased family functioning, in addition to their own dysfunctional experience as parents, and as a consequence, they exhibit more stress as parents and experience their quality of life as being lower (Pisula & Porebowicz-Dorsmann, 2017). Studies also report an association between ADHD and problematic family functioning, and factors connected to increased stress, higher rates of psychopathology addressed to parents, and conflicting relationships between children and parents are reported. Furthermore, this problematic family functioning can be exacerbated in children by increased comorbid behavioral and ODDs (Deault, 2010; Foley, 2011).

Studies demonstrate that training and interventions for parents have an influence on family functioning and relations between family members (Barlow et al., 2014; Dretzke et al., 2009; Factor et al., 2019; Michelson et al., 2013). As an example, parents of adolescents with ADHD reported a higher quality of life, better family functioning, and better functioning as parents after they had participated in an intervention called Therapeutic Conversation, which has been recommended to health care professionals working in ADHD centers in Iceland (Gisladottir & Svavarsdottir, 2017). Furthermore, parents who have ADHD themselves have a lower family functioning and poorer sense of coherence compared to parents without ADHD (Moen et al., 2015).

Overall, health service support has been seen to have a strong positive impact on family functioning (Moen et al., 2015), but there are many unfavorable experiences regarding family functioning and family health, including marital problems in families that have a child with NDD (Caicedo, 2014; Craig et al., 2016; Duarte et al., 2005; Hartley et al., 2010; Hartley & Schultz, 2015). Parents with an excellent or good relationship with each other also have better family functioning and family health. But because family members have an interrelated influence on each other, the dynamics and interactions within the family need to be highlighted when focusing on family health (Cavonius-Rintahaka et al., 2019).

2.3 Social support in families with a child with NDD

Raising a child with NDD increases the stress levels and demands relating to family functioning. Impairments associated with and stemming from NDDs can place demands on interaction, cause frustration, and contribute to challenging behavior within the family. As family environments play a significant role in children's development, treatments and interventions that target a range of symptoms and risk areas can offer benefit regarding the whole family`s wellbeing (Spain et al., 2017; Tarver et al., 2015; Zorcec & Pop-Jordanova, 2020).

Increasing parents` knowledge and management in daily life can decrease parental stress levels and increase their experience of empowerment (Craig et al., 2016). Functional outcomes associated with NDD are heterogeneous, and promotive and protective factors can be of tremendous help when addressing family support. There is strong evidence that reports and recommends psychosocial treatments (behavior management interventions, training interventions, physiological treatments as physical activity) and psychoeducation to be effective (Ferrin et al., 2020; Shrestha et al., 2020). Psychosocial services, counselling and behavioral management interventions have been urged to be made available to families without delay. Yet, the Finnish society lacks knowledge regarding these interventions, and there is also a lack of professionals and provider networks that offer these interventions. As a result, many families seek help in this area, but have difficulties to find it. (Sonuga-Barke et al., 2013; Tarver et al., 2014a; Tarver et al., 2014b).

The importance of psychoeducation for parents is well described, but parents often need continuous support because the symptoms of NDD can change over time, along with the child`s development (Ferrin et al., 2020; Paidipati et al., 2020; Roughan, et al., 2019). There are new findings demonstrating e.g., interventions using resilience for parents with children with ASD (Dvorsky & Langberg, 2016; Schwartzman et al., 2021), and interventions based on mindfulness and stress relief aimed at parents with children with ADHD and developmental delays (Neece, 2014; Siebelink et al., 2021).

Offering parents knowledge regarding their child`s condition, and integrating NDD into family daily life with appropriate management skills can lead to an effective intervention. But solutions, encouragement and support should be offered to all family members, and naturally, the outcomes for one family member will influence the outcomes and experiences of other family members (Deatrick et al., 2018; Paidipati et al., 2020).

2.4 Summary of the literature

NDD is an umbrella term describing psychiatric and neurological disorders with symptoms appearing already during childhood, including disorders such as ASD, ADHD, learning disabilities, tic disorders, and OCD. NDDs (also known as neuropsychiatric disorders) cause impairments in multiple functional areas and affect the child`s health condition in varying ways, along with having consequences for the entire family (Biederman, 2006; Biederman et al., 2006; Cohen et al., 1997; Herring et al., 2006; Puka et al., 2020). Family studies show a strong familial incidence with NDDs, for example 80% in ASD (Robert et al., 2017; Tick et al., 2016a; Tick et al., 2016b) and 76% in ADHD (Faraone & Larsson, 2019). This means that a child with NDD in the family often implies that there is a major possibility that at least one another family member may also have an NDD, or symptoms of an NDD (Blesson & Cohen, 2020). Along with the diagnosis label, one or several comorbid disorders are common, sometimes causing considerably more severe impairments than the main diagnosis. Common comorbidities can be e.g. aggression, anxiety, language disorders, ODD symptoms, eating problems, or sensory sensitivity disorders (Gillberg et al., 2014; Lai et al., 2014; Posserud et al., 2018; Simonoff et al., 2008).

Early detection and intervention are recommended (Lai et al., 2014; Paidipati et al., 2020; Tarver et al., 2015). Pharmacological treatments are available for some NDDs, while non-pharmacological treatments are available for all NDDs. NDDs are heterogenous and vary greatly between individuals. However, effective child, parent and family interventions need to be more widely disseminated and evaluated (Dykens, 2015; Tarver et al., 2015). Study data clearly shows that training can reduce children`s hyperactive, aggressive and defiant behavior, as well as improve parent management, and reduce parent stress (Danforth et al., 2006). Generally, psychoeducational programmes seem to be beneficial and considered to be key components regarding the treatment of NDDs (Dykens, 2015; Nussey et al., 2013).

Children with NDD often pose a challenge to parents, causing increased stress and difficulties in raising these children consistently. The child`s impairments can have a negative effect on the child`s development, but they also bring difficulties to parents` management of their child`s symptoms. A dysfunctional family system can lead to consequences related to negative parent mental health. Symptoms such as heightened stress levels, and feelings of anxiety or depression can follow as symptoms of parents` illbeing (Dykens, 2015).

During the planning of treatment, clinicians should consider factors involved in NDD`s and their co-morbidities, as well as parental NDD symptoms, parenting efficacy, and the mental health risks the parents face (Tarver et al., 2015). Particularly, the parent’s perspectives on their family and their self-reported management in daily life need to be given attention, including efforts to strengthen the collaboration between professionals and families to achieve improvements in the care of children with NDD (Paidipati et al., 2020).

3 PURPOSE AND AIM OF THE STUDY

The purpose of this study is to develop and implement a family intervention, DFG and to evaluate the outcomes of the intervention regarding family functioning, health, and social support in families with a child with NDDs. FAFHES instrument was modified and tested in this study. Furthermore, parents` hopes and expectations regarding the support they receive from health care professionals are described.

The aim of the study is to increase the knowledge and understanding concerning the daily management (family functioning) and health of family members (family health) of families with a child with NDD, and their experiences of received support (social support).

The tasks of the study were to:

(1) describe the experiences of parents of children with NDD in terms of family functioning, family health, and received support, and their associations with background data using the modified FAFHES instrument. (Publication I)

(2) describe over a three-month period whether there were any changes in parents` experiences of family functioning, health, and social support. (Publication I)

(3) describe parents` opinions about their hopes and expectations regarding the support received from health care professionals. (Publication I)

(4) evaluate DFG training and to describe the development and implementation process of the DFG family intervention. (Publication II)

(5) study outcomes of DFG based on parent reports regarding family functioning, family health, and social support. (Publication III)

4 METHODS

4.1 Setting and procedure of the study

This study includes an initial phase, phase I (Pilot study), phase II (DFG development and implementation study), and phase III (Randomized clinical study). This study includes six main phases (Figure 1)

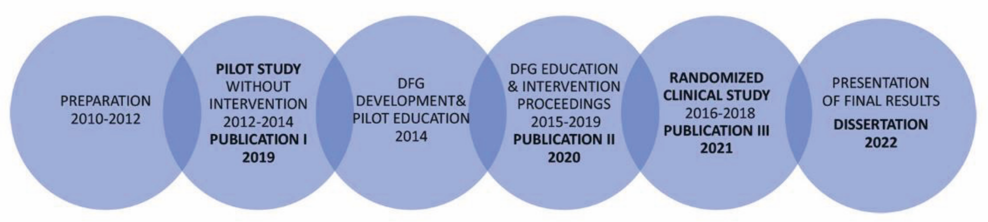


Figure 1. Study timeline and phases

All phases (I-III) were performed in collaboration with Helsinki University Hospital (HUH) and neurocognitive / neuropsychiatric units were chosen suitable arenas for data collection for this study. Personnel within these units provide multidisciplinary assessments and collaborate as a multi professional team to provide knowledge regarding diagnosis and habilitation plans for children. The ordinary clinical treatment is mainly focusing on the child. Importantly, no family interventions are usually available, nor any systematic guidance regarding siblings or couple relationships or possibilities to discuss dynamics in the family. The data collection, procedures and sampling of the total study (phase I-III) are presented in Figure 2.

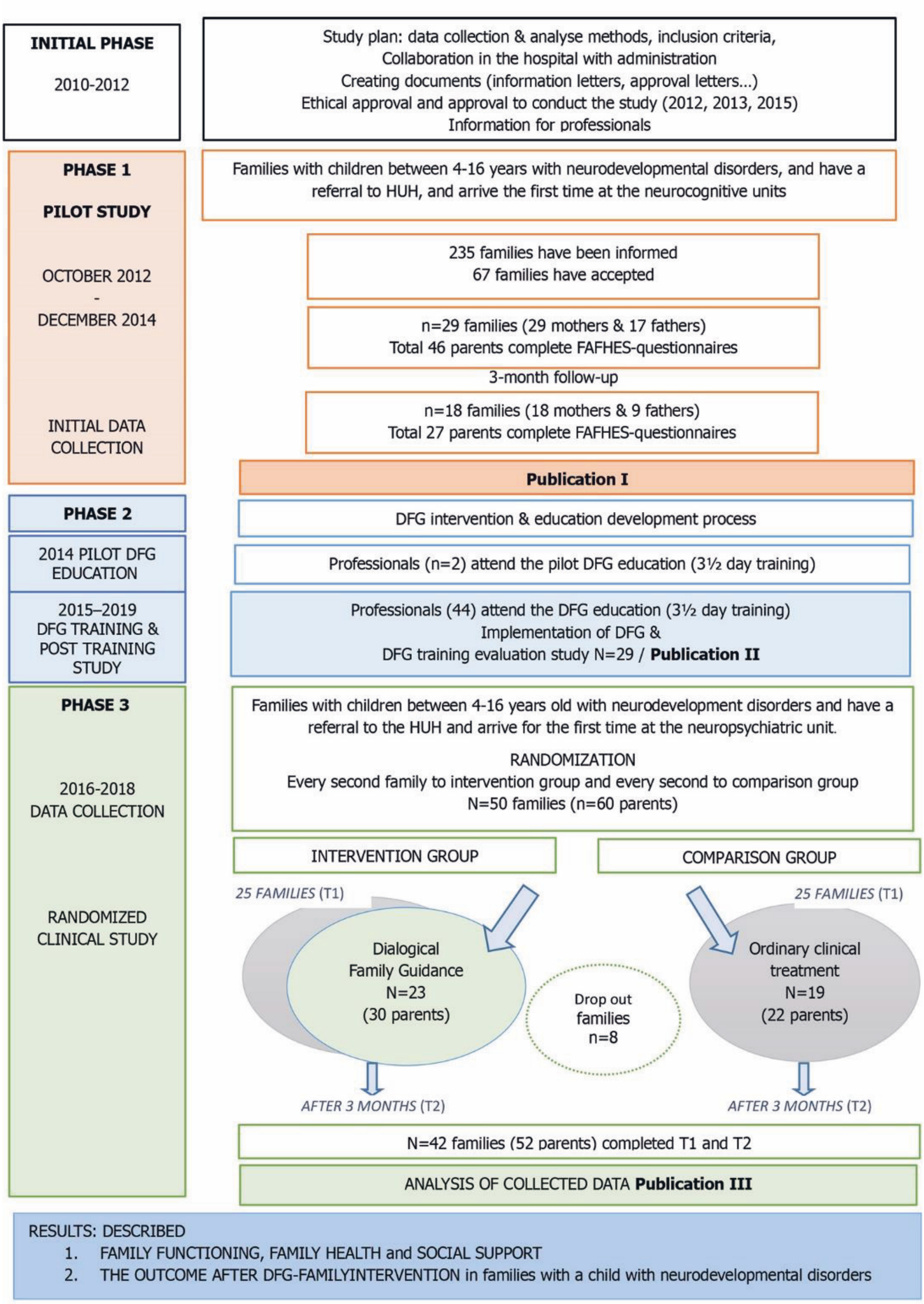


Figure 2. Design, data collection, and samples of the study

4.2 FAFHES and DFG – data collection instruments

The FAFHES instrument was originally developed and used in studies with patients with heart disease and their family members (Åstedt-Kurki et al., 2004). FAFHES was tested the first time in 2002 and this instrument has been found to be valid and reliable according construct validity and internal consistence (Åstedt-Kurki et al., 2002). Report of further testing of the instrument has been published 2009 (Åstedt-Kurki et al., 2009), and has been used as a data collection tool in different contexts ever since (Hakio et al., 2015; Lepistö et al., 2017). Translations and psychometric evaluations of a German (Ris et al., 2020) and Danish (Østergaard et al., 2018) version has also been done and reported as being valid and reliable. FAFHES instrument contain three dimensions: family functioning (19 items), family health (23 items), and social support (21 items).

Permission to modify, translate into Swedish and English, and to use this modified FAFHES instrument in the applied setting was received from the Tampere University copyright holders in 2012. The modified FAFHES instrument was used for data collection in both the Pilot study and the Randomized clinical study. Three open-ended questions are included in the modified FAFHES questionnaire: 1) *What kind of hopes and expectations do you have of the professionals when they meet you and those close to you?* 2) *How would you like to develop the family interventions provided by the professionals? 3) Is there anything else that you would like to add?* (Publications I and III).

Minor modifications allowed certain questions to be more clearly targeted towards families with a child with NDD. As an example, item 53 "Concern for the ill family member`s condition causes distress in other family members" was changed to "The child`s symptoms cause stress in other family members".

Some additional demographic questions were also added. For example, because studies report a high rate of heritability within NDDs, it seemed important to add a question regarding other family members with NDD.

The Dialogical family guidance (DFG) instrument was also used for the Randomized clinical study to gain knowledge regarding parents' experiences regarding DFG (DFG questionnaire for parents, Appendix 8). The questions featured in the DFG instrument were designed side by side with the development of the overall intervention. The goal was to gain parent perspectives that would help in verifying or refuting researcher's assumptions about what the intervention should include. An open-ended question gave parents the opportunity to share their opinions, and to give suggestions of how to improve the intervention. The questionnaire comprised of 14 questions answered using a Likert scale changing between 1-6 (Appendix 8), in addition one open-ended question: *"Could you describe your experiences, comment and/or provide ideas about how to improve DFG?".* (Publication III)

4.3 Pilot study

Preparations for the Pilot study were initiated in 2010 by modifying and translating the FAFHES instrument and preparing documents for submission to the HUH ethical board. Information regarding the study was distributed on different administration levels at HUH. The research proposal for this study along with consent form, information letter for participants, and the questionnaires used, were accepted by the HUH ethical board before initiating the research process.

Data collection: The data for Pilot study was collected between 2012 and 2014. Families with a child referred to the neurocognitive units (the name changed later on to neuropsychiatric unit) within HUH were asked to participate in this study if they met the inclusion criteria of being the biological parent or legal guardian living with a child (age 4-16 years) with NDD symptoms and having sufficient language competency in Finnish, Swedish or English. Nurses distributed information regarding the study both orally and in written form to the parents. Parents who gave their written consent (Appendix 4) received the FAFHES questionnaire by mail sent to their home address. Both parents in the family received their own questionnaire. There was also a prepaid return envelope included for sending the FAFHES questionnaire back to the researcher. A three-month follow-up was included for parents who filled the questionnaire at the baseline stage, meaning that an additional FAFHES questionnaire was sent out for completion. Parents` who did not return this second FAFHES questionnaire received one reminder. Families taking part in the Pilot study received ordinary clinical treatment for their child, and no family interventions were available. (Publication I)

Participants: During this time, 235 families met the inclusion criteria and received information regarding the study. Of these, 67 families gave their written consent to participate in the study, and 29 (43%) of these families returned completed FAFHES questionnaires (baseline). As both parents were given the opportunity to complete their own FAFHES questionnaire, 46 parents (from 29 families: 29 mothers and 17 fathers) completed the questionnaires and returned them. The three-month follow-up FAFHES questionnaire was completed by 18 families (62% of those who participated at baseline: 18 mothers and 9 fathers) (Figure 2). (Publication I). The knowledge received in the Pilot study recommended the suitability of this modified FAFHES instrument also in the upcoming *Randomized clinical study*.

Data analysis: The *Pilot study* used both quantitative and qualitative analysis to derive data comparable with earlier studies, but also to receive genuine, individual experiences and opinions from parents. The written Likert scale answers were transferred to the SPSS data analysis program (version 23) and statistical analyses were carried out. Descriptive statistics help to describe and summarize quantitative data in a meaningful way (Mishra et al., 2019) and were used in this study to describe data derived from the FAFHES questionnaires. The domain variables of family functioning, family health, and social support were reported from mothers`, fathers` and their combined perspectives. (Publication I)

Spearman correlations are used to evaluate the relationship between background variables and domains - in this study the FAFHES domains. These background variable relationships can be further investigated using Pearson`s correlation coefficient, resulting in correlations being seen as positive or negative, strong or weak. This gives information about the association, relationships and direction of two particular variables (Akoglu, 2018). A T-test is a statistical test and describes how significant the differences between the means of groups are (Wadhwa & Marappa-Ganeshan, 2021). T-test was used in the Pilot study to analyze the differences between Family health, family functionality and social support domains, and could be used since the data was normally distributed. The Mann-Whitney U test is used when comparing differences between two groups that have values that are normally distributed. The Mann-Whitney U test was used in this study to compare two different groups, and the Kruskall-Wallis test was used for categorial variables. The alpha level for statistical significance was set a priori at 0.05. (Publication I)

The Pilot study also included three open-ended questions which were analyzed using inductive content analysis, meaning there were no predefined variables identified in advance. Open ended questions give participants the possibility to express genuine experiences and thoughts opening aspects and bringing supplement knowledge and understanding to the research objectives. Raw text is systematically defined into brief, summary format. Units are defined from the selected text and categories are created. (Graneheim et al., 2017). In this research likewise parents' written responses were read, collated, and text and comments that seemed repeat or were similar were highlighted. When combining similar answers, classifications of "subcategories" were raised and given names nearby the raised contents. In this way, subcategories were created and named. Additionally, the creation of "main categories" arose from the subcategories. Both the sub- and main categories are presented as part of study results. (Publication I)

4.4 DFG development and implementation study

Simultaneously with the pilot data collection, the development process of the DFG programme was initiated. The results from the Pilot study confirmed and highlighted the content needed to be included in the DFG training programme and intervention. DFG training was initiated in 2013 for a pilot group including two psychologists, in order to test the structure and content of the education programme, and the results drawn from the Pilot study were found to be in line with earlier studies.

Data collection: The next stage included DFG training proceedings carried out at HUH. Data from DFG training was collected during the last lesson from professionals who took part in the three-day long DFG training. All the participants had gone through DFG training between 2014-2019. A questionnaire was specifically developed to obtain detailed feedback regarding the educational issues and contents.

The Dialogical family guidance post-training questionnaire included 10 questions using a Likert scale of 1–7. The questionnaire consisted of two background questions and eight questions regarding the content of the training. The questions included in the questionnaire were: Did you get new tips to use in your work with families having NDDs? Did you get working materials? Did you gain any new understanding regarding working with the entire family when the child has NDD? Did you gain new knowledge regarding dialogue? Did you gain new understanding regarding the importance of collaborating with the child`s family? Did the DFG training programme meet your expectations? Would you recommend DFG training to other professionals? Would you recommend DFG to families? One open ended question was added to encourage openness by allowing additional comments: "*Could you share your experiences, ideas for improvement, and/or comments regarding the Dialogical Family Guidance training*". (Publication II)

Participants: The DFG training included 44 professionals, of whom 26 (59%) filled out the questionnaire after their DFG training. Completing the questionnaire was voluntary, and respondents were not recognizable from their returned questionnaires. Only codes to identify the training course were used by the researcher. (Publication II)

Data analysis: The quantitative data collected from professionals after their DFG training was analyzed using the SPSS statistical program, and the most important questions regarding usefulness and recommendations were presented as percentages (%). The results of the open-ended question regarding experiences, suggestions for improvement, and/or comments regarding DFG training are presented as a summary. (Publication II)

4.5 Randomized clinical study

Data collection: The data collection for the Randomized clinical study was initiated in January 2016 (Publication III). Families with a child (4-16 years old) with NDD symptom who arrived at the HUH neuropsychiatric unit for the first time between 2016-2018 were informed about the study. Professionals at the unit received oral and written guidance regarding the study (Appendix 5), and thereby felt confident to deliver the study information, as well as general information about the DFG initiative to parents (Appendix 7). When carrying out the Randomized clinical study, the data collection was performed differently compared to the Pilot study. Families (parents) filled out the FAFHES and DFG questionnaires at the clinic, while visiting the neuropsychiatric unit with their child, and parents had an opportunity to fill out the questionnaires in a peaceful room during their visit.

As a randomized controlled study, families were randomized by placing alternate families into the intervention and comparison groups. Randomization was made in advance, and parents could not affect which group they were placed in. When parents gave their consent to participate in the study, they knew which group they belonged to (intervention group or comparison group). The FAFHES questionnaires completed at baseline did not influence the decision of group allocation in any way. Participants were informed about the proceedings and the DFG by a nurse who was familiar with the intervention. Intervention group families received DFG right away (starting point at baseline), alongside ordinary clinical treatment. Families in the comparison group received only ordinary clinical treatment during this initial three-month period, but then received their DFG once this period had expired (Figure 3). As well as the FAFHES questionnaire, families who received DFG (the intervention group) filled out the DFG questionnaire during their last DFG session (Appendix 8).

A session checklist (Appendix 2) was monitored after every DFG intervention to ensure that the professionals was delivering DFG in line with the manual.

Participants: Data in the Randomized clinical study was collected between January 2016 to December 2018. From the beginning, the goal was to proceed with data collection until fifty families had given their written consent to participate in the study. From these fifty families (n=50), sixty parents attended the study at baseline. Both parents from each family were given a questionnaire of their own. 42 families and 52 parents completed both phases (baseline T1, and three-month follow-up T2). Regarded randomization: of the 52 parents, 30 parents were placed in the intervention group, and 22 parents in the comparison group (Figure 3). (Publication III)

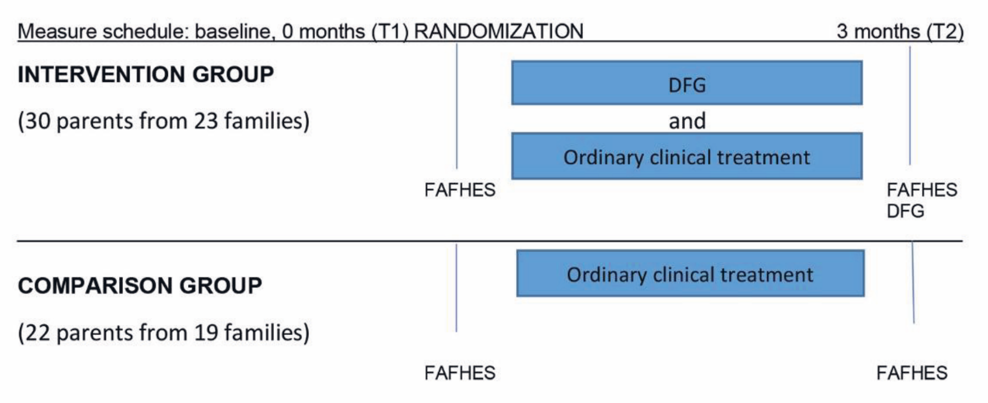


Figure 3. Randomization design in the Randomized clinical study (Publication III, Cavonius-Rintahaka et al., 2021)

Data analysis: This Randomized clinical study includes both quantitative and qualitative analysis. It seemed important to collect measurable data in order to realize the effects of the intervention, but additionally, parent perspectives as end users of the intervention are of great value to help improve and develop the intervention further.

IBM SPSS Statistics for Windows version 27 was used to analyze the data in the Randomized clinical study. The total scores for the three FAFHES variables were calculated by summing the score for all the items in the variable and dividing the sum by the number of items. The Kolmogorov-Smirnov test is used to compare two samples and quantify a distance between the empirical distribution function of the samples. This test was used in the study to verify that the FAFHES sum variables were normally distributed. (Publication III)

The Shapiro-Wilk test is used to examine if a variable is normally distributed. The distribution of FAFHES variables in the intervention group and comparison group was checked using this test, and nearly all the variables had a normal distribution, with the exception of social support for the comparison group at baseline. (Publication III)

The Chi square or Fisher's exact test was used to determine whether a difference exists between the intervention group and comparison group and the demographic variables. Some categories of demographic variables being small, the relationship between dependent variables (FAFHES) and demographic variables was analyzed using the Mann-Whitney U-test or the Kruskal-Wallis H-test with Bonferroni correction. In this randomized control study, repeated measures to examine the effect of time between the intervention and the comparison group ANOVA was used. The level of significance (p) was set as ≤0.05. The DFG questionnaires were analyzed using SPSS statistical program and participants` assessments were presented as percentages. (Publication III)

Qualitative data were produced by parents by reporting more freely their experiences on the open-ended question: *"Could you describe your experiences, comment and/or provide ideas about how to improve DFG?"* were analyzed using inductive content analysis (Graneheim et al., 2017), and the qualitative results were presented as sub- and main categories. The researcher monitored the DFG session checklists, filled by the professionals after finalized DFG interventions in this study. (Publication III)

4.6 Development and implementation of the DFG intervention

Psychosocial interventions have been widely introduced, but there are some factors missing and unmet needs, when looking for family interventions that may be suitable for this target group (Pahlavanzadeh et al. 2018; Sikira et al., 2015). As heterogeneous units bearing individual history, unique needs and demands of families has not received enough attention. Psychoeducational interventions are often targeted only at parents, leaving the children of the family outside, meaning that they actually represent parent-mediated interventions (e.g. Potvin et al., 2018; Mazzucchelli et al., 2018). The dialogical elements or dialogue itself is rarely mentioned, and education and psychoeducation are often the primary, and perhaps only approach adopted.

Although many differently labeled interventions have been described in the literature, the theories, development and implementation procedures may be missing from the descriptions. As an example, summary of seven different interventions aimed towards families with a child with NDD was presented as a table in Publication II.

Background theories of DFG

The background theory of DFG is based on traditional elements from family therapy, including dialogue (Seikkula & Trimble, 2005), family systems perspectives (Haefner, 2014), and reflection (Weingarten, 2016). Nevertheless, DFG is not a therapy, but rather a family guidance intervention. As such these elements reflecting the importance of communication and reciprocal social interaction regarding family members and professionals. It is recognized that NDDs can bring special difficulties and challenging behavior, causing stress and frustration in relationships with family members (Spain et al., 2017). However, Seikkula and Trimble (2005) consider dialogue as possible healing element.

Open dialogue was originally initiated within psychiatric care in Finland to help adult psychosis patients (Seikkula & Trimble, 2005). Today open dialogue has been implemented in different countries and has been modified to be used in various healthcare units and organizations as a promising and favorable approach in mental health care. Open dialogue is not only seen as a therapeutic method, but rather the ability to see the polyphonic nature of human reality. Open dialogue is realized in clinical setting by professionals listening carefully what the client and family members have to say, and who share in the moment. (Anderson, 2002; Buus et al., 2017; Seikkula, Arnkil, & Eriksson, 2003). A dialogical approach is present throughout this intervention.

Systems metaphor and theory helps us understand the social and emotional development of children and their families. This aspect reflects on all the levels of the family system and can bring important information about e.g. processes like co-parenting, family sub-systems, interactions between family members, confusions about roles, conflicts regarding family functioning, and the formation of coalitions in the family. (Cridland et al., 2014). These theories influence and lead the DFG principles, and are clarified during the DFG training.

The goal of this novel intervention is to improve health and functioning for all of the members in the family, by offering a space to voice concerns and personal questions, or just to communicate with a professional familiar with NDDs. These principles and flexible attitudes were combined with a professional approach during the development process of the DFG intervention. Both nursing and medical knowledge have been considered in comprehending the diverse symptoms of NDD (Thapar et al., 2017) and ESSENCE (Gillberg, 2010, Gillberg et al., 2014), and this combined knowledge and understanding was used to develop psychoeducational, concrete guidance for families to support them in managing their daily life.

A novel approach including the combination of psychoeducation, practical and emotional guidance was highlighted when this new intervention development process was initiated. Furthermore, parents can also face barriers in navigating the system to obtain the most suitable services for their family (Caicedo, 2014; Doig et al., 2009; Evans et al., 2015), and it was noted that while effective parenting strategies are important, at the same time, many families simply need the opportunity to talk about their worries, and to open their minds and experiences.

The DFG family intervention combines theories, previous studies, and implications collected from clinical practice. The DFG development and implementation process is described in Figure 4 (Cavonius-Rintahaka et al., 2020).

DFG implementation into clinical praxis

The development of the DFG intervention was carried out over a long time of period, but a transformation towards a clear concept and content led to use this as a base for a PhD study. Thus, the articulation of clinical knowledge was combined with research expertise, so allowing DFG development to be implemented in the clinical setting.

The development of this intervention study proceeded from the first author`s and other professionals` insights and experiences working with parents of children with NDDs, who shared their concerns and needs for psychoeducation, guidance on how to manage better in daily life and wanting to have discussions with someone familiar with the NDD area. Clinical praxis knowledge was substantiated with literature and earlier studies, deepening, and broadening the earlier insights that indicated need to carry out a pilot study among parents in this target group. The results of the Pilot study (Publication I) lead to a more detailed awareness of a need to develop and refine the intervention targeted towards families with a child with NDD.

Communication and the delivery of information to different levels of the HUH organization and different focus groups initialized the implementation. The implementation of DFG continued with e.g. recruitment, the delivery of DFG training courses, and also the supervision of delivery. DFG training programmes to professionals gave them the possibility to deliver DFG to families. Overall, it was seen that professionals were motivated to take part in and deliver DFG to families. After this stage, the DFG initiative was studied and evaluated.

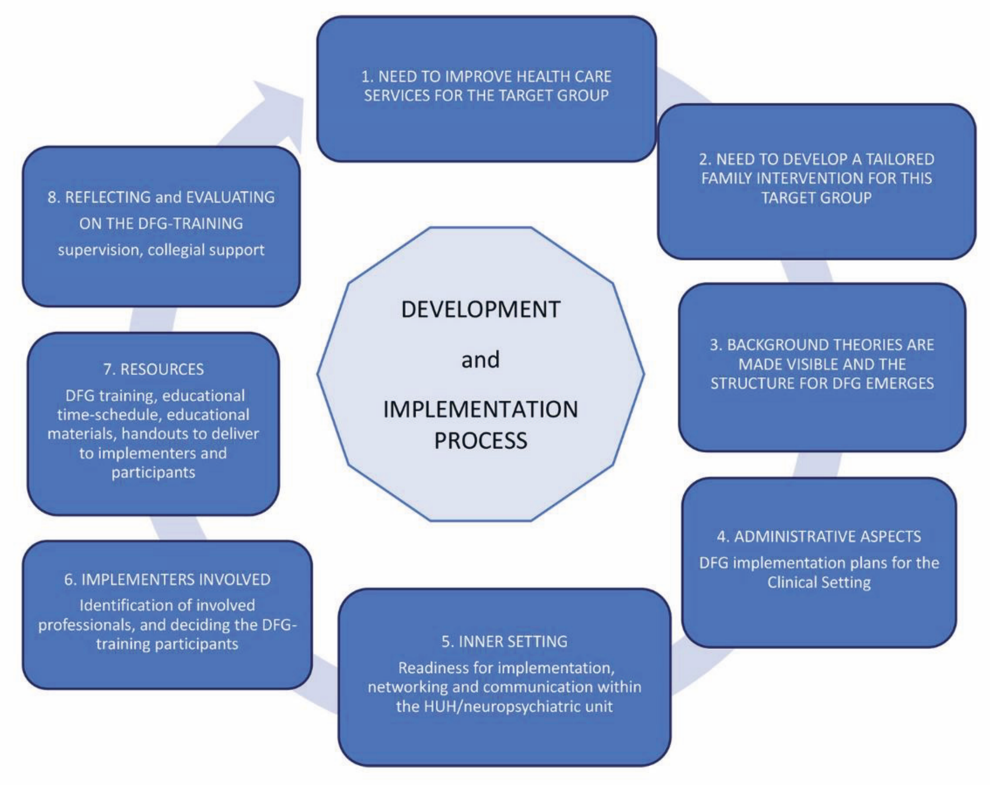


Figure 4. The DFG development and implementation process (Publication II, Cavonius-Rintahaka et al., 2020)

In 2015, the first professionals were selected for training at the HUH, and they participated in the DFG training programme the same year. These professionals were tasked with delivering DFG for new families attending the neuropsychiatric unit. Data collection was initiated in January 2016 by offering DFG to families. Professionals comprised of nurses and social workers attended a three-day education that enabled them to proceed with delivering DFG to families. The first author of this dissertation arranged informational meetings for personnel at the unit, carried out the DFG training, and supervision and consultation were carried out with clinicians on a regular basis throughout the entire DFG implementation period (2016-2018).

The DFG training programme delivered seemed well accepted among participants. The content of the programme is presented in Table 1. Since then, the DFG training programme has been carried out several times at HUH, followed by an implementation of DFG in several units, giving professionals an opportunity to offer DFG for families within child psychiatry services at HUH.

Table 1. DFG Education programme components (Publication II, Cavonius-Rintahaka et al., 2020)

Components	Core topics
Background & the DFG implementation process	DFG development process Why is DFG needed? Educational goals Target group Administrative and inner setting DFG implementation process
Introduction to DFG training	Content Educational goals Time schedule
Parenthood	Parenthood –factors and skills needed Different roles as parent, spouse, and person
Parenthood and a child with NDD (Theory and praxis examples)	Feelings as a parent Stress Crisis Defense and coping mechanisms
NDD in the family (Theory and praxis examples)	Family system theories When the parent has NDD Couples` relationship when the spouse has NDD Sibling relationships
Introduction to family interventions (Theory and praxis examples)	Common principles when working with couples and families Parent groups 'Incredible Years' programme, and literature presentation Family school Psychoeducation Psychotherapy / family and couple therapy Family evaluation
Introduction to dialogue (Theory and praxis exercises)	Active listening Reflective attitude Use of family narratives Dialogue and dialogical attitude Social and emotional coaching towards dialogical working
DFG	Common principles in DFG Setting Goals when working with families Structure Manual Check list Discussion about targeting DFG to the right families
Tips and materials that can be used with children and parents	Written materials are shared and can be used during the DFG process

4.6.1 Content of the DFG

DFG is aimed to offer family members knowledge of NDD/ESSENCE symptoms and to help them to understand their complexity. In addition, it offers help with processing the feelings, emotions and impacts that the impairment has on the family. One of the DFG guidance areas is called psychoeducation, meaning information offered on the right level to both children and adults in the family. DFG includes three guidance areas: psychoeducational guidance (didactic element), practical guidance (skill training), and emotional guidance regarding sensitive, more private experiences and feelings (Figure 5). Dialogue is used during all steps as an attitude, along with a resilient and adjustable manner of approach to help create an emancipated and respectful atmosphere in the sessions.

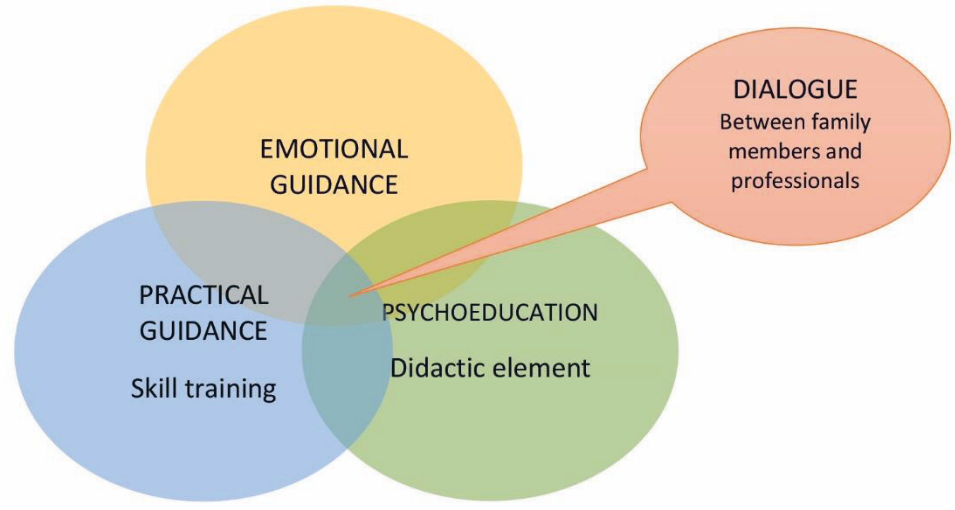


Figure 5. Content of the DFG guidance areas (Publication II & III, Cavonius-Rintahaka et al., 2020; 2021)

The DFG structure involves six different sessions, each lasting 90 minutes. A DFG manual was developed to include fundamental content for all six sessions, and offer a framework for the whole DFG intervention process (Appendix 1). There is flexibility as to how and when to use these topics within the DFG process, depending on the family's needs to discuss them. The topics are: Your family, What does NDD mean for your child, The child's development issues related to NDD, Demands in daily life, Resources in your family, Networks, Communication in your family, Relationships between family members, Sibling issues, Parents' reciprocal collaboration (Publication III).

4.6.2 Content of the DFG family intervention themes

A checklist was used to remind and help professionals to proceed in a correct and logical way, and use the manual provided during the DFG process. During the study, the checklist also functioned as an important quality test to make sure that the professionals delivered the intervention according to the manual and in line with the DFG training they had received (Appendix 2). A more detailed content of the DFG intervention themes is presented in Appendix 3.

4.7 Summary analysis

Quantitative and qualitative synthesis can be used to combine the findings and results on a topic. Synthesis aims to generate new knowledge, build bridges, and make evidence easily accessible, and can increase the generality and applicability of findings as well as distributing evidence to practitioners in a more beneficial way. (Thomson Coon et al., 2020; Kadykalo et al., 2021).

Because this dissertation consists of three publications, it is important to combine and compare the research findings to generate new understanding through the process of integration. Therefore, synthesis is used in this dissertation to draw together the quantitative and qualitative findings from the published Pilot study, DFG development and implementation study and Randomized clinical study (Publications I-III). (Figure 6).

Experiences of parents of children with NDD in terms of family functioning, family health, and social support are summarised from both the Pilot study and the Randomized clinical study. FAFHES values at baseline from both the Pilot study and the Randomized clinical study are presented in Table 2. From these studies (Publication I and III) qualitative data was collected using open ended questions and analysed by using content analysis. The main categories representing Parents´ hopes and expectations of health care professionals have been summarised and are presented in Table 3.

Development and implementation of the DFG family intervention includes the DFG training evaluation and professionals shared experiences are reported in section 5.4. (Publication II).

The outcome of DFG regarding family functioning, family health, and social support are presented as ANOVA results for FAFHES, along with parent perceptions from the open-ended question. (Publication III)

Synthesis in this study is aimed to increase knowledge concerning parent`s experiences and priorities for healthcare and providing knowledge and understanding concerning the family functioning, health of family members of families with a child with NDD, and their experiences of received support.

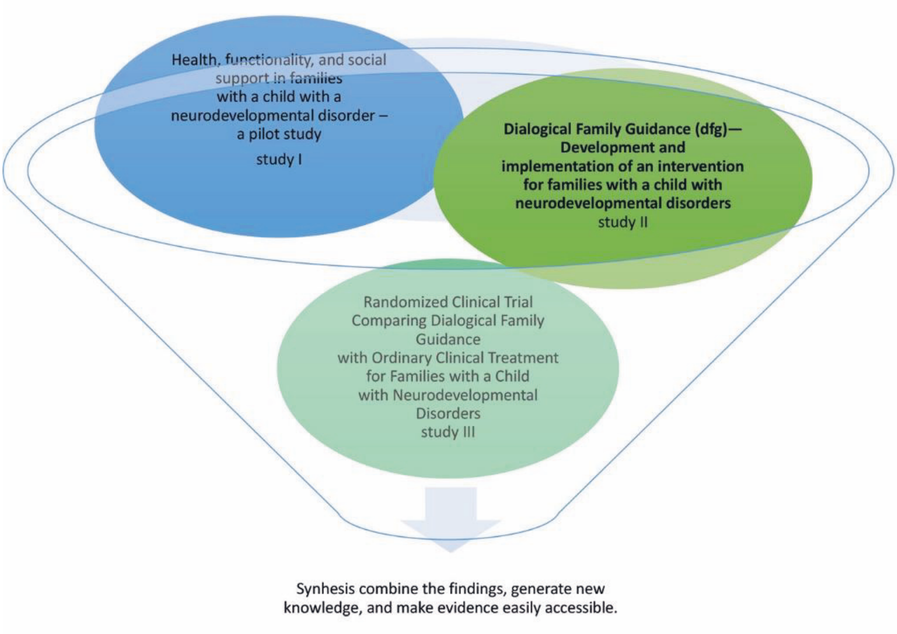


Figure 6. Synthesis design of the study I-III

5 RESULTS

5.1 Experiences of parents of children with NDD in terms of family functioning, family health, and social support

The results of background variables reveal that 22% of parents in the *Pilot study* and 31.9% of parents in the *Randomized clinical study* reported that there were also other family members with NDDs in addition to the child in question. Questions regarding the relationship between parents and parents' self-reported health also initiated from earlier studies reporting parental stress and increased rates of depression. Stemming from this, it emerged that 15 % of parents in the *Pilot study* and 23.1% of parents in the *Randomized clinical study* reported their own health as being moderate or poor. Referring to the quality of the relationship between parents, 19% of parents in the *Pilot study* and 40.4% of parents in the *Randomized clinical study* reported the quality of the relationship between parents as being moderate or poor.

Families participating in the *Pilot study* received ordinary clinical treatment and no family intervention. When comparing family functioning, family health and social support, parents reported social support as being lower than family health and family functioning. A strong positive correlation was found between family functioning and family health, meaning that if family functioning was good, the health of the family was also good. Also, a positive correlation was found between family health and social support. Negative correlations were found between family health and family functioning and the quality of the relationship between parents and their own health. This means that family health and functioning are affected negatively if the quality of the parents` relationship or the health of the parents is not good. Also, the experience of strength in parenthood is connected to family health and functionality. Overall, mothers and fathers reported similar results and the number of children did not affect the results. No significant changes were seen between baseline and three-month follow-up regarding the FAFHES domains. (Publication I)

Families participating in the *Randomized clinical study* reported similar results regarding FAFHES at baseline as had been in the *Pilot study* (Table 2). In both studies the baseline values regarding FAFHES subdomains were relatively good, where family functioning, family health, and social support were seen as poor if the median was 1.00-2.7, moderate if it was 2.8-4.5, and good if it was 4.6-6.00). (Publication III)

Table 2. FAFHES values at baseline (Pilot study and Randomized clinical study)

Median 1.00-2.7 = poor 2.8-4.5 = moderate 4.6-6.0 = good (Lepistö et al., 2017)	**Pilot study**	**Randomized clinical study / Intervention group**	**Randomized clinical study / Comparison group**
Subdomains	Total n=46	Total n=30	Total n=22
	Mean (SD)	Mean (SD)	Mean (SD)
Family Functioning	4.6 (0.8)	4.44 (0.74)	4.63 (0.82)
Family Health	4.4 (0.7)	3.89 (0.52)	4.24 (0.63)
Social Support	3.7 (1.3)	4.10 (0.68)	3.93 (0.99)

Associations between background variables and FAFHES at baseline show the relationship between parents and parents managing in daily life as being meaningful. Furthermore, managing in daily life and the relationship between parents were connected to family functioning and family health. Parents who felt the quality of the relationship was good or excellent had better family functioning than those parents, who felt the quality of their relationship as moderate, poor, or very poor. Likewise, parents who felt their relationship to be good or excellent, also felt their family health to be better. Parents, who reported that they managed extremely well or quite well in their daily life had better family functioning and better family health than those parents who reported managing only moderately well or poorly or extremely poorly as parent in daily life. (Publication III)

5.2 Modified FAFHES instrument

One purpose of the study was to pilot the modified FAFHES in the *Pilot study*. Previous FAFHES Cronbach`s alpha values are reported for family functioning as 0.92, family health 0.80 and social support 0.98 (Åstedt-Kurki et al., 2009). These values are in line with the values derived from the modified FAFHES at baseline being 0.90 for family functioning, family health 0.86, and social support 0.95. The modified FAFHES instrument was tested during the *Pilot study* and used again in the *Randomized clinical study* without incident, and can therefore be deemed to be applicable for use with families with a child with NDD.

5.3 Parents` hopes and expectations of health care professionals

In both the *Pilot study* and the *Randomized clinical study*, the similarity of parent answers to the open-ended questions was apparent. This qualitative part of the study offered parents` the opportunity to express genuine opinions, and so raised important issues additional to those seen in the quantitative data analysis. In both studies, the answers to the open-ended questions were aligned, and the sub- and main categories were similar (Table 3). The qualitative analysis of the open-ended questions revealed that parents hoped for practical guidance in their daily life, as well as advice and concrete help with how to deal with the daily demands of raising their child. Parents hoped that healthcare would be more personalized and family centered, meaning that any information given to them should be personalized to their specific child, the NDD in question, and that any support should be tailored to the family. Also, support for parents as a couple and peer support from other parents in similar conditions was raised. Notably, positive feedback regarding their own parenthood, being heard, and the experience of dialogue were included in the expectations and hopes they had regarding the support received from professionals. (Publication I & III). The results of the open-ended questions are formulated as main categories to illustrate parents` hopes and expectations of health care professionals and are presented in Table 3.

Table 3. Result of the qualitative analysis (Pilot study and Randomized clinical study)

Main categories Pilot study	Main categories Randomized clinical study
Parents want dialogue	Being heard
Parents want knowledge	Getting information
Parents want support to daily life	Practical guidance for daily life
Parents hope the whole family to be included by healthcare professionals	Positive feedback about own parenthood
Parents hope to get competent professionals for their child and family	DFG was a needed and rewarding experience

5.4 Development and implementation of the DFG family intervention

All the steps carried out over the development and implementation phases of the DFG intervention served to refine the intervention and make it clearer, more explicit, and more transparent to others. At times, it turned to be a shared experience between the researcher and professionals of different levels, positions, and occupations within the clinical setting.

Professionals taking part of the DFG training shared their opinions and experiences that dialogue needed attention in order to be realized in clinical settings, and that some changes might be needed in regard to one's own attitude. DFG can bring new habits to ordinary work at the clinic in regard to meeting parents and children and bringing them knowledge and understanding of NDDs. Professionals reported considerable satisfaction with their DFG training, and would recommend DFG training to other professionals (yes, or absolutely yes 96%) and also to families (yes, or absolutely yes 100%). (Publication II).

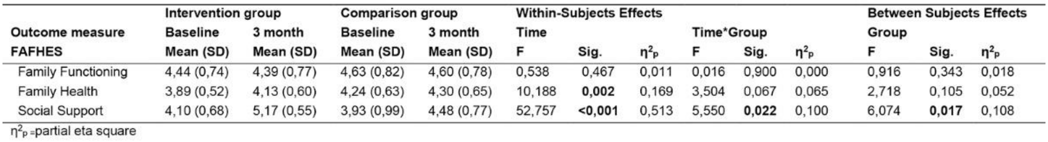
The open-ended question ("*Can you describe your experiences and offer suggestions to improve the DFG training programme*") confirmed that it was meaningful to professionals themselves of being heard during the training. The theory-based parts of the education programme became more comprehensible, while their own narratives could be shared and discussed during their DFG training, so creating a possibility for simultaneous peer support. Generally, the DFG training programme was experienced to include essential lessons, and to be comprehensive, well structured, and professionally delivered. (Publication II).

5.5 The outcome of DFG regarding family functioning, family health, and social support

The effects of the DFG intervention were tested in the *Randomized clinical study*. A significant within-subjects effect of time was found on family health and social support, meaning that family health and social support increased in both groups over the three-month period. However, a significant between-subjects effect of group and interaction between time and group appeared, indicating that families who received the DFG intervention experienced a significant increase in social support. However, family functioning did not increase in either group. Repeated measure analysis of variance (ANOVA) was used as an analytical strategy. ANOVA results for FAFHES are reported in Table 4. (Publication III)

In both groups (intervention and comparison groups), managing in daily life and the relationship between parents were found to associate with family functioning and family health. On the other hand, family functioning did not increase in either of the groups. As expected, DFG seemed to offer support to families, but did not help increasing their family functioning. Family health increased slightly in the intervention group, meaning that DFG seems to have helped families regarding their health-related issues. (Publication III).

Table 4. ANOVA results for FAFHES (Publication III, Cavonius-Rintahaka et al., 2021)



	Intervention group		**Comparison group**		**Within-Subjects Effects**						**Between Subjects Effects**		
Outcome measure	**Baseline**	**3 month**	**Baseline**	**3 month**	**Time**			**Time*Group**			**Group**		
FAFHES	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**F**	**Sig.**	**η^2_p**	**F**	**Sig.**	**η^2_p**	**F**	**Sig.**	**η^2_p**
Family Functioning	4,44 (0,74)	4,39 (0,77)	4,63 (0,82)	4,60 (0,78)	0,538	0,467	0,011	0,016	0,900	0,000	0,916	0,343	0,018
Family Health	3,89 (0,52)	4,13 (0,60)	4,24 (0,63)	4,30 (0,65)	10,188	**0,002**	0,169	3,504	0,067	0,065	2,718	0,105	0,052
Social Support	4,10 (0,68)	5,17 (0,55)	3,93 (0,99)	4,48 (0,77)	52,757	**<0,001**	0,513	5,550	**0,022**	0,100	6,074	**0,017**	0,108

η^2_p =partial eta square

Parent`s perception of DFG

Parents, who received DFG gave their answers regarding the intervention by filling the DFG questionnaire. The analysis of this questionnaire reveals that most parents felt that DFG was delivered at an appropriate time for them, and that they felt the starting point for DFG should be very soon after the child`s first visit to the unit. Six sessions were seen as adequate, and all parents reported that all of the family members had been receiving attention during DFG. Parents reported of having received information, and practical guidance which helped them to manage better at home with the child with NDD, and all parents answered "yes" or "absolutely yes" to the question "Would you recommend DFG to other families?". Overall, parents reported DFG as offering them practical guidance, and they would recommend it to other families. (Publication III)

5.6 Summary of the results: the DFG family intervention for families with children with NDD

Parents managing in ordinary daily life and experiencing the relationship between parents as being good affects both family functioning and family health. The FAFHES domains do not necessarily change within a three-month period if no family intervention is carried out. However, families receiving the DFG intervention can get help as a family, experiencing increased family health and social support. Family functioning did not increase within three months, even after DFG. Parents report managing in daily life, the relationship between parents, practical guidance, psychoeducation, dialogue, and receiving positive feedback on their parenting as being strengthening factors. Additionally, parents felt they needed practical guidance, psychoeducation and advice, because it helps them to cope more constructively with their child. Communication in terms of listening, feelings of being heard, and being able to engage in dialogue with professionals are seen as offering parents an important space to express their emotions. Furthermore, positive feedback regarding one´s parenthood and managing parenting skills seems to have a positive impact on parents' experiences of getting social support. However, the results of this study are acknowledged as being preliminary and cannot be more widely generalized, among other reasons because only parental opinions were studied from within the family group and the sample sizes being small.

6 DISCUSSION

Ongoing communication and communication between professionals and parents can among other things lead to an experience of increased social support in families with a child with NDD. Dialogue offers a shared understanding and the opportunity of learning from each other, as well as creating engagement and trust. Providing parents with essential tools and solutions (practical guidance), and offering them encouragement, support (emotional guidance) and knowledge (psychoeducation) can create a solid foundation for family-oriented care. The results of this study show that without an intervention, there are likely to be no significant changes in parents` experiences of family functioning, health, and social support within an initial three-month period, indicating that ordinary clinical treatment is not necessarily enough to give families the support they need.

6.1 Overview of the findings

Experiences of parents of children with NDD in terms of family functioning, family health and social support

When comparing FAFHES domains, parents in the pilot study reported at both baseline and at three-months follow up lower levels of social support than family functioning and family health (Publication I). This indicates that their experience of receiving help from professionals was not sufficient, despite the child being cared for in the clinical setting at the time.

There was a positive correlation between family functioning and family health, meaning that if their practical life is functioning well on a day-to-day basis, the family health is also better (Publication I). However, negative correlations were found between family health and social support, meaning that the support received from outside the family matters and should be highlighted during the development of health care professionals and staff working with this target group. This is in line with several earlier studies, that recommend interventions for these families to be used (Ahlberg et al., 2020; Barlow et al., 2014).

Negative correlations were found between family functioning and family health and the quality of the relationship between parents (Publication I). This issue is relevant for any further developments regarding clinical work in this area and particularly implementations of family-centred interventions. However, this result was somewhat expected given that several studies highlight the issue of stress in families with a child with NDD (e.g. Biederman et al., 2006, Herring et al, 2006). Also Craig et al. (2016) reports the high scores of parenting stress among parents of children with ADHD and ASD compared to control groups and suggest that both fathers and mothers of children with NDDs should be provided with interventions that empower them with knowledge and skills that will allow them to reduce their stress.

The result of the Pilot study and the Randomized clinical study shows no significant changes (without family intervention) between baseline and three-month follow up regarding the FAFHES domains, indicating that the ordinary process of clinical treatment needs additionally family targeted interventions to increase the health and functionality of the family. There were no differences seen between the experiences of fathers and mothers in this study (Publication I). This is a similar observation to that seen by Craig et al. (2016), although there are also studies where differences between parents have been shown (e.g. Falk et al., 2014). However, data in the Pilot study was collected during 2012-2014 and most likely the understanding, knowledge and awareness has increased over the years amongst professionals.

Family-centred care has also been given more recent attention, but there are issues that still need attention such as dialogue, how to include the entire family and how to enable family interventions to become customized practice in society. Underpinning this, recent studies affirm the importance of supporting family members to improve their understanding, allow them to express their concern with each other, supporting them to work through various experiences, and also the importance of tailoring programmes to particular needs (e.g. Ahlberg et al., 2020; Ferrin et al, 2020; Paidipati et al., 2020). The DFG intervention includes emotional guidance, which mean offering emotional support and dialogical approach to the sensitive and more private experiences and feelings of the family highlighting a collaborative partnership between families and professionals.

Development and implementation of the DFG family intervention

The development and implementation phases of the study, as well as the DFG training, looked to synthetise findings from earlier research and include the knowledge received from the Pilot study needed for DFG. The dialogical approach used in the

DFG initiative seemed to be a success. Both the professionals attending the training and also the parents taking part in both the Pilot study and Randomized clinical study reported the importance of being listened to. Although professional attendees already possessed some knowledge of NDDs, they also experienced being heard, which increased their understanding of the parent perspective. The theory-based parts of the training also became more understandable, and discussions connected to the attendees clinical experiences allowed them to sharing on a more serious level using dialogue. Leoni et al. (2020) highlight the challenge of professionals to be taken seriously, especially when working with caregivers of individuals with NDD on daily basis. The psychological processes support individual learning, offering guidance, the opportunity for discussion, and sharing experiences of how oneself and others can react to challenging behaviours were essential and appreciated elements in the DFG training programme. (Publication II)

The *DFG development and implementation study* brings greater awareness of the importance for organizations to address the concerns of professionals working with people with NDDs. Although working primary with children with NDDs, professionals often meet parents having similar NDD symptoms because of the high hereditary factor (Biederman et al., 2006; Blesson & Cohen 2020; Faraone et al., 2015). Helping professionals with these parental issues and how they may deliver help to parents in the clinical setting is worth supporting. Especially, the NDD symptoms of adults can place unexpected demands on professionals working with children and they should be prepared to manage in such situations.

The outcome of DFG regarding family functioning, family health, and social support

The Randomized clinical study (proceeded by the two earlier study phases) tested how this novel intervention met the end-users` needs and expectations. Coping as a parent in daily life and the relationship between parents were connected to family functioning and family health. Because coping as a parent in daily life and the relationship between parents seems to be connected to how the family is experiences their health, it would seem important to include support for parents as a couple, as well as supporting their general daily management whenever possible. However, Hartley & Schultz (2015) have shown that the high level of unmet support needs experienced by parents, and the differences between mothers and fathers' general wellbeing has resulted in only moderate agreement between spouses in terms of the family's unmet needs. Therefore, finding ways for professionals to better support parents in their relationship as a couple is an important intervention strategy included within the DFG initiative.

The outcomes following DFG regarding family functioning, family health and social support were studied by adopting a randomization approach. Families in the intervention group were delivered DFG along with ordinary clinical treatment, whereas families in the comparison group only received ordinary clinical treatment. When comparing these two groups at baseline and at three-month follow-up, the family health and social support increased in both groups (Publication III). An experienced increase in social support was expected to occur in the intervention group, but not in the comparison group. One explanation for the experience of increased social support in the comparison group could be the fact these parents already knew from baseline that they would have the possibility to receive DFG after three months of waiting.

The significant increase of parents' experiences of social support and especially the answers given in the DFG questionnaire indicate that DFG helped families as intended. The structure of the intervention seemed to be suitable as it was originally designed, with six sessions, structured themes, and a target of 90 minutes/session. Based on the responses given by the parents in this study, no significant changes are needed to DFG intervention structure, or the themes addressed. (Publication III)

The increased experience of social support strengthens the original hypothesis of the importance of being heard and having the opportunity to share opinions, feelings, and experiences. Notably, the experience of sharing and not being alone as a parent regarding the child`s demands, increased the experience of social support.

Family functioning did not improve after DFG, despite practical guidance being one of the DFG guidance areas intended to help families to manage better in their daily life. It could be that practical changes in daily living at home may require a longer time than the programme's six meetings within three months. Another explanation could be that six meetings are not enough to target all three guidance areas (psychoeducation, practical and emotional guidance) sufficiently, in order to meet parents' expectations. This result could indicate that emotional guidance is in fact most needed from the parental point of view during DFG and is supported by the findings of increased parent experiences of social support in this study.

Approaches to increase practical value

Although it is not possible to totally replicate the research process used throughout the study, it is important for the reader to be able to follow the research steps taken. When dealing with an intervention study, the core components and appropriate adaptations of the intervention and its implementation strategies need to be described and reported in detail (Hasson et al., 2020, Nilsen et al., 2019). This dissertation includes a detailed content of DFG intervention training and the intervention substance that was offered to families (Publication II, Appendix 1-3).

A participatory approach and co-creation between the researcher and professionals in the units involved served to increase the usability of the intervention. This intervention study approach aims to benefit end users, both professionals and families. Descriptions of the intervention, its core components, and how it is delivered in the clinical setting are needed in reports of high-quality implementations. Additionally, the outcomes in everyday practice, implementation strategies, and knowledge regarding the context where the intervention is meant to be effective are matters that have been discussed during the process of this study and dissertation. However, implementation strategies are not always described in intervention research, and sometimes implementation strategies need to be tailored to address local needs, possibilities, and the level of available staff competence (Hasson et al., 2020).

The theoretical basis, training and intervention components have all been given attention during the development and testing of the intervention, and openly shared in the reporting publications (Publication II). Insights from professionals delivering the intervention and families receiving the intervention are essential when developing future adaptions or making changes to the intervention, and their opinions and experiences can increase the usefulness of findings in this respect. This study was designed for clinical practice, and the effect of the intervention was tested in the clinical setting in an appropriate context (Cope, 2015; Hasson et al., 2020; Lochman, 2021).

6.2 Ethical issues and approval

Previous studies highlighted a need to develop and implement family interventions that offered strength and wellbeing to families with a child with NDD (Factor et al., 2019; Lai et al., 2014; Schwartzman et al., 2021; Smith & McQuade, 2021). Although numerous interventions existed, none targeted the entire family through use of dialogue, or highlighted the uniqueness of existing resources in families. It therefore seemed justifiable to develop such an intervention.

The HUH ethical committee processed the application regarding the Pilot study and granted ethical approval for the study in 2012 (The Ethical Committee of women, children, and psychiatry, no. 106/13/03/03/2012). After the ethical approval was granted, detailed information regarding the study was submitted to the HUH Medical board, which granted permission to conduct the research (2012).

The ethical standards of the Declaration of Helsinki (WMA 2013) were followed during all of the stages of this part of the research. The Ethical Committee was informed about changes in the study plan regarding units involved, new information letters, and an extension to the study approval was requested. Updated approvals were received in 2013 and 2015 from the same HUH Ethical Committee. Research permissions were granted in 2012, 2013 and 2015.

Some international publishers require intervention studies to be registered, in order to increase transparency and to ensure all of the quality aspects appropriate to an intervention study have been followed, including ethical standard compliance. To this end, this study was retrospectively registered to ClinicalTrials.gov with the identifier: NCT04892992 on May 18, 2021.

Ethical aspects of the study also need to be considered from the implementers point of view. Implementer assignment to take part in the DFG training was voluntary, but was required in order to proceed with implementing DFG in the clinical setting. Although the professionals were familiar with working with families with concerns, anxiety and worries, DFG seemed to bring out communication on a deeper level between the professionals and families involved. As a supporting measure, consultation and supervision were put in place from the beginning and carried out on a regular basis through the study period, so as to provide help for professionals during the implementation.

Data protection and confidentiality of participants

In developing and evaluating such an intervention, it is necessary to study the lives, perspectives and experiences of potentially vulnerable people. Therefore, certain ethical considerations need to be acknowledged when studying human participants and their families` sensitive and personal experiences (Åstedt-Kurki & Kaunonen, 2018), and the ethical guidelines and processes followed in this study are presented in the next paragraphs.

The study information was delivered both orally and in writing (Appendix 6) to parents in both studies, including the information that supported their informed consent to participate, and the possibility for them to interrupt their participation without reason (Appendix 4). The voluntary nature of their participation was highlighted. Parents were also informed that giving negative responses to requests to participate in the study would not affect the ordinary clinical treatment of the child. The possibility to gain further information from the researcher was given and their contact details were included in the information letter (Horner, 1998; Rohrich, 2007; WMA 2013).

The anonymity of participants was protected by using codes for the families that took part throughout the whole research process. The hospital professionals involved were bound by professional confidentiality, and completed questionnaires were delivered immediately from parents to the researcher by the nurses, who stored the material appropriately in a locked box. The questionnaires will be destroyed when the questionnaires are analyzed, the reports are written, and the total study is completed and this is mentioned in the informational letter (Appendix 6). Participants were aware that the study results were to be published, and their anonymity would be protected (Åstedt-Kurki & Kaunonen, 2018). As a further ethical measure, both parents in the families were given the opportunity to fill out their own questionnaires, promoting an open disclosure and freedom of expression.

6.3 Validity and reliability of the results

Validity and reliability were important baseline issues because the family intervention development process intended from the beginning to target the practice level, offering health care professionals a tool to deliver more organized support to the entire family of a child with NDD. Quantitative and qualitative data were collected, providing diverse and wide perspectives to the functioning, health and received support of these families from a parental point of view.

Knowledge from clinical practice and earlier studies regarding a lack of tailored family interventions for this target group was used in this clinical setting (Frye, 2016; Lai et al., 2014; Soke et al., 2018). Although the common issue was children with NDD, there was also a need to highlight their families as being different and their need for support being unique. Still, there appeared to be some common issues affecting the daily lives and family health of these families which needed to be addressed in the novel intervention.

The development of DFG proceeded in a more structured and goal-directed way both during and after the Pilot study, and the results revealed and strengthened the ideas of the sectors needed to be included in a DFG intervention. National, Scandinavian and international studies were used to confirm important issues considering the needs and demands in these target families (e.g. Carlsson et al., 2016; Lämsä et al., 2015; Smith & McQuade, 2021; Zakirova-Engstrand et al., 2021) and the working knowledge regarding the undertreatment of NDDs in the family confirmed a need to proceed with the development process of this novel intervention.

During the development of the intervention, both qualitative and quantitative international studies were used to identify already existing interventions for this target group. Issues regarding NDDs, and the family aspects and interventions that are needed are discussed worldwide and share the common opinion of NDD incidence steadily increasing. For example, there are studies from Finland (Jokiranta-Olkoniemi et al., 2019; Gyllenberg et al., 2014), Sweden (Taylor et al., 2020), UK (Sayal et al., 2018), USA (Sharma et al., 2018; Zablotsky et al., 2019), India (Manohar et al., 2018), along with several other international (Alabaf et al., 2018; Stein et al., 2020), referring to the need to improve treatment services and deliver easily accessible interventions to different levels of health care. Especially, a broad range of experts seems to be in agreement about the current lack of knowledge and lack of effective evidence-based treatments as well as the need for developing novel therapies and interventions that can be implemented into practice.

Although, the preliminary goal of this process was to develop a family intervention to be used in Scandinavian countries, the baseline literature mentioned above suggests that this intervention can be suitable for implementation also in other countries outside Scandinavia where professionals meet these families. However, cultural differences, national settings, and the differences between health care systems in other countries need to be taken into account when discussing the suitability and implementation of the DFG intervention outside Finland.

Objective and critical approaches were used during the intervention's development and implementation stages, which were carried out in meetings with professionals from different sections of health care. The data collected from the Pilot study offered important baseline knowledge for the intervention development process, despite only 29 families (29 mothers and 17 fathers) participating. The fact that all of the families in this study were from Finland lends the intervention creditability in a Finnish health care context.

The research group has been familiar with this target group and subject for many years, which also gives validity and reliability to this study. This is an important factor in intervention studies, because it is recognized as an advantage if the researcher is acquainted with the context, has good interpersonal skills, and can administrate group dynamics. A researcher`s diary was kept throughout the entire study to maintain a dialogue between facts and subjective opinions and experiences that arose. The journal served as a method of giving the research critical intent, helping with reflection, and reminding the researcher of the two existing positions and roles as a nurse and as a researcher. The journal was used to reflect on aspects arising in practice, which became clearer and more objective when viewed through "researcher's glasses". This reflexivity was found to be a continual individual and collective process of producing common learning within a shared culture and context (Barrett et al., 2020; Cudmore & Sondermeyer, 2007).

The research group´s objectivity was protected and kept in mind throughout the study. Researchers were not involved with the participants taking part in the study, which supported their objectivity and helped them to stick to the role of researcher. Rather, the researcher was in a role as consultant, educator of the intervention and supervisor, with a responsibility to inform professionals of the study proceedings, and to maintain confidentiality among professionals and participants. The goal was to create a positive atmosphere and give support to health care professionals to help them in being confident in their role of an independent implementor of the intervention. Researcher has a long history of work in developmental neuropsychiatry, and this helped when giving information and educating the professionals and created a sense of credibility among professionals during the whole study process.

During the study, cooperation was maintained with HUH professionals representing different occupations, such as child psychiatrists, child neurologists, nurses, social workers, psychologists, occupational therapists, speech therapists, and leaders of the hospital in various units and sections. The University of Gothenburg and Tampere University collaborated and were involved in the research from the very beginning, offering supervision including a multidisciplinary scientific perspective.

The first author has constantly been aware of the importance to proceed diligently in the different study phases. The combination of administering the study proceedings and the DFG implementation process side by side in the clinical setting has been both demanding and challenging. However, the validity and reliability of the study have been strengthened by detailed documentation, and by transparently describing the study proceedings and how the results have been gathered. This study is meant to be easy to follow, allowing the reader to evaluate the researcher's choices and decisions.

The sample in the Pilot study (n=29) was smaller compared to the preliminary study plan, and this affects the validity and reliability of this study. We compared the sample with the families who had been given their consent and the group who met the inclusion criteria but did not want to take part in the study. This group was similar regarding the child diagnosis, gender and age, when compared to the group who participated. This procedure also included a three-month follow-up study (n=18), where families were intended to return their questionnaires by mail to the researcher. However, despite the mailing procedure being made easy for the parents by way of providing a pre-paid envelope, it seems that asking them to return the questionnaire by mail was not a good choice. While NDDs are strongly heritable, it is possible that parents themselves had similar symptoms, giving them difficulties in filling out and mailing questionnaires. The FAFHES instrument is also quite long, including 88 questions, and this could have had a causative effect on the large drop out rate. On the other hand, postal surveys are commonly known to suffer low response rates (Jones et al., 2013).

Both parents received their own FAFHES questionnaire (a red color for mothers and a blue color for fathers) to fill out independently, the goal being to give both parents the equal possibility to give individual answers, and this was one background variable analyzed in the study. However, it is possible that the spouses may have influenced each other, which consequently might have an impact on the results.

When the effects of DFG intervention were studied, randomization was used to offer greater validity and reliability to this study. The randomization design and the construction of control conditions were not typical but were deemed suitable for this study considering the clinical setting (Mohr et al., 2009). This randomization approach was seen as an ethical way to provide additional support to all families meeting the inclusion criteria and wanting to receive the DFG intervention for their family. It is possible, that this knowledge of having the possibility to receive DFG later can influence the results of this study. Upcoming possibility to receive DFG can already be supporting itself. The Hawthorne effect needs attention, and should be remembered when discussing implications for the generalizability of results (e.g. Sedgwick & Greenwood, 2015).

The qualitative data in the Pilot study and Randomized clinical study was collected with open-ended questions. Such questions give an opportunity for parents to share their opinions using their own words, in addition to the answers they have given in the structured questionnaire questions. The inductive data analysis generated themes and produced valuable and insightful knowledge from a parent perspective (Graneheim et al., 2017). Qualitative analysis requires the researcher to observe the data from different perspectives, and additionally to engage in creative and abstract thinking. The inductive method used for analysis of the qualitative data seemed suitable because concrete findings were of interest, and were applicable for use in the development process of the intervention. Especially, understanding how family members describe their experience is beneficial in providing family-centred care.

There are factors that increase the validity and reliability of the present study. The DFG is manualized, the implementation included supervision for the implementers, a checklist was used, and the intervention was carried out by health care professionals being familiar with NDDs through their earlier work. The professionals also implemented the DFG by working in pairs. The significance of this kind of approach is that the impact of personal and individual components is minimalized. Among other things, the DFG interventions delivered to families were meant to be homogeneous regarding their structure and coverage of themes included in the manual. The first author monitored the completed checklists after every finalized DFG intervention, and all (100%) of the DFG interventions fulfilled the requirements of DFG programme and followed the manual.

The DFG training was equal for all of the implementers involved because it was conducted by the same educator. The fact that the intervention was maintained in a similar way during the whole study increases the validity of the intervention effects. These procedures served to improve the quality of the intervention and reduce variability between professionals. However, the impact of individuality between professionals can be different due to their personal way of implementing DFG is acknowledged. According to Firth et al. (2020), differences regarding the skill levels of implementers may also bring variability in quality, and even introduce vulnerability into a study.

Cronbach`s alpha is used to score an instrument's reliability or internal consistency, especially in questionnaire development and validation studies (Bujang et al., 2018). FAFHES psychometric properties have been reported as good with a Cronbach's alpha for family functioning of .92, family health .80, and social support .98 (Åstedt-Kurki et al., 2009). Values from the original FAFHES instrument are in line with values gathered from the modified FAFHES instrument used in the Randomized clinical study*,* as at T1 (baseline), family functioning was scored at .90, family health .86, and social support .95, and at T2 (3-month follow up) family functioning scored .92, family health .88, and social support .95 (Cavonius-Rintahaka et al., 2021). The FAFHES instrument was used in the baseline and three-month follow-up measures in both studies (Pilot study and Randomized clinical study). This has a positive effect on the validity and reliability of this dissertation, allowing a comparison between the two studies, in addition to the two groups (intervention and comparison group) featured in the Randomized clinical study.

This study provides preliminary evidence showing that parents can have positive perceptions of the usefulness of DFG. However, a larger-scale of data collection is warranted to ascertain the effects of this DFG intervention.

6.4 Implications for practice

This study provides parent perspectives regarding family functioning, family health, and social support addressing families with a child with NDD. The study indicates that the development and implementation of the DFG process has been perceived as important, and the target families appear to have given it a positive evaluation. The detailed information reported in the publications connected to this study can be useful for professionals working with this target group. Currently, the DFG intervention is already being used at HUH, and continuing to collect knowledge from the clinical setting and allowing it to be shared with other professionals. The development and implementation knowledge can be applied by various occupations working with this target group. This study can offer guidance to developers when improving family interventions and ideas of how to succeed with similar implementation strategies. As a key point seen in this study, while psychoeducation is obviously important, many families also need the opportunity to have discussions regarding their worries and to have dialogues with the professionals they encounter.

6.5 Further research recommendations

The presented study results are acknowledged as being rather preliminary, and they reflect only the families attending a single unit, rather than having several different units to compare. As all of the children in this study were patients at HUH, they also represent children receiving support from other professionals, alongside the DFG intervention featured in this study. Larger numbers of families are needed to examine the effectivity of DFG and the child perspective is needed along with that of their parents in future studies using objective child outcome measures. The condition regarding the child`s NDD symptoms before and after DFG would bring understanding towards how DFG may benefit the child.

Only questionnaires were used in this study for data collection. However, further qualitative research using interviews as a data collection method could bring new and deeper aspects and perspectives to this topic, and can be recommended as supplemental data collection method.

The comparison group informants were parents who knew about their possibility to receive DFG after a three-month waiting period. Another selection of comparison group conditions would be necessary to make more objective assumptions. Studies focusing more precisely on family functioning during the DFG intervention could bring more detailed knowledge to develop this section of DFG, and help meet families` daily needs more effectively.

Comparisons regarding the effects seen by and among professionals implementing DFG could reveal new relevant factors needing consideration in future developments and deliveries of DFG. Regarding the use of DFG addressing families with children with different psychiatric or somatic diseases could bring visions how to widen the clinical usefulness of DFG.

7 CONCLUSIONS

The study investigated parents' perspectives on family functioning, family health and social support regarding families with a child with NDDs.

Modified FAFHES instrument deemed to be applicable for use with families with a child with NDDs.

Parents want knowledge, dialogue with professionals, and support for their daily life.

Parents have hopes of the whole family to be included in collaborations with professionals, and they are assigned competent professionals familiar with NDDs.

There was a strong positive correlation between family functioning and family health.

Negative correlations were found between family health and family functioning, and the quality of the relationship between parents and their experience of their own health. Managing in daily life is connected to family functioning and family health.

The experience of strength in parenthood is connected to family health and functionality.

Parents experiences regarding family functioning, family health and social support did not improve within a three-month period, unless they had received the DFG family intervention.

DFG introduced the concept of dialogue to professionals, and new habits were incorporated into the ordinary clinical work of many professionals. A high level of satisfaction was reported after the DFG training.

Parents in the intervention group experienced that social support increased compared to parents in the comparison group.

DFG can strengthen parental experiences of social support.

The experience of family functioning did not increase during DFG.

Managing in daily life, the relationship between parents, practical guidance, psychoeducation, dialogue, and receiving positive feedback on parenting are strengthening factors for parents.

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APPENDICES

Appendix 1. Dialogical Family Guidance manual

Dialogical Family Guidance DFG

Manual

SETTING of the intervention

Place: The place is booked in forward. The place is quiet and peaceful. One meeting can take place at the family´s home.

Time schedule: Six (6) sessions; á 90 minutes/session The session time schedule will be discussed with the parents All six sessions within 3 months period

General approach: dialogical, flexible, understanding, co-operative, interested

SESSION 1

- The first session is only for the parents. DFG setting & principles; cooperation, for whom, initial plan together with parents for DFG prosess
- Needs & expectations of the family, themes that need attention during DFG. Who belongs to your family? (family map). Discuss the personalities of family members and family relations. Plan next session. For whom?

SESSION 2

- Follow up; what was discussed last time
- Discussion about the child`s development, treatment history, diagnoses, actual situation. Do parents` understand the child`s diagnoses?
- Discussion about the guidance of their child`s/family daily management
- How does the family manage in their daily life and do they need guidance?

SESSION 3

- Follow up; what was discussed last time
- Discussion about parent management in the family, consistence. How does the child`s diagnosis affect other family members
- Discussion concerning parents` principles in the family. Do parent´s share a common understanding & view, how to operate with/help the child

SESSION 4

- Follow up; what was discussed last time
- Discuss/offer concrete guidance to family daily life. Discuss practical & skill issues
- Discuss network issues; does the family get help when needed, who can help?
- Communication in the family. How is the dynamics and communication between family members?

SESSION 5

- Follow up; what was discussed last time
- The strengths and resources in the family
- Sibling issues
  Parents as a couple. How do they manage?
  Stress in the family?

SESSION 6

- Follow up; what was discussed last time
- Repetition of what has been discussed, important themes that has come up
- Discussion aboutt he future; how are they managing, what kind of help do they still need?

Appendix 2. Dialogical Family Guidance checklist

DIALOGICAL FAMILY GUIDANCE/ CHECKLIST FOR PROFESSIONALS

I HAVE GIVEN THE PARENTS THE INFORMATION ABOUT THE PRINCIPLES REGARDING DIALOGICAL FAMILY GUIDANCE

THE PRINCIPLES:

YES

- The place and time schedule are clear ☐
- The place is quiet and peaceful ☐
- 6 sessions; 90 min/session ☐
- The session time schedule is discussed with the parents. All six sessions are held within 3-month time frames ☐
- The first session is only for the parents/parent ☐
- Discussion and decision with the parents, which family members to meet and in which order. You can meet every family member, if needed ☐
- It is possible to do a home visit, if needed ☐
- During the last session you make conclusions and recommendations on how to proceed ☐
- Who can do this? Every professional within healthcare who has received education called “Dialogical Family Guidance” ☐

INFORMATION (I) / PSYCHOEDUCATION

- The family has been told what kind of treatment is recommended to their child ☐
- The family has been sufficiently guided regarding the treatment/rehabilitation of their child ☐
- The family has sufficient opportunities to discuss guidance of their child´s daily tasks ☐
- The staff shows interest in how the family manages at home daily ☐
- The family has been sufficiently informed about the support and rehabilitation available for neurocognitive difficulties ☐
- The family has been sufficiently informed about the importance of clear and consistent guidance in the child´s daily life ☐
- The family has had sufficient opportunity to discuss the effect of the child´s neurocognitive difficulties on all members of the family ☐
- Issues regarding parenthood have been sufficiently covered ☐
- The parents have received sufficient information regarding the importance of daily rehabilitation of the child and about the parents’ important role in it. ☐

PRACTICAL GUIDANCE (P)

- The family receives sufficient practical guidance for the child´s daily life ☐
- The family receives concrete guidance for their normal daily life ☐
- The family receives help as it is needed ☐
- The family receives sufficient opportunities to discuss the planning and progress of treatment/habilitation ☐

- The family receives sufficient opportunities to discuss the effect of the neurocognitive difficulties on all members of their family and receive guidance for these issues ☐
- The family receives sufficient information and practical guidance regarding how the family members can take part in the child´s daily rehabilitation ☐
- The child´s day care, school or other important networks are included as a part of the discussion and practical guidance ☐

EMOTIONAL GUIDANCE (E) / DIALOGUE

- The staff cooperates with the family ☐
- The staff is listening to the family members and having a dialogue ☐
- The staff shows appreciation for the family´s participation in the treatment of their child ☐
- The staff is concerned about the well-being of the family ☐
- The family members have been listened to as a whole family ☐
- The family´s own resources have been discussed and made visible ☐
- Questions and issues about parenthood have been discussed and covered ☐
- The staff has granted the family members sufficient opportunity to express their feelings ☐
- The staff give professional support to the parents ☐
- The family provides sufficient positive feedback about the family´s participation in the child´s daily rehabilitation ☐

Appendix 3. Content of the DFG intervention areas (Publication II)

Practical and concrete guidance	Emotional guidance	Psychoeducation
Parents get concrete guidance, tips, and advice for daily life with a child with special needs.	Professionals collaborate with the family members (FM).	Information about the child`s symptoms, special needs, diagnostic procedures, diagnosis, treatment, therapy, and habilitation.
All FM get concrete guidance for their daily life.	Professionals listen to the FM and to their hopes/needs.	Repetition about the child`s history regarding diagnosis and the current situation (medical history, appointments, hospitals, meetings with professionals, etc.).
Family gets help as a whole family unit.	Professionals show respect to the family because the family are willing to be active and participate in the habilitation of the child with special needs.	Guidance about the child`s special needs, treatment, therapy, and habilitation.
Dialogue about the child`s special needs, special training, how achievements are seen at home, impacts on daily life.	Professionals show their concern for the wellbeing of FM.	Dialogue about the child`s diagnosis, symptoms, rehabilitation, therapy, treatment, proceedings, achievements – the parent`s (mother and father) perspective, knowledge, understanding are made visible.
The family get guidance about child`s neuropsychiatric /ESSENCE/ NDD disorders and discussion of how it can impact all FM.	Professionals are interested in the family as a unit.	Information, education about the child`s daily life needs. Professionals show interest in how the family is handling/managing daily life.
Discussion with the family about their opinions about how the child`s special needs specifically affect their family.	Dialogue about the child with special needs – personality, demands and resources.	FM get guidance about available assistance, support groups, habilitation facilities, outpatient clinics, social resources etc. that are available.
FM get information and guidance on how they can participate in the habilitation of their child at home in daily life.	Resources of the family are mapped and made visible.	Parents get education about why structure and consistent guidance is important for the child`s daily life.
Other surroundings (school, day care) and people (family network) are also included in the discussion.	Dialogue about parenthood, being parents together, being the child`s mother and father.	FM get guidance about neuropsychiatric /ESSENCE/ NDD disorders and commonly known impacts on family individuals and how family function can be affected.
	Professionals give enough space for family members to express their feelings.	Information about important principles as a parent, parental roles and responsibility, parent-child communication, and interaction.
	Professionals confirm parents` hope to have strength as parents and in parenthood.	Professionals give information to parents about the importance of their participation as family members in the everyday habilitation plan.
	Professionals give positive feedback to the FM about participating and being concerned about the child`s/siblings` daily habilitation.	

Appendix 4. Written consent to participate (Pilot study & Randomized clinical study)

XX.XX.XXXX

A consent agreement

Study: The Effect of Dialogical Family Guidance in Families with Children with Neurocognitive Symptoms

I've been asked to participate in the above-mentioned scientific research, and I have received both written and oral information about the study and the opportunity to submit questions for researchers.

I understand the study is voluntary and that I have the right to refuse and withdraw my consent without notice at any time and without giving any reason, this will not bring me any consequences or harm. I also understand that information's shall be dealt confidentially and are stored safely.

Helsinki ____.____.20___ Helsinki ____.____.20___

I agree to participate in the study: **Consent receiver:**

____

Participant's signature Researcher's signature

____

Name in print Name in print

____

Researchers study number

____

Address:

____

____

Contact information: XXXXXXXXXXX
XXXXXXXXX

Appendix 5. Information letter for professionals (Randomized clinical study)

DIALOGICAL FAMILY GUIDANCE (DFG)®
PRACTICAL ISSUES TO PROFESSIONALS REGARDING THE STUDY

- INCLUSION CRITERIA: NEW FAMILIES, who come to the neuropsychiatric unit for the first time:
  - The child is between 4-16 years old
  - The child has NDD or NDD symptoms
  - No exclusion criteria, although the child has visited HUH other units
  - Families to children with a contact to neuropsychiatric unit already are not included
- The nurses is giving information about the DIALOGICAL FAMILY GUIDANCE STUDY and offer the possibility to participate if the family fills the inclusion criteria. This means that the family can have DFG, including 6x90minutes family sessions.
- Give the information i**n writing** to families. (DFG and the study information documents)
- Explain to the family that the meetings are realized at the neuropsychiatric unit.
- If they give their consent to the study, explain what questionnaires are included in the study (FAFHES and DFG questionnaires –baseline and three-month follow-up)
- BEFORE they fill the questionnaires, parents need to read and give written consent to the study
- If parents give the written consent, give the information regarding when the DFG is initiated for their family. Look at the list and write the child`s name on the list.
- Tell the family that DFG is part of the hospital treatment and no extra costs are delivered
- Tell the family, there are two nurses being responsible for the DFG for the family, they work on this unit and received 3-day long DFG training.
- The schedule will be planned together with the family, but DFG sessions are going to be realized within three months period
- It is enough if one family member is attending to the sessions, but it is recommended for both parents and the children in the family as needed. Tell the family that we discuss with the parents and decide together who will attend. The most important thing is "what helps the family"
- The nurses who deliver DFG to families will contact the parents and schedule the first meeting.
- It would be beneficial if several/all sessions could be scheduled in forward.
- Remember to book the room for the meetings at the unit.
- Registration and documentation to the hospital system normally regarding all visits.
- You find the questionnaires for every family attending the study in XXXXXXX

Appendix 6. Information letter for parents (Pilot study)

INFORMATION LETTER

The Effect of Dialogical Family Guidance in Families with Children with Neurodevelopmental Disorders

Parents,

We kindly ask you to participate in research, which will explain the experiences of health, everyday functionality and the support families receive. Families are children having neurodevelopmental disorders. The aim is to provide information about the families` health, everyday functioning and the importance of the support received, as well as to create an evidence-based family intervention model for families whose children have neurodevelopmental symptoms. The research is carried out in HUS/Helsinki University Hospital/Children´s hospital, Gillberg Neuropsychiatry Centre (Gothenburg, Sweden) and Tampere university (Tampere, Finland). The Ethics Committee of HUS/Children's Hospital has evaluated the research plan and issued a favorable assent.

The course of the study

The data for the pilot study will be collected via a survey from the parents of children with neurodevelopmental disorders. The child`s neurodevelopmental symptoms can include several symptoms for example attention-deficit/hyperactivity disorder (e.g., ADHD, ADD), autism spectrum disorders (such as Asperger's Syndrome), speech and language development disorders, developmental delays and learning disabilities. The data collection phase is planned for the years 2012-2014.

We would appreciate it, if you could look favorably on this study; because thanks to your participation we will have the opportunity to get information from parent perspective, which will eventually help the development of the family interventions for the families whose children have neurocognitive symptoms, and for the professionals.

If you would like to participate, we kindly ask you to fill in and sign the attached consent form. The completed consent form is to be sent to the researcher. The return envelope is already prepaid. Upon receiving the consent letter, the researcher will send you by mail a questionnaire to fill.

The study questionnaire will have few questions concerning your background information (such as age, sex, diagnosis, treatment). In addition, the questionnaire has questions about your family's health, functionality and about the support you have received. This study is a follow-up study, where questionnaire will be filled in twice. The second round of questionnaires will be delivered after three months from the first round.

Confidentiality, data processing and preservation

The collected data and research results will be treated confidentially as required by law. The results are reported at the level of a group; hence the identification of individuals is not possible. The investigation files and returned questionnaires are kept in a locked space, which only the researcher has access to. Questionnaires are destroyed after the material is analyzed and the research report written.

Voluntary

Participation in the research is completely voluntary. To refuse in this study does not in any way affect your child's treatment or the support you will be given.

Additional Information

The study is a Health Science's doctoral student Diana Cavonius` dissertation research, which is governed by the Tampere University PhD Anna Liisa Aho and Gothenburg University professor Christopher Gillberg and PhD Eva Billstedt. The person in charge of this research from HUS / Children's hospital is child neurologist Arja Voutilainen. If you have any questions related to the survey or questionnaire, you can be directly in contact with the researcher by telephone or email.

We express our warmest gratitude for your efforts and cooperation in the promotion of this research.

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Appendix 7. DFG information letter for parents (Randomized clinical study)

DIALOGICAL FAMILY GUIDANCE (DFG)®

Dialogical Family Guidance (DFG)® is aimed for families with a child with special needs, for example learning disabilities, obsessional defiant disorder, ADHD, autism spectrum disorder. There can also be something else, that bring worries to parents. All these issues can be discussed and handled during the DFG sessions.

Description of DFG:

Dialogical Family Guidance (DFG)® is a family intervention including individual guidance regarding issues and questions family members have. DFG includes six meetings (à 90minutes) and the meetings are delivered at HUH, neuropsychiatric unit. Who are taking part on these meetings? This question is discussed during the first meeting and together with the parents a plan for this is made. All family members can be included to these sessions. Family members can discuss issues regarding the family, the child with NDDs or other special needs, and how these symptoms effect the family functioning. The goal is, that the family gets tools to handle situations at home and increased understanding regarding NDDs and for each other.

DFG includes following principles:

- ☐ Every family member and her/his personal experience and story is important
- ☐ New solutions can be found together with the help of dialogue and when sharing perspectives
- ☐ New solutions and management tools can be found when professionals and parents collaborate
- ☐ Families` own motivation and willingness to collaborate is crucial criteria for DFG intervention

Practical issues:

- ☐ 6x 90 minutes
- ☐ place: HUH/ child psychiatry, neuropsychiatric unit. Adress: XXXXXXX
- ☐ no extra costs for families having their child as a patient at this hospital
- ☐ professionals delivering DFG to families have got a three day DFG training executed by the researcher
- ☐ how to get started: professionals delivering DFG intervention together with you and your family will contact you to schedule the first session.

More information:
Diana Cavonius
XXXXXX
XXXX
t.XXXXX
XXXXX@XXXX

Appendix 8. DFG questionnaire for parents (Randomized clinical study)

Code:

QUESTIONNAIRE FOR PARENTS REGARDING DIALOGICAL FAMILY GUIDANCE (DFG)

You have been informed by health care professionals regarding the study *The effect of Dialogical Family Guidance in families with a Child with Neurodevelopmental Disorders*. We politely ask for your experiences of this family intervention you have received at HUH. Following questions are intended to examine functionality of this intervention. Please, circle the alternative that suits you and write your answers to the lines on this formular.

1. How did you get information about having the opportunity to receive DFG?
    1 Doctor
    2 Nurse

2. Did this intervention become at the right time for you?
    1 Yes
    2 No

3. When do you think this intervention should be realized for families?
    1 Immediately, when the child visits neuropsychiatric unit for the first time
    2 1 month after the first visit to neuropsychiatric unit for the first time
    3 2 months after the first visit to neuropsychiatric unit for the first time
    4 3 months after the first visit to neuropsychiatric unit for the first time
    5 4 months after the first visit to neuropsychiatric unit for the first time or later
    6
4. How many DFG sessions did you attend to?
    1 One
    2 Two
    3 Three
    4 Four
    5 Five
    6 Six – The ordinary in DFG
    7
5. Are six sessions the right amount?
    1 Yes
    2 No
    3
6. How many sessions is adequate?
    1. One
    2. Two
    3. Three
    4. Four
    5. Five
    6. Six

7. Were DFG sessions realized outside the hospital?
    1 Yes
    2 No

8. Do you think sessions outside the hospital is needed and should be included to DFG?
    1 Yes
    3 No

9. How much time do you think one DFG session should take?
    1 45 minutes/session
    2 60 minutes/session
    3 90 minutes – ordinary in DFG

10. What occupations/professions did the persons have delivering the DFG intervention with your family?
    1 Nurse
    2 Family therapist
    3 Socialworker
    4 Psychologist
    5 Something else_________________________

11. Did all family members get attention during DFG?
    1 Yes
    2 No If the answer was NO. Why not?
    ____
    3

12. Would you recommend DFG to other families, who have a child with NDD?
    1 Yes, absolutely
    2 Yes
    3 Maybe
    4 No If your answer is NO. Why not?
    ____
    5

13. How much did DFG help you to manage with your child with NDD in your daily life?
    1 Much
    2 Little
    3 Very little
    4 Not at all

14. Did you get practical guidance to your daily life?
    1. Yes, absolutely
    2. Yes
    3. Maybe
    4. Not much
    5. Not at all

Could you tell about your experiences, improvement ideas and/or comments regarding DFG?

PUBLICATIONS

PUBLICATION

I

Health, functionality, and social support in families with a child with a neurodevelopmental disorder – a pilot study

Cavonius-Rintahaka, D., Aho, AL., Voutilainen, A., Billstedt, E., Gillberg, C.

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Open Access Full Text Article ORIGINAL RESEARCH

Health, functionality, and social support in families with a child with a neurodevelopmental disorder – a pilot study

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Introduction: Several studies have reported that having a child with a neurodevelopmental disorder (NDD) increases parental stress and that parental psychosocial functioning influences child`s development and behavior. It is unclear how parents of children with NDD experience family functionality, family health and receive support and if there are differences between experiences of mothers and fathers.

Methods: Families with children referred to a neurocognitive unit were invited to the study. A modified version of the FAmily Functionality, HEalth, and Social support (FAFHES) questionnaire was used. Open-ended questions were also included.

Results: Parents rated their social support lower than their family functionality and family health. Family functionality correlated positively with family health. No significant differences were found between mothers' and fathers' experiences. A three-months test-retest using the FAFHES showed no significant change in ratings of family functionality, family health, and social support.

Conclusions: Family functionality was connected to family health in families with a child with NDD. Mothers and fathers experienced their family health, family functionality, and received social support in similar ways.

Keywords: parents, family health, family functionality, social support, neurodevelopmental disorders

Introduction

Neurodevelopmental disorder (NDD) is a term used to describe neurological and psychiatric disorders with onset in early childhood. NDD includes learning and language disorders, motor coordination disorders, intellectual disabilities, autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), tic disorders, and oppositional defiant disorder (ODD). Comorbidities are common and include sleeping disorders, feeding problems, and various sensory processing problems. A change of symptom/developmental profile may occur during the childhood period[1] which is emphasized in the concept of ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) coined by Gillberg.[1,2] All NDDs are included under the ESSENCE umbrella. At least one in ten of all children has a diagnosable NDD.

ADHD manifests in the parents or siblings of children with an ADHD diagnosis 2–8 times more frequently than in the population in general.[3] On average, the heritability of ADHD has been reported to be around 70%.[4,5] Genetics have an

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important role in the etiology of ASD[6] and heritability of ASD is estimated to be approximately 80%.[7] Consequently, having a child with NDD often means that other members of the family need support since the parent and/or one or several of the siblings in the family are likely to also have NDD or symptoms of NDD.[8]

Raising a child with NDD presents special challenges. Compared to parents with "typically" developing children, stress levels and parental tiredness are higher/more frequent. This affects family functioning.[8,9] Parental stress appears to be even more pronounced when the child has an NDD with high level of comorbidity,[10,11] and also when parents are older.[11,12] Increased rates of depression[13,14] and of depressive personality disorder have also been reported in parents of children with NDD compared to parents of "neurotypical" children.[15,16] On the other hand, parental psychosocial health and family dysfunction influence the child's development regardless of whether the child has NDD or not.[17,18]

Families with children with NDD benefit from parental education programs. These should focus on enhancing parent communicative skills, provide psycho-education and behavioral management strategies.[19] Interventions should also aim to help parents resolve possible emotional conflicts associated with their child's diagnosis[20] and promote their own psychosocial well-being.[18]

According to some studies, there are differences between mothers' and fathers' ways to cope with their child's diagnosis and with stressful life events for example.[12]

In summary, parental stress, family dynamics, and family functionality are key issues to be considered when designing interventions for families with children with NDD.[21,22] However, there is need for more knowledge regarding how families with a child with NDD are managing their daily lives.

In this study of families with children with NDD, we focused on the parents' subjective perspective on their own family health, family functionality, and on received support and what expectations they have regarding support. We also wanted to explore whether mothers and fathers had different or similar perspectives, and whether parental age had an impact. We used the FAmily Functionality, HEalth, and Social support (FAFHES) questionnaire that has been modified for use – for the first time – in this target group. Previously, FAFHES has been used only in families with cardiac patients and pediatric intensive care patients.[23,24] The FAFHES is a check-list style questionnaire providing quantitative data. We also included some open-ended – free-writing – questions for qualitative analysis.

The first aim of the study was to report the experiences of parents of children with NDD in terms of family functionality, family health, and received support and their association with background data using the modified FAFHES questionnaire. We are particularly interested in how family health and function correlate with perceived social support. The second aim was to study over a three-month period whether there were any changes in parents' experience of family functionality, health, and social support. The third aim was to study parents' opinions about their expectations regarding support from health professionals.

Methods

Procedure

The data were collected at the neurocognitive outpatient clinic of the Child Neurology department at Helsinki University Hospital (HUH), which provide multidisciplinary assessments performed by child neurologists, neuropsychologists, nurses, occupational therapists, speech therapists, and social workers. After assessment at HUH, a habilitation is carried out within HUH or at a clinic within the primary health care system.

Parents of children referred to the neurocognitive clinic at HUH for the first time were invited to take part in the study when they met the following inclusion criteria: biological parent or legal guardian living with a child (age 4–16 years) with suspected NDD, and having good language skills in Finnish, Swedish, or English and visiting HUH for the first time. Trained nurses at the clinic gave oral and written information about the study to the parents at the first visit and invited them to participate in the study.

Participation in the study included completing the FAFHES questionnaire (with some open-ended questions) that was mailed to both parents after written informed consent had been obtained. The envelope also included a prepaid envelope for returning the questionnaires by mail. Those who approved and completed the FAFHES questionnaire at the inclusion of the study received an additional FAFHES questionnaire for completion three months later. Reminder was sent to parents who did not return the second FAFHES questionnaire after 3 months.

Participants

The number of families who received detailed information about the study and who agreed to participate was 67. However, only 29 (43%) of these families actually sent back completed FAFHES questionnaire in the first round of data collection (Time 0 months). In total, 46 completed

FAFHES questionnaires were returned (by 29 mothers and 17 fathers). The group which did not return the questionnaire was very similar in terms of children`s diagnosis, gender, and age with the participating group. (Table 2)

For the three-months follow-up study (Time 3 months), 18 families (62% of those who participated at Time 0 months, 18 mothers and 9 fathers) completed the FAFHES.

Families taking part of this study had children at the neurocognitive outpatient clinic of the Child Neurology department at HUH with following NDD diagnoses: delayed milestone, speech and language disorder, specific learning disorder, developmental coordination disorder, mixed specific developmental disorder, autistic disorder, attention deficit/hyperactivity disorder, selective mutism, Tourettes syndrome, and phobic anxiety disorder (Table 2).

Instrument used

The FAFHES questionnaire[25] was developed for patients with cardiac disease and their family members with a view of studying their experiences regarding family functionality, health, and the social support received from staff at a hospital unit. The FAFHES has been tested since 2002,[26] and used in several clinical contexts.[23,27–29]

The FAFHES instrument was modified for this study so as to be applicable in families of children with NDD. The permission to use and modify the instrument was obtained from the copyright holders.

In the modified FAFHES, certain questions have been changed (for example, the item nr.53 "Concern for the ill family member's condition causes distress in other family members" was changed to "The child's symptoms give rise to stress in other family members"). In this study, the FAFHES was used as a parent questionnaire.

The first section in the modified FAFHES instrument is related to demographic (age, marital status, and educational level) and background data (quality of family relationship, and mental health problems in the family, and how this affects the family). In this modified version, additional demographical items were added such as the frequency of NDD in the family. Background variables that were included in the analysis of association to family functionality, family health, and social support were age of the parent, number of siblings of the index child, quality of the relation between parents (Likert scale 1–5, 1=excellent, 5=very poor), experience of own current health (Likert scale 1–5, 1=excellent, 5=extremely bad), age of onset of neurocognitive disorder problems in the index child, and experience of strength in being a parent (Likert scale 1–5, 1=extremely well, 5=extremely poorly).

The FAFHES then continues with three additional sections: 1) Family functionality (19 items), 2) family health (23 items), and 3) social support provided by professionals (21 items). The items are measured on Likert-type scale ranging from 1 (I disagree totally) to 6 (I agree totally). The internal consistency of the scale on the basis of Cronbach`s alpha values was. 78-0.98. The modified FAFHES questionnaire also included three open-ended questions: 1) What kind of hopes and expectations do you have for the staff when they meet you and those close to you? 2) How would you like to develop the family interventions provided by the staff? 3) Is there anything else that you would like to add?

Data analysis

Statistical analysis was conducted with SPSS version 23. Descriptive statistics were used to describe the large number of quantitative data from FAFHES questionnaires. Family functionality, family health, and social support domain variables are reported from the parents' combined perspectives, but also mothers' and fathers' separate perspectives. The relationship between FAFHES domains was investigated using Pearson correlation coefficient, and Spearman correlation was used in studying background variables and FAFHES domains. Differences between family health, family functionality, and social support domains were analyzed using Paired Samples *t*-test, which could be used since the data were normally distributed. The Mann–Whitney test was used for dichotomous variables, and the Kruskall–Wallis test for categorical variables. The alpha level for statistical significance was set a priori at 0.05.

The three additional semi-structured open-ended questions were analyzed following a research procedure using inductive content analysis.[30] Predefined variables were not identified in advance. Parents' written responses were read and text that was relevant to the research question was highlighted. At the next stage, similar sentences were identified and classified to a "subcategory" (grouping and combining similar or related answers) and named close to the actual content received. Different themes were identified and subcategories were created. In the last stage, "main categories" were created from the subcategories focusing on similarities and differences close to the content received. The results are presented as four main categories (Table 4). Steps included in the qualitative analysis procedure were:

1. Reading the responses.
2. Writing all respondents' answers under the three open-ended questions.
3. Creating condensed meaning units (description close to the text=reduction).
4. Grouping and combining similar or related answers.
5. Identifying themes and creating subcategories.
6. Creating main categories.

Ethical approval

The Medical Ethical Committee of Helsinki University Central Hospital approved the study (106/13/03/03/2012). All procedures performed in the study were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants included in the study.

Results

Demographic and background data of parents and children

Mean parental age was 40.5 years (SD=5.3), very similar for mothers and fathers. The majority (87%) of the 29 families were married or cohabiting (Table 1), and 41% of the parents described the relation with the other parent as excellent. The majority of the parents (85%) reported their own health being very good or good. Ten families (22%) reported having one or more than one family member with a NDD. The majority of the parents (76%) rated "extremely/quite well" on the item "How are you managing as a parent in daily life?" (Table 1).

In all, 30% had visited another clinic or hospital regarding their child's NDD symptoms before coming to the neurocognitive clinic at HUH, but for 70% of the families the visit to HUH was their first contact with a clinic for their child's NDD. At the time of the study, the number of visits to the HUH ranged from 1 to 3 in the study group.

During the daytime, the children were either at school (n=16, 55% of the whole group), at daycare (n=10, 35%), or at home (n=3, 10%). The diagnoses of the children at the HUH varied (Table 2). The majority of the parents (63%) reported that the NDD symptoms often affected their children`s daily life.

Table 1 Demographic data of the study group.

	n	%
Relationship		
Mothers/fathers	29/ 17	63/ 37
Age of parents (mean age 40.5, SD 5.3)		
<40-years old	19	41
≥40 -years old	26	56
Marital status		
Married/cohabiting	40	87
Do not live together (including 1 widowed)	6	13
Quality of the relationship between parents		
Excellent	19	41
Good	17	37
Moderate	7	15
Poor/very poor	2	4
Basic education of parents		
Comprehensive school	14	30
Matriculation examination	30	65
Professional education		
No vocational qualification	4	9
Basic-level qualification	4	9
College-level education	14	30
University degree/academic degree	23	50
Numbers of children in family totally		
1 child	2	4
2 children	20	43
3 children	11	24
>4 children	11	24
Other members of the family have neurocognitive disorders or diagnoses?		
Yes	10	22
No	34	74
Parents self-reported health		
Very good/good	39	85
Moderate	6	13
Poor/very poor	1	2
How are you managing as a parent in daily life?		
Extremely/quite well	35	76
Moderate	10	22
Rather/extremely poorly	1	2
Long-term illnesses or neuropsychiatric disorders		
Yes	10	22
No	35	76

Note: Number of the participants (N=46).

Parents' experience of family functionality, health, and social support

The mean score for family functionality was 4.6 (SD=0.8), for family health 4.4 (SD=0.7), and for social support 3.7 (SD=1.3). No statistically significant differences were found between mothers and fathers in FAFHES (Table 3). There was a strong positive correlation between family functionality and family health (r=0.75, n=46, p<0.001), a medium correlation between family health and social support (r=0.36, n=43, p=0.019) whereas the correlation between social support and family functionality was non-significant (r=0.19, n=43, p=0.224) (Table 3).

Associations between background data and FAFHES domains

No correlation was found between parental age and FAFHES or amount of siblings and FAFHES. Negative correlations were found between family functionality and quality of relations between parent (rs=−0.643, n=45, p<0.001), experience of own health (rs=−0.552, n=46, p<0.001), and age of onset neurocognitive disorder problems (rs=−0.374, n=43, p=0.014). Negative correlations were also found between family health and quality of relations between parent (rs=−0.331, n=45, p=0.026), and experience of own health (rs=−0.420, n=46, p<0.001). Finally, experience of strength in parenthood correlated to family health (rs=−0.724, n=46, p<0.004) and family functionality (rs=−0.636, n=46, p<0.001).

FAFHES follow-up over a three-month period

The FAFHES shows no statistically significant changes in parents' experience of family functionality, health, and social support between the two measures performed over three-month period (Table 3).

Open-ended questions

Results of the open-ended questions part of the study were presented as four main categories that illustrate parents' hopes and expectations towards health care professionals (Table 4).

The first main category "Parents want dialogue" included the following subcategories "Interaction with staff", "Communication between professionals at school, daycare and hospital", "Hope to be listened to", and "Hope to get more time from personnel". Parents wrote for example "I hope to have more time for discussion with staff".

Table 2 Characteristics of the children taking part in the study (n=29) and of the children not taking part in the study (n=36).

Participating group			**Non-participating group**	
	n	**%**	**n**	**%**
Age of child (range 4.6–16.1, SD 3.2, average age 8,5)				
<7 years old	11	38%	12	33%
≥7 years old	18	62%	24	67%
Gender of child				
Girl	5	17%	9	25%
Boy	24	83%	27	75%
Daytime activity for child				
In daycare	10	35%		
At school	16	55%		
Other	3	10%		
Reasons for child referral				
Delayed milestone	2	7%	7	19%
Speech and language disorders	3	10%	5	14%
Specific learning disorder	8	29%	9	25%
Developmental coordination disorder	1	3%	1	3%
Mixed specific developmental disorders	6	21%	7	19%
Autistic disorder	4	14%	1	3%
Attention- deficit/hyperactivity disorder	2	7%	4	11%
Selective mutism	1	3%	0	0%
Tourette syndrome	1	3%	1	3%
Phobic anxiety disorder	1	3%	0	0%
No diagnosis	0	0%	1	3%
First concern according to parents about child neuropsychiatric problems				
1-3 years	20	43%		
>3–7 years	23	50%		
The child's neuropsychiatric problems affect his/her daily life (n=46 parents)				
No symptom/hardly any symptoms	13	28%		
Symptoms occasionally	10	22%		
Symptoms often	29	63%		
Symptoms disturbing all the time	2	4%		
Visit to the clinic/hospital of his/her neurocognitive disorder earlier				
Yes	*14*	30%		
No	32	70%		

(*Continued*)

Table 2 (Continued).

Participating group			Non-participating group	
	n	%	n	%
Number of visits to the clinic/hospital				
Once	5	36%		
Twice	4	29%		
≥3 times	5	36%		

“We want open communication in both directions during the child`s evaluation process at the hospital”.

“We hope that the staff has a genuine ability to listen to the parents”.

The second main category is ‟Parents want more knowledge and support in daily life“ including subdomains “Need to get knowledge about the child’s symptoms and care”, “Need to get knowledge about how to support the child’s development”, “Support for daily living”, and “Economical support and possibilities to peer support”. One parent wrote “I hope to get information about habilitation possibilities for the child”.

“We want somebody to come home and observe and giving us concrete guidance in daily life”.

“We hope somebody tells us about the child`s diagnose and tells us what we need to do as parents”.

The third main category was “Parents hope to get competent staff for their child and family” including sub domains “Professional staff” and “Organized/well planned care”. One parent wrote, “we hope the personnel highlight the strengths of the child and support the child’s self-esteem”.

“We want professionals, who know about NDD and tells us what is going to happen in beforehand about evaluation-, care-, and rehabilitation processes”.

The fourth main category was “Parents hope the whole family to be included by health professionals” including subcategories “All family members need attention”, “Concrete help”, and “To believe in tomorrow”. One example from a parent is “We need knowledge about how the family as whole finds the strength to carry on”.

“We want to know where to get help for the whole family”.

“The family situation is always including all family members and we hope to get help as a family”.

Discussion

The results from this study suggest that in families with children with NDD family health is connected to the experience of family functionality. Family health is affected positively if eg responsibilities concerning family chores are divided evenly in the family and everyone in the family participates. Furthermore, the experience of receiving social support from outside the family matters regarding the family health. This is in line with what Duffy[31] has proposed, that internal family dynamics and external environmental factors interrelate and affect the health promotion behaviors inside the family. Positive, although weak correlation, was also found in another study using FAFHES in pediatric intensive care between social support given by nurses and family health experienced by parents.[23] In addition, earlier studies using FAFHES in families of adult patients with cardiac disease report an association between family health and family functionality.[32] However, we found no correlation between social support and family functionallity which would have been expected considering the general knowledge and impression of the importance of support. Also, the parents' qualitative responses highlighted the need for social support in their parenthood. This suggests that other factors than social support, in addition to family health, might have an impact on functionality in families with children

Table 3 FAFHES questionnaire at baseline and three-months later.

Subdomains	Total n=42–46	Mothers n=29	Fathers n=17	*p*-value	3 months n=27	*p*-value	Mothers* n=17	*p*-value
	Mean (SD)	Mean (SD)	Mean (SD)		Mean (SD)		Mean (SD)	
F Function	4.6 (0.8)	4.5 (0.9)	4.6 (0.6)	0.793	4.3 (0.6)	0.119	4.6 (0.9)	0.760
F Health	4.4 (0.7)	4.4 (0.7)	4.6 (0.6)	0.586	4.2 (0.6)	0.056	4.3 (0.7)	0.198
S Support	3.7 (1.3)	3.8 (1.3)	3.5 (1.3)	0.576	3.5 (1.3)	0.158	3.7 (1.1)	0.591

Note: *Paired sample *t*-test between mothers (n=17) and fathers (n=17) of the same child.

Table 4 Results of the open-ended questions presented as four main categories that illustrate parents' hopes and expectations towards health care professionals.

Reduction	Sub category	Main category
Interaction about/during the child's clinical visit and therapies Meetings Regular appointments	Interaction with staff	Parents want dialog
Open communication Open attitude How to reach right professionals	Communication between professionals in school, daycare, and hospital	
Taking parent concerns seriously Staff to have ability to listen Staff to support parents` opinions if problems in school	Hope to be listened to	
More time for discussion Staff to have time for parents	Hope to get more time from personnel	
Knowledge about neurocognitive symptoms Knowledge about the diagnosis Knowledge about the child's symptoms Knowledge about child's medication Knowledge about examinations	Need to get knowledge about the child's symptoms and care	Parents want more knowledge and support in daily life
Knowledge about the educational possibilities Knowledge about hobbies Knowledge about habilitation Knowledge about how to help the child with learning difficulties Knowledge about how to tell the child about learning difficulties Info about how to support the child with language problems Knowledge about parenting issues Parenting advice to parents	Need to get knowledge about how to support the child's development	
Knowledge about how to help child manage independently Tips how to manage daily living at home and daycare	Support for daily living	
Concrete help for daily living Concrete help for daily demanding situations Advice how to habilitate the child at home Help to make routines for the whole family		
Knowledge about social benefits Guidance to find peer groups Examples about other similar families	Economical support and possibilities to peer support	
Educated staff Competent staff	Professional staff	

(*Continued*)

Table 4 (Continued).

Reduction	Sub category	Main category
Guidance in English		
Guidance in Swedish		
Staff to keep promises		Parents hope to get competent staff for their child and family
Highlight the child´s strengths	Organized/well planned care	
Support self esteem		
Systematically organized care		
Clear time schedules		
Hope about noticing the whole family	All family members need attention	
Hope that somebody would arrange free time for the parents as couple		
Knowledge about how the family as whole can find the strength to carry on		Parents hope the whole family to be included by health professionals
Help from family workers	Concrete help	
Support for couple relationship		
Childcare help		
To get some help as parent to find the strength to carry on		
To get some help in believing in future	To believe in tomorrow	
To get support as a parent		

with NDD. For example, we have not studied if the parents themselves had NDD deficits which might have an impact on parenthood and which is likely considering the heritability of NDD disorders.

Parents of the children with NDD who visited the neurocognitive units at HUH for the first time reported family functionality to be generally quite good. The fact that the relationship between parents was assessed as quite good might suggest that the parents support each other in their parenthood. Parents' own opinions about having strength during parenthood seems to be connected to their opinion of having good health and good relationship with the other parent. Similar results were reported from pediatric intensive care as the main outcome where parents using FAFHES considered their family functioning and health to be good.[23]

No statistically significant difference was found in this study between fathers and mothers, although studies made before have shown the differences between parents eg, quality of life and stress experiences and also unique support needs.[33,34] Reilly and colleagues[35] have in their study reported eg, how epilepsy of young children can have a very significant impact on parental well-being and how mothers particular are being at risk. The same report suggests screening for mental health problems on a regular basis in parents to children with epilepsy.[35] Another study shows fathers rating their children as having less problems than mothers.[36] There are also findings that suggest that depressive symptoms found in mothers of children with ASD may be attributed both to the increased stress of raising a child with ASD as well as autistic features in the mothers.[37] These kinds of findings did not appear in our study.

It is known that parents' perceptions of family functionality are often affected by the symptoms of other family members.[38] This study emphasizes the parental perspective and how NDD often affects the whole family. Family functionality and the emotional climate in the family are significant factors regarding family health. Maybe this is the reason why parents in this study expressed their hopes for the whole family to be noticed and taking into consideration as a unit. Moreover, according to these parents, siblings situation in the families need more attention.

Parents expressed the need for additional communication and considered the dialogue with professionals concerning their child as very important. By maintaining a dialogue with the parents, the family perspective can be included and a deeper understanding of the child is provided.

The open-ended questions tapped into the parents' hopes and expectations. Although parents felt they managed well as parents, they all had similar hopes about more collaboration between professionals. This has also been confirmed in other studies.[39–41] Parents hope for practical guidance in their daily life, for advice and concrete aid in how to deal with daily demands in raising their child. Parents also hoped for more individualized family focused healthcare such as individualized information regarding the child. Parents further expressed the need for tailored support to all family members, and for peer support from other families with children with similar symptoms. This was mentioned as an important "parenthood strengthening factor".

A systematic review by Goode and colleagues[42] revealed that despite the wide use of several parent programmes and intervention approaches, there are still significant gaps in knowledge regarding the effectiveness of ADHD nonpharmacological treatments. The information delivered by parents in this study can fill an important gap of knowledge when developing interventions for this target group.

The study showed that FAFHES questionnaire results obtained three months after the initial round yielded similar results as at the first time. This suggests that family functionality and health did not improve during the three-month-period, even though families received an assessment of the child and a habilitation plan. Possible explanations for this are that three months of follow-up is not long enough for more positive changes in functionality and health factors in the families, or that diagnosis/intervention for the child does not affect family functionality or health.

Limitations

A major limitation of the study is the very considerable attrition, and only 43% of the families who agreed to participate actually completed the FAFHES questionnaire. However, there was no obvious difference between questionnaire completers and non-completers. Nevertheless, it is known from other studies that, overall, families with certain types of NDDs (for instance ADHD) are less likely to adhere to agreed protocols or appointments. The generalisability of the findings to all families with children with NDDs is therefore in doubt, and it is possible that more problems related to family functionality and health might have been present in non-responding families.

The strength of the study is the information that responding parents shared concerning their everyday life with a child having NDD and their expectations vis-a-vis health professionals. This information confirms that there is a need to tailor family interventions for this target group.

Conclusion

Family functionality was found to positively correlate with family health. Also, experience of strength in parenthood correlated to family health. Neither parental age nor number of siblings correlated with any of FAFHES subdomains. The quality of the relationship between the parents, experience of own health, and age of onset of child NDD problems correlated negatively with family functionality. Surprisingly, no correlation between social support and functionality was found. Negative correlations were also found between Family health and quality of relations between parents. No differences between mothers and fathers were found. There were no significant changes in parents' experience of family functionality, health, and social support over a three-month follow-up period. Parents wanted dialogue, information, and concrete guidance from staff in daily matters regarding their child.

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Disclosure

The authors report no conflicts of interest in this work.

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II

Dialogical Family Guidance (DFG) – Development and implementation of an intervention for families with a child with neurodevelopmental disorders

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DISCURSIVE ARTICLE

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Dialogical Family Guidance (dfg)—Development and implementation of an intervention for families with a child with neurodevelopmental disorders

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[Correction added on 5 October 2020 after first online publication: The authors' forenames and surnames have been listed correctly in this version.]

Abstract

Aim: To describe the development and implementation of a Dialogical Family Guidance (DFG) intervention, aimed at families with a child with neurodevelopmental disorders (NDD).

Design: The DFG components are presented and the content of a DFG training course. Professionals' experiences after the DFG training were evaluated.

Methods: Dialogical Family Guidance development phases and implementation process are examined. The Revised Standards for Quality Improvement Reporting Excellence checklist (SQUIRE 2.0) was used to provide a framework for reporting new knowledge.

Results: The DFG training course seemed to increase possibilities of a more independent role as a nurse to deliver the DFG family intervention. The project showed that the use of dialogue can be difficult for some professionals. Analysis of the questionnaire completed after DFG training reported a high level of satisfaction. DFG training offered a new approach to deliver knowledge and understanding to families using dialogue, including tailored psychoeducation and emotional and practical guidance.

KEYWORDS

dialogue, family, implementation, intervention, neurodevelopmental disorders, parents

1 | INTRODUCTION

Articles presenting guidelines for implementation processes and detailed frameworks offer important sources to promote knowledge between professionals (Breimaier, Heckemann, Halfens, & Lohrmann, 2015; Hickey et al., 2016; Kwak, Wahlin, Stigmar, & Jensen, 2017). Systematic development and implementation of interventions is essential for their interpretation, and they need to be carefully planned and designed. The implementation of evidence-based interventions is crucial to professional nursing, but more research is still needed. The professional responsibility of nurses is aimed at providing high-quality nursing interventions and, in that way, positive health outcomes (van Achterberg, Schoonhoven, & Grol, 2008; Whittemore & Grey, 2002). However, it is important that the development and implementation of these interventions are evaluated. Thus, implementation research studies systematically document how an intervention has been carried out in clinical practice (Goldenhar, LaMontagne, Katz, Heaney, &

Discursive paper presenting professional development, implementation and integrated professional practice

Landsbergis, 2001). This article describes the development and implementation process of a family intervention called Dialogical Family Guidance (DFG) aimed at families with a child with NDD (neurodevelopmental disorders). The DFG-educational elements are also presented.

Neurodevelopmental disorders is a general appellation to describe neurological and psychiatric disorders with an early onset in childhood. Neurodevelopmental disorders includes learning and language disorders, motor coordination disorders, intellectual disabilities, autism spectrum disorders (ASD), attention-deficit/hyperactivity disorder (ADHD), tic disorders and oppositional defiant disorder (ODD). Common comorbidities are sleeping disorders, feeding problems and various sensory processing problems. A change in symptom/developmental profile may occur during the childhood period which is further emphasized in the concept of ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) created by professor Gillberg from University of Gothenburg. The ESSENCE concept covers NDD, and problems/symptoms not meeting the criteria for a certain NDD diagnosis (Gillberg, 2010; Thapar, Cooper, & Rutter, 2017). A family intervention model designed with a focus on the individual family's needs and questions has been advocated for this particular group (Cavonius-Rintahaka, Aho, Voutilainen, Billstedt, & Gillberg, 2019).

1.1 | Background

Parenting stress, family dynamics and family function surrounding the child´s disorder should be considered when developing interventions for families with a child with NDD (Ho, Chien, & Wang, 2011; Wiener, Biondic, Grimbos, & Herbert, 2016). Subsequently, there is also a need to translate the heightened stress, illness and psychiatric problems occurring in parents of children with NDD into effective interventions (Dykens, 2015). Dykens (2015) points out that both parents and the siblings in the family need accurate and targeted guidance and information. It is known, for example, that ADHD is associated with problematic family functioning, including greater stress in the family, higher rates of parental psychopathology and conflicted parent–child relationships, and this appears to exacerbate in children with comorbid oppositional and conduct disorders (Deault, 2010). Also, autism symptom severity is significantly correlated with maternal stress (Duarte, Bordin, Yazigi, & Mooney, 2005).

When providing support to parents with children with NDD, the focus needs to be on the entire family and not only on the child with the diagnosis. However, it is also noticed that there are differences between mother's and father's ways of coping with their child's diagnosis and stressful life events. Parents have different personalities and parenthood behaviours. Studies highlight the need to translate parents' heightened stress and siblings' needs, to give accurate and targeted guidance and offer effective interventions to strengthen the well-being of the whole family (Duarte et al., 2005; Falk, Norris, & Quinn, 2014).

Open dialogue was originally developed as a method for healthcare teams to help adult psychosis patients in Finland but has since been implemented in different countries and modified to fit different healthcare organizational needs. Consequently, open dialogue no longer seems to be a therapeutic method but rather the ability to see the polyphonic nature of the client's reality. The base from which to offer professional help is realized by listening carefully to what the client and family members have to say (Anderson, 2002; Buus et al., 2017; Rober, 2010; Seikkula, Arnkil, & Eriksson, 2003). By using the dialogue approach and supporting dialogue in conversation, nurses and other professionals can help families with a child with NDD get through distressing life events and demands. Especially, giving grass-root attention to the voices of individuals and families, speaking from experience is important over the treatment (Post, Pomeroy, Keirns, Cover, & Dorn, 2017). As a further consideration, NDD symptoms and diagnoses are strongly heritable, and subsequently, more than one family member can have special needs or special difficulties that fall under the NDD symptom umbrella (Lichtenstein, Carlstrom, Rastam, Gillberg, & Anckarsater, 2010; Thapar & Cooper, 2016).

There is no doubt that providing education increases knowledge and positive attitudes and behaviours towards individuals with NDD. To accomplish dialogue, professionals themselves need to adopt a positive and cooperative attitude. This attitude includes aspects such as understanding, empathy, flexibility, a high motivation to cooperate with families and a willingness to help them (Anderson, 2002; Buus et al., 2017; Seikkula et al., 2003). It is known, for example, that primary caregivers of adolescents with ADHD experience better quality of life, family functioning and parental coping after Therapeutic Conversation Intervention, and therefore, this intervention has been recommended for nurses in hospitals and at healthcare centres, where ADHD services are provided (Gisladottir & Svavarsdottir, 2017). Negative attitudes and a lack of time can be a threat to parents' confidence. Thus, the attitude of the parents and their willingness to cooperate is also an important factor when trying to achieve optimal results.

Cavonius-Rintahaka et al. (2019) conducted a pilot study about families' health, functionality, hopes and expectations and confirmed that families with a child with NDD seemed not to get the help they expected from professionals. Notably, parents, both hoped and expected professionals to listen, have dialogue and give attention to the entire family. Therefore, the Dialogical Family Guidance intervention is an important step forward in trying to meet parental and family needs.

2 | METHODS

The aim of this paper is to describe the development and the implementation process of the Dialogical Family Guidance (DFG) family intervention. Important components of the intervention and the implementation process into the clinical setting are presented, including the DFG-educational process developed

TABLE 1 Summary of seven interventions aimed towards families with a child with NDD

Author	Intervention	Content
Potvin et al., 2018. USA	Coaching in context (CinC)	Family-driven support for children with autism and their families combining coaching and context therapy. Professionals coach the whole family, and the intervention is said to be family-driven. However, it is actually a parent-mediated structured process. Parents deliver the intervention in practice to their child. This involves families in goal setting, designing, implementing and evaluating during the process. The coach gets support from an inter-professional team, and this is called the "key" in this process. This is a descriptive paper, and CinC has not been tested.
Dunn, Cox, Foster, Mische-Lawson & Tanquary,2012. USA	Occupational therapy contextual intervention	This ten-session Occupational Therapy Contextual Intervention is aimed to improve participation in everyday life for children with autism spectrum disorders and develop parent competence. Combines context therapy with coaching elements and is provided by occupational therapists. Effectiveness was evaluated using pre-test–post-test design. Results indicated that parents felt more competent and children increased participation in everyday life. This intervention is mainly about coaching parents in daily life to achieve their own goals concerning their family.
Oruche, Robb, Aalsma, Pescosolido, Brown-Podgorski & Draucker, 2017. USA	Multiple caregiver group	For caregivers of adolescents with disruptive behaviours. Six-week caregiver group intervention for primary caregivers of adolescents diagnosed with oppositional defiant disorder or conduct disorder. Aim of this intervention is to increase primary caregivers' self-efficacy in managing interactions within and outside the family. This is a descriptive paper.
Mazzucchelli et al., 2018. Australia	Building bridges triple P (BBTP)	Eight-week long group format parenting programme for parents of adolescents with autism spectrum disorders. The aim is to study the feasibility of the BBPT initiative targeted at the needs of parents of adolescents with a developmental disability. Study results are, for example parents' decreased symptoms of depression and stress, and increased parenting confidence. Results provide preliminary support and acceptability for BBTP.
Gisladottir & Svavarsdottir, 2017. Iceland	Therapeutic conversation intervention (TCI)	Combination of group and individual sessions focusing on reinforcing, improving and sustaining an active family life for families with adolescents with ADHD, targeting caregivers/parents. The aim is to evaluate the effectiveness of the Therapeutic Conversation Intervention on caregivers of adolescents with ADHD. The result was, for example a significant improvement of quality of life.
Moen, Hedelin & Hall-Lord, 2014. Norway, Sweden	Use of dialogue	Empirical study about the role of public health nurses (PHN) and families with a child with ADHD. The aim of the study was to explore the PHN role in relation to families with a child with ADHD. The paper points out the importance of building a good relationship with parents using dialogue and, continuity. Supervising parents also requires dialogue, and the PHN's support for parents and the entire family is important.
Bauer & Webster-Stratton, 2006. USA	Importance of prevention by, for example parenting programmes	This paper reviews selected parenting programmes for children aged 2–8 years to inform the options available to families with children with behaviour problems. Parent training programmes are an effective option to promote positive parenting. It is essential to think not only of how to screen and treat, but also of how to prevent behavioural problems.

for professionals. A post-training evaluation was carried out for professionals who had taken part in DFG training to collect data about their satisfaction concerning the training they had received. A tailored questionnaire with 10 questions about DFG training (Likert scale 1–7) was completed after the training by 26 professionals. One open-ended question was included. The quantitative data were analysed by using the SPSS statistical programme, and the results of the open-ended question are presented as a summary. The Revised Standards for Quality Improvement Reporting Excellence checklist (SQUIRE 2.0) has been used to provide framework for reporting new knowledge about how to improve health care (Ogrinc et al., 2015) and has also been employed in this study (Appendix S1).

2.1 | Literature review

A review of the literature presents psychoeducation as a commonly used and valuable intervention for families with a child with NDD (Nussey, Pistrang, & Murphy, 2013). It has been defined as a systematic and didactic approach, adequate for informing patients, relatives, school staff, etc., about the condition and for implementing educational programmes related to a child's disorder. According to the literature, effective psychoeducation is carried out by a sensitive and sympathetic therapist, lasting approximately 60–90 min and including 4–6 sessions (Bauml, Frobose, Kraemer, Rentrop, & Pitschel-Walz, 2006). Studies of psychoeducation show that children and adults with NDD, and families and teachers, benefit from this

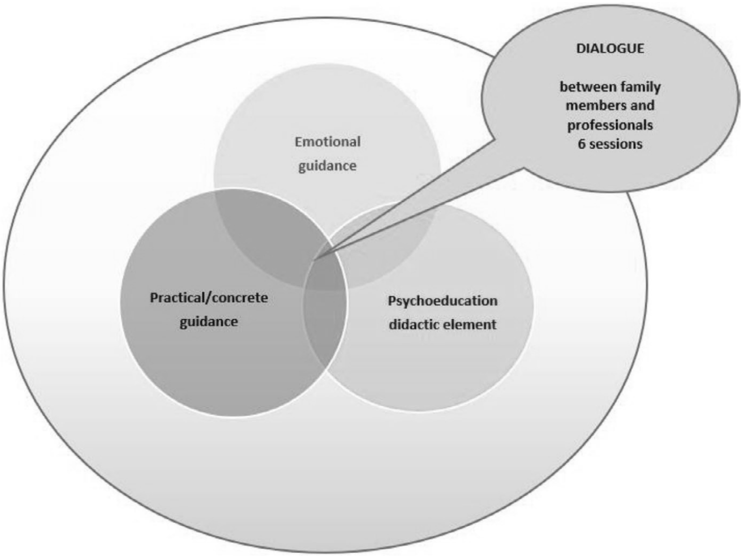

FIGURE 1 Content of the DFG areas

intervention regarding their psychosocial well-being (Antai-Otong & Zimmerman, 2016; Ferrin et al., 2014; Hirvikoski et al., 2017; Jackson, Liang, Frydenberg, Higgins, & Murphy, 2016; Nussey et al., 2013; Richardson et al., 2015; Sonuga-Barke, Daley, Thompson, Laver-Bradbury, & Weeks, 2001; Tonge, Brereton, Kiomall, Mackinnon, & Rinehart, 2014).

Although many psychosocial interventions have been tested as effective (Mazzucchelli, Jenkins, & Sofronoff, 2018; Potvin, Prelock, & Savard, 2018), the development processes and theories behind these interventions are not always described nor published. Also, the information about how the intervention has been implemented into clinical setting can be missing and the new intervention can be presented more as a project plan. Occasionally, there is too little said about the process of implementation design. The literature also offers us examples of psychoeducational interventions for families with a child with NDD (see Table 1 for examples). However, it seems that any dialogue or dialogical elements are often overlooked or missing because dialogue is only randomly mentioned. It should be noticed that although many interventions seem to offer a family intervention, they often only target the parents in the family and are thus parent-mediated. This means that it is much easier to find "parenting programmes" than "family interventions" where siblings are in focus alongside the parents. However, earlier studies highlight similar important elements that are included in DFG, for example collaboration, discussion, family-identified goals, family uniqueness and reflective listening. Given the inclusions and omissions seen in the literature, a family intervention that target all family members and which includes dialogue along with psychoeducation and gives the family tools to cope with their daily life is needed. To offer readers a perspective of the elements covered across previous literature, a summary of seven papers including examples of various intervention aspects is presented in Table 1.

The results and knowledge from earlier studies (Barlow, Bergman, Kornor, Wei, & Bennett, 2016; Barlow, Smailagic, Huband, Roloff, & Bennett, 2012; Barlow & Stewart-Brown, 2000; Bearss et al., 2015; Cavonius-Rintahaka et al., 2019; Dretzke et al., 2009; Farmer & Reupert, 2013; Fosco, Sarver, Kofler, & Aduen, 2018; Kane, Wood, & Barlow, 2007; Peasgood et al., 2016; Trillingsgaard, Trillingsgaard, & Webster-Stratton, 2014) have been taken into account during the development and implementation process of the DFG family intervention.

2.2 | Theoretical basis for the DFG

The review of the literature revealed that while psychosocial interventions have been developed, the uniqueness and individuality of the specific family and its family members have received insufficient attention. The structure of rigid psychoeducational programmes does not necessary give space or time for family members to express their individual needs or to ask questions. Crises or other adversities may occur in all families; yet having a child with NDD can have different impacts on different family members. However, all of family members have an effect on each other and the family dynamic and communication inside the family are therefore crucial considerations when addressing family health (Cavonius-Rintahaka et al., 2019).

Based on previous literature, studies and clinical experience, we believe that professionals need to find the right balance between psychoeducation and having a sensitivity to the voices of families and individuals speaking from experience. Dialogue with professionals and family members of a child with NDD only deepened our understanding of a family's vulnerability and their individual resources and needs. This knowledge has directly influenced the approach taken during the development of the DFG intervention.

The medical and nursing knowledge behind DFG is a combination of understanding the complexity of NDD (Thapar et al., 2017) and ESSENCE (Gillberg, 2010) and then having the competence to transform it into practical guidance for families to help them in their daily life. Traditional background elements of family therapy such as *Open dialogue* (Seikkula & Trimble, 2005), *reflection* (Weingarten, 2016) and *systems therapy* (Haefner, 2014) are influencing DFG background theories. But especially, the dialogic approach is key to this family-targeted intervention.

2.3 | Development of the DFG family intervention

Dialogical Family Guidance is designed to help all family members to receive knowledge and gain an understanding of NDD/ESSENCE. DFG differs from other family interventions, because it targets on all family members and not just the parents. The DFG guidance areas (Figure 1) focus on both the need and benefit of psychoeducation, and giving continuous attention to the individuality of family members (practical and emotional). The DFG development process is seen as a combination of theory-based research and knowledge based on clinical experience.

As mentioned earlier parents with children with NDD can have symptoms similar to their children due to the high degree of heritability (Thapar et al., 2017). Attention-deficit/hyperactivity disorder symptoms in adults may present as inner restlessness, impatience and difficulties to sit still in meetings (Zalsman & Shilton, 2016). Poor time management skills can also appear, and these features need to be noticed, because the parent's own symptoms along with, for example impulsivity and attention disorders, can cause difficulties for parents to complete longer intervention processes. Low self-concept might decrease parental expectations of being able to deal with emotional situations, and an experienced failure of emotion regulation might stabilize negative thoughts about oneself (Hirsch, Chavanon, Riechmann, & Christiansen, 2018). As mentioned before, psychoeducational interventions usually last 60–90 min including 4–6 sessions (Bauml et al., 2006). Accordingly, the DFG intervention includes six different sessions lasting 90 min per session. Given the issues mentioned above, any longer intervention process could potentially minimize the parents' own motivation and commitment, so establishing a time schedule for the sessions provides a sense of security for the family members.

2.4 | Description of the DFG sessions and its three main components

The general approach in DFG is dialogical with an emphasis on collaboration between DFG therapists and family members to find solutions and make family resources visible. Using dialogue, DFG therapists gain knowledge about, for example the family system, parenthood, family crises and siblings´ reactions within the family. Open dialogue invites family members into a mutual learning process (Rober, 2010; Seikkula & Trimble, 2005). DFG offers a collaborative working process for all family members over six meetings within 3 months.

2.5 | The three main components in DFG

Dialogical Family Guidance consists of three main components, (a) psychoeducational (didactic element) (b), practical guidance (skill training) and (c) emotional guidance including guidance and discussion about the personal, sensitive and unique experiences of family members. Dialogue between DFG therapists and families enables a response to families' unique needs regarding all three guidance areas (Figure 1). This also saves time when issues already familiar to the family do not need to be repeated.

Psychoeducation about NDD/ESSENCE. The goal of this component is to increase parents' knowledge about their child's special needs, diagnosis and symptoms, developmental factors and to increase their overall understanding of the child. Other family members' possible NDD symptoms are often of interest in this component because of the potentially strong hereditary impact. Worth noting is that this may be the first opportunity for parents to talk openly about these matters (Table 2).

Practical/concrete guidance includes tailored guidance connected to the daily living of the entire family, to help parents to find solutions to their daily life and how they can meet the needs of a child with NDD while also meeting the needs of the rest of the family. In meetings where only the parents are present, attention is paid to both parents' individual desires, resources and habits. The goal of this component is to find common solutions suitable to both parents. Mothers and fathers operate and function from their own personal starting point, and therefore, the guidance is also personalized. A different approach is needed if there are children/siblings present (Table 2).

Emotional guidance includes DFG therapists being reflective and listening to family members' unique life situations without prejudice or pre-held attitudes. One goal is to increase families' own activity and functionality, by making the family members' own resources visible. In this way, the family's overall well-being can be increased. Emotional support is provided by listening and verbally supporting family members as they discuss their concerns and helping them to develop personal skills and abilities (Table 2).

2.5.1 | Family sessions 1–6

Session 1 is dedicated to practical arrangements termed as the *setting* (place, time schedule, planning and frequency of the meetings). This first session also includes dialogue about who is living in the family, the actual family situation and the NDD symptoms of the child. Only the parent(s) attend session 1, so as to allow them to talk freely about their actual family situation, their child's special needs,

TABLE 2 Content of the DFG family intervention areas

Practical and concrete guidance	Emotional guidance	Psychoeducation
Parents get concrete guidance, tips and advice for daily life with a child with special needs. All FM get concrete guidance for their daily life. Family gets help as a whole family unit. Dialogue about the child's special needs, special training, how achievements are seen at home, impacts on daily life. The family get guidance about child's neuropsychiatric/ ESSENCE/NDD disorders and discussion of how it can impact all FM. Discussion with the family about their opinions about how the child's special needs specifically affect their family. FM get information and guidance on how they can participate in the habilitation of their child at home in daily life. Other surroundings (school, day care) and people (family network) are also included in the discussion.	Professionals collaborate with the family members (FM). Professionals listen to the FM and to their hopes/needs. Professionals show respect to the family because the family are willing to be active and participate in the habilitation of the child with special needs. Professionals show their concern for the well-being of FM. Professionals are interested in the family as a unit. Dialogue about the child with special needs—personality, demands and resources. Resources of the family are mapped and made visible. Dialogue about parenthood, being parents together, being the child's mother and father. Professionals give enough space for family members to express their feelings. Professionals confirm parents' hope to have strength as parents and in parenthood. Professionals give positive feedback to the FM about participating and being concerned about the child's/siblings' daily habilitation.	Information about the child's symptoms, special needs, diagnostic procedures, diagnosis, treatment, therapy and habilitation. Repetition about the child's history regarding diagnosis and the current situation (medical history, appointments, hospitals, meetings with professionals, etc.). Guidance about the child's special needs, treatment, therapy and habilitation. Dialogue about the child's diagnosis, symptoms, rehabilitation, therapy, treatment, proceedings, achievements—the parent's (mother and father) perspective, knowledge, understanding are made visible. Information, education about the child's daily life needs. Professionals show interest in how the family is handling/managing daily life. FM get guidance about available assistance, support groups, habilitation facilities, outpatient clinics, social resources, etc. that are available. Parents get education about why structure and consistent guidance is important for the child's daily life. FM get guidance about neuropsychiatric/ ESSENCE/ NDD disorders and commonly known impacts on family individuals and how family function can be affected. Information about important principles as a parent, parental roles and responsibility, parent-child communication and interaction. Professionals give information to parents about the importance of their participation as family members in the everyday habilitation plan.

their concerns and what their needs and expectations are towards DFG. The DFG therapist will gain knowledge about what issues are important for the parents and what kinds of demands are the most acute to address during the DFG sessions. A preliminary plan is made during session 1, and the following sessions (2–6) follow themes from the DFG manual, taking into account the unique and individual needs of the family members. The themes covered in the manual are supposed to help the DFG therapist to bring up most common important issues concerning the focus group families. These themes are presented in Table 2.

After each session, the DFG therapist makes notes on the DFG checklist about which themes have been discussed and which themes still need attention. This assures that all three of the DFG guidance components and themes have been handled during the DFG sessions. This checklist policy provides a quality factor for the DFG family intervention and helps providers to take commonly important themes into discussion, while paying attention to the individuality of the family at the same time.

2.6 | Training for professionals to become a DFG therapist

The DFG training course includes theory- and experience-based knowledge. The topics of DFG training are presented in Table 3.

The educational goals for professionals are as follows:

1. That the principles and substance of DFG are well understood.
2. That participants increase their knowledge or confirm their own existing knowledge about family dynamics and parenthood in families with children with NDD, including emotional aspects.
3. That participants can proceed and perform DFG independently (or with another DFG therapist).

A pilot training course was carried out in 2014. Subsequently, five DFG training courses were held between 2014–2019 for a variety of professionals, mostly nurses. The total length of DFG training was 27 hr. The researcher conducted the DFG training courses and

TABLE 3 DFG education programme components

Components	Core topics
Background & DFG implementation process	DFG development process Why is DFG needed? Educational goals Target group Administrative and inner setting DFG implementation process
Introduction to DFG education	Content Educational goals Time schedule
Parenthood	Parenthood—factors and skills needed Different roles as parent, spouse and person
Parenthood and a child with NDD (theory and praxis examples)	Feelings as a parent Stress Crisis Defence and coping mechanisms
NDD in the family (theory and praxis examples)	Family system theories When the parent has NDD Couples' relationship when the spouse has NDD Siblings' relationships
Introduction to family interventions (theory and praxis examples)	Common principles when working with couples and families Parent groups Incredible Years programme and literature presentation Family school Psychoeducation Psychotherapy/ family- and couple therapy Family evaluation
Introduction to dialogue (theory and praxis exercises)	Active listening Reflective attitude Use of family narratives Dialogue and dialogical attitude Social and emotional coaching towards dialogical working
DFG	Common principles in DFG Setting Goals when working with families Structure Manual Checklist Discussion about targeting DFG to the right families
Tips and materials that can be used with children and parents	Written materials are shared (can be used during the DFG process)

has acted as the clinical supervisor for DFG therapists. Participants received a certificate of training and can be called DFG therapists once their DFG training course was completed.

Dialogical Family Guidance training can also be seen as a way of updating education for professionals from various occupations (e.g. nurses, medical doctors, social workers, psychologists and psychotherapists). The expectation for DFG therapists is to follow the DFG principles and to avoid any modification when delivering DFG to the families. The aim is to keep the DFG content and structure genuine and to secure the original quality of the DFG programme.

2.7 | DFG implementation

Readiness for implementation to a clinical setting requires a lot of communication between actors on different administration levels. The personnel involved are in the best cases motivated to work alongside each other and cooperate during the implementation phase (Figure 2). The DFG initiative was launched in the children's neuropsychiatric unit of a university hospital in a clinic administered by child psychiatry. The DFG intervention implementation process started with administrative issues such as selecting suitable units, gaining permission from the administration, sharing information about this new family intervention model and initializing the recruitment of suitable professionals to the DFG education programme. The realization of DFG courses and how the clinical supervision of professionals would be administered was included in the implementation process. This was important as nurses and other professionals proceeded with their training and prepared for independent work as DFG therapists. In some case (mainly involving nurses), the professional's job description needed modification to assure their possibility to proceed with the DFG intervention after DFG training as a part of their clinical work. The professionals own motivation and willingness to attend DFG training were seen as an important selection criteria.

Approval from the hospital ethical board was applied for, so as to be able to test the effectiveness of DFG in the future from the families' point of view. Acceptance from the hospital ethical committee of psychiatry (106/13/03/03/2012) and research approval from the hospital board was received from 2012–2019.

A manual has been created to help DFG therapists in their work. The manual includes six different themes which can be used flexibly during the DFG sessions. The manual gives structure to the DFG process, and using the manual has been felt to be highly beneficial by DFG therapists.

Data regarding the experiences and satisfaction of DFG training were collected with the consent of those who participated. A total of 44 professionals completed the DFG training (2014–2019) and 26 of those (59%) answered a questionnaire mostly consisting of questions about their opinions about the DFG training they had received. Together with two background data questions, eight questions asked about how the training had aided their work with families, given them tools to use in practice, a new understanding about focus group families, new understanding about the importance of

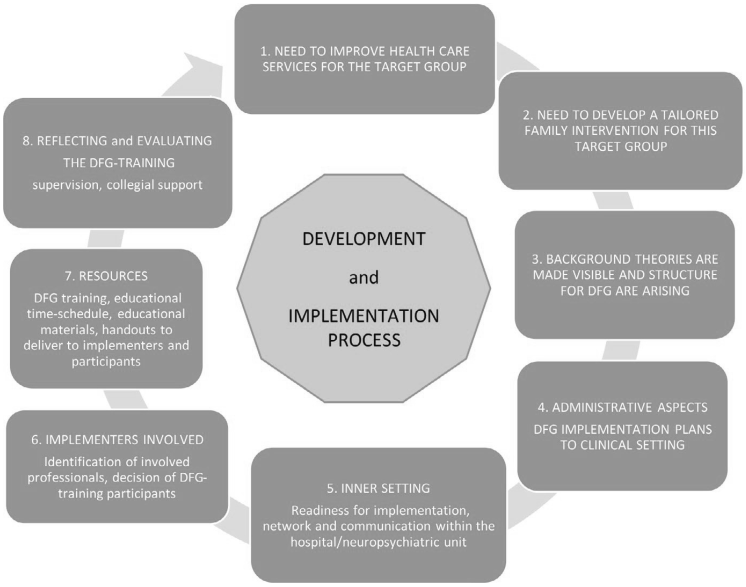

FIGURE 2 The DFG development and implementation process

dialogue and whether they would you recommend DFG for families and DFG training to other professionals. The survey data were analysed using the SPSS statistical programme.

3 | RESULTS

At this hospital, nurses and social workers completed the education programme between 2016–2019. However, it is mainly nurses, often working in pairs with families during the DFG process. This helps professionals to learn and internalize this new intervention and minimize their own tension. Participating on the DFG training course seemed to increase the possibilities of a more independent role as a nurse being able to deliver the DFG intervention to families.

The education programme offered the possibility to rehearse the dialogue that can be used in practice. The use of dialogue was also an important pedagogical method giving experiences of being listened to during the DFG training process. Comments, questions and the narratives of participants were important dialogical elements that featured in the DFG training. Worth noticing in this project was that using dialogue can be difficult for some professionals. Also, the expectation of taking all of the family members into consideration, instead of focusing only on the child with NDD, can be demanding. Therefore, one assumption is that not only experience and skills, but also the personality of the professionals involved, affects how DFG is delivered for the family.

The analysis of the questionnaire completed after DFG training reported a high level of satisfaction concerning the training itself and the question "*Would you recommend the DFG education to other professionals*" was answered "absolutely yes" or "yes" by 96% of respondents. Regarding their perceptions of the usefulness of DFG initiative itself, the question "*Would you recommend DFG for families*" was answered "absolutely yes" or "yes" by 100% of respondents.

The analysis of the open-ended question ("*Can you tell about your experiences and suggestions to improve the DFG training programme*") revealed that the professionals' personal experience of being heard during their DFG training increased their understanding of how parents can feel when DFG therapists are listening to them. The participants' experience was that the theory-based parts of the education became more understandable when they connected to the participant's own narratives during their DFG training. DFG training gave them a new approach to delivering knowledge and understanding to families using dialogue, including tailored psychoeducation and emotional and practical guidance. The DFG training programme was felt to be professionally delivered, comprehensive and well structured. DFG training participants also appreciated having an opportunity to share their experiences with other professionals.

4 | DISCUSSION

This article describes the development and implementation of a Dialogical Family Guidance intervention, aimed at families with a child with NDD. As previously mentioned, the DFG development and implementation process evolved from clinical experiences involving parents' narratives, and drawing from data from a pilot study (Cavonius-Rintahaka et al., 2019). Forming a functioning family intervention for this target group and implementing it successfully in clinical practice has been a long-term project.

Reflecting previous knowledge and literature, there is no doubt that family interventions are needed for families with a child with NDD, especially when a specific demanding behaviour is involved (Dykens, 2015; Post et al., 2017). It is also well known that information about symptoms and diagnoses, as well as tips and advice when operating with these children in daily life are important parts of psychoeducation initiatives (Bauml et al., 2006; Nussey et al., 2013). But this knowledge alone seemed not to be enough. According to families on whom the demands of not only taking care of the child with special needs, but also the siblings and the relationship between parents had an impact, raising children with NDD is challenging for parenthood and over time there are risks to the parents' own mental health in terms of anxiety and depression if they do not receive help (Falk et al., 2014). Thus, there seemed to be a need to develop family-focused approach including dialogue with all of the family members. The DFG intervention development looked to improve the quality of life of all family members.

The development of DFG (and especially the implementation process) has improved the attitude of nurses and other professionals to realize the wider impact the child's NDD has on the entire family. Listening to the voices of families plays an important part in understanding families of children with NDD or other disabilities (Post et al., 2017). Therefore, DFG therapists can be seen to be in a unique position to promote the health of all family members. This insight was strengthened among professionals during the DFG development and implementation process, and it seems that the implementation of DFG provided greater understanding for the whole team to make common efforts towards providing more family-centred care at the unit.

Gathering the knowledge from earlier studies and existing interventions for this target group and combining it with clinical experience was a long, but necessary starting point. Before identifying the DFG components, a multitude of decisions were systematically made and a pilot study was carried out 2012–2014 (Cavonius-Rintahaka et al., 2019). The intervention development process described here included many phases, and each activity made DFG development and implementation more meaningful. The ultimate goal was to develop an intervention that is theoretically based, acceptable to the target group and suitable as a systematic family intervention that could be used continuously at the clinic. In light of the experiences gained during the development and implementation process, we have succeeded with this goal. During the implementation process, it appeared that DFG is a feasible intervention for delivery in the community and in different healthcare settings. Additionally, DFG can also be viewed as a treatment that can be used across a range of paediatric diagnostic labels, because there are many common and similar background factors and stressors that are similar in families of children with different kinds of special needs.

The next step in this project is to conduct a study that will clarify the effectiveness of DFG in families with a child with NDD. There is also a further need to study whether DFG has positive implications for children with NDD and whether the family function in daily life, family dynamics and family health improves as a result of the intervention. To gain accurate knowledge of the impact of DFG has on families requires randomized, controlled studies to gain knowledge of DFG's effectiveness and efficacy and such a study is in progress and will be analysed using validated tools. In detailing the development and implementation of the DFG intervention, this paper can hopefully provide guidance for nurses and other professionals aiming to develop new mental health interventions for families with a child with NDD.

4.1 | Limitations

Relatively, few professionals have taken part in the DFG training course, although many more are on a waiting list for DFG training. Unfortunately, the DFG training course evaluation received responses only from 26 of the 44 professionals who had taken part, so the lack of depth in data makes it too early to know whether the training course needs modifying, although preliminary experiences and feedback from participants were very good. The DFG implementation process described in this paper relates only to one university hospital, and therefore, the results cannot be generalized. A more long-term perspective concerning DFG training experiences and expanding the implementation process to several units could give a wider perspective. Also, the experiences of DFG therapists of delivering the DFG in clinical practice to families would give important additional knowledge about the individual components of the intervention, and its overall impact. More objective knowledge about how the child with NDD and the rest of the family are affected by the DFG intervention would have given this paper more impact; however, this study is in progress and once complete; findings will be used to modify the DFG if necessary.

5 | CONCLUSIONS

The published literature and clinical experience indicated a lack of a family-focused intervention including dialogue for this particular target group. The development and implementation of the DFG initiative answered this need. The DFG training has received a positive reception among professionals who have taken part, and this has helped the implementation process in the clinical setting. Also administrative actors on different levels at the university hospital positively facilitated the implementation of the initiative. Overall, the DFG development and implementation process have improved the attitude of nurses and other professionals towards realizing the wide impact of the child's NDD on the entire family.

5.1 | Relevance to clinical practice

This paper presents the DFG family intervention development and implementation processes, together with the details of the DFG education process and programme components. This information can be useful to nurses working with similar families and clinical surroundings, but the information can be applied by various professionals working in a setting that involve families with a child with NDD. This paper can offer tips to developers working in different areas to help them develop their own family interventions and implement them in different units. This paper hopefully increases the awareness of the importance of offering these families dialogical interventions that include all family members.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

DC-R, ALA, EB and CG: Study design. DC-R and ALA: Data collection. DC-R, ALA and EB: Data analysis. DC-R, ALA, EB and CG: Manuscript writing. All authors listed (a) meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors. (b) all authors are in agreement with the manuscript.

DATA AVAILABILITY STATEMENT

Data are available on request from the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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PUBLICATION

III

Randomized Clinical Trial Comparing Dialogical Family Guidance with Ordinary Clinical Treatment for Families with a Child with Neurodevelopmental Disorder

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ORIGINAL PAPER

Randomized Clinical Trial Comparing Dialogical Family Guidance with Ordinary Clinical Treatment for Families with a Child with Neurodevelopmental Disorders

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Abstract

Objectives Previous studies have highlighted the need to offer targeted interventions to strengthen the wellbeing of family members in families with children with neurodevelopmental disorders (NDD). Interventions for this target group require research and development. The purpose of this study was to test a new family intervention: Dialogical Family Guidance (DFG).

Methods Families of children with NDD were randomized into an intervention group that was delivered DFG and a comparison group provided with ordinary clinical treatment. The Family Functioning, Family Health and Social Support (FAFHES) and the DFG instrument were used to collect data at baseline and after 3 months. Repeated measure analysis of variance (ANOVA) was used as an analytical strategy.

Results There was a significant within-subjects effect of time on family health and social support, indicating that family health and social support increased in both groups over time. There was also a significant between-subjects effect of group and interaction between time and group on social support, indicating that social support increased more in the intervention group than in the control group. Managing in daily life and the relationship between parents were associated with family functioning and family health.

Conclusion DFG can strengthen parental experiences of social support. Managing in daily life, relationship between parents, practical guidance, psychoeducation, dialogue, and receiving positive feedback on parenting were strengthening factors during DFG. However, the results of this study must be considered as only preliminary, as they relate only to parental perceptions of the intervention effects.

Trial registration ClinicalTrials.gov NCT04892992 (retrospectively registered).

Keywords Dialogical Family Guidance · Family functioning · Family health · Social support · Neurodevelopmental disorders · Effects

Neurodevelopmental disorders (NDD) are a group of disorders with an onset in the developmental period of childhood. NDD is a general term used to describe neurological and psychiatric disorders such as learning and language disorders, intellectual disabilities, motor coordination disorders, autism spectrum disorders (ASD), attention deficit hyperactivity disorder (ADHD), tic disorders, and oppositional defiant disorder (ODD). NDDs are characterized by high rates of impairment or comorbidities between various disorders within this diagnostic grouping (Morris-Rosendahl & Crocq, 2020). ADHD and ASD are both highly heritable and impairing NDDs but can also be triggered by pre- and postnatal risk factors. Smoking during pregnancy, prenatal exposure to alcohol, young maternal age, and maternal stress increase the risk for ADHD in children (Oerlemans

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et al., 2016). According to Faraone et al. (2015), ADHD is a persistent neurodevelopmental disorder that affects 5% of children and adolescents and 2.5% of adults worldwide, and involves a risk of psychiatric disorders, educational and occupational failure, accidents, criminality, social disability, and addictions. A study by Simonoff et al. (2008) revealed that 70% of children with ASD had at least one comorbid disorder, and 41% had two or more comorbidities. Moreover, Lai et al. (2014) reported that ASD affects more males than females and that over 70% have comorbidities. Common comorbidities in NDD include ODD symptoms, aggression, language disorder, anxiety disorder, and sensory integration disorder. Soke et al. (2018) compared the prevalence of co-occurring symptoms between 4-year-old and 8-year-old children with ASD in a large population-based group. Over 95% of the 8-year-olds had at least one co-occurring symptom while this was the case with 67% of the 4-year-olds, as some conditions may have not yet been identified at that age. The findings obtained in this study are informative and therefore useful for professionals when developing interventions and services for this target group.

The symptoms and profile of NDD development may also change during childhood, and these multiple NDD symptoms are presented by Gillberg (2010) in the concept of ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations). ESSENCE refers to children presenting impairing symptoms before the age of 3 (to 5) years in clinical settings in the domains of general development, communication and language, social inter-relatedness, motor coordination, attention, activity, behavior, mood, and/or sleep. According to Gillberg (2010), major problems in at least one ESSENCE domain before the age of 5 should be paid attention to as (very likely) markers for the presence of a neurodevelopmental disorder, and which can indicate later, continuing problems. Children who screen positive for ASD have considerable and clinically relevant impairments and psychiatric problems, and their impairment is often mainly caused by their comorbidities. In a population-based study by Posserud et al. (2018), only 2% of children could be characterized as having "autism only," and they recommend comprehensive clinical assessments that include neurodevelopmental, psychiatric, and cognitive assessments and follow-up meetings, regardless of the final clinical diagnosis. This study supports taking an ESSENCE-based approach, as there is very high overlap across a wide range of symptom domains.

Having a child with NDD often means that other members in the family (parent or siblings) are also likely to have NDD symptoms due to strong genetic influences (Biederman, 2006). According to findings from twin, family, and adoption studies, the heritability of ADHD is estimated to be at 70–80% (Biederman & Faraone, 2005; Hudziak et al., 2005; Thapar et al., 2000). Similarly, Faraone and Larsson (2019) have referred to decades of research showing strong heritability in the etiology of ADHD. As a result of the high heritability rate, it is possible that several parents have ADHD and their own symptoms can have an impact on their parenting skills (Tarver et al., 2014). According to Chen et al. (2017), ADHD for example manifests in parents or siblings of children with an ADHD diagnosis 2–8 times more frequently than seen in the general population. Genetics also affect the etiology of ASD, and the heritability is estimated to be between 64 and 91% (Robert et al., 2017; Tick et al., 2016a, b). It is also known that both disorders co-occur with a frequency of 20–50% in children with ADHD meeting criteria for ASD, and 30–80% of ASD children meeting criteria for ADHD (Rommelse et al., 2010). In their recent study, Okyar and Görker (2020) argue that autistic traits are frequently detected in children with ADHD. As expected, not only more symptoms of autism were detected in boys, but also the presence of ODD. According to this study, maternal and paternal ADHD symptoms predict autism symptoms in children with ADHD.

There is a need for interventions to improve health and functioning aimed at both parents and children. Parents of children with special needs demonstrate fatigue and exhaustion, and emotional problems ranging from frustration to hopelessness (Caicedo, 2014). We also know that parents of children with NDD such as ASD experience more stress than parents of typically developing children (Craig et al., 2016; Duarte et al., 2005; Johnston et al., 2012). Studies have revealed that there is a relationship between family functioning, quality of life and the typical characteristics of children with a range of NDD disabilities, and parental stress levels (Craig et al., 2016; Falk et al., 2014; Pisula & Porebowicz-Dorsmann, 2017). Van Steijn et al. (2014) have reported that both parents of children with ADHD and ASD are at a risk of experiencing higher levels of stress. Paternal ASD and maternal ADHD symptoms have been related to increased stress, and these factors have been found to be associated with a higher incidence of depression. High levels of parenting stress may have negative effects on the entire family system and the individual's quality of life. Divorce rates remain higher in parents of children with autism compared to parents of normally developed children (Hartley & Schultz, 2015; Hartley et al., 2010).

Providing parents with an opportunity to voice their concerns, communicate with other adults, or to get temporary relief from their role as caregivers can prove to be effective interventions for reducing the stress that parents often experience. According to Seikkula and Trimble (2005), this is called reflective dialogue.

Families play an important role for children with NDD, and parents are often the first ones to recognize the child's symptoms. While the positive impact of families is well-known, there is a need for more knowledge to understand how parents manage their child's ADHD in their everyday lives. It is also important for nurses working with children and families to recognize the effort and skills required from caregivers in managing their child's condition, and to introduce behavioral management strategies as early as possible, along with support, counseling, or psychosocial services (Paidipati et al., 2020).

It is also known that parents who also have ADHD have a weaker sense of coherence and poorer family functioning than parents without ADHD, and support from health services is strongly associated with a positive effect on family functioning (Moen et al., 2015). Adults with ADHD are known to have more depression, anxiety, greater childhood dissatisfaction, a more external locus of control, and lower self-esteem (Rucklidge et al., 2007). A less organized family environment can exacerbate impulsive and hyperactive child behavior to a more serious level, instead of facilitating self-regulation skills in the child. Shared genetic vulnerabilities combined with child difficulties and stress in families are an environmental risk for families. ADHD in parents appears to confer specific impairments in parental functioning in families of children with ADHD (Johnston et al., 2012). Parenting may also be a protective factor associated to functioning outcomes in children with ADHD as parents play a major role in their child's social environment. Parents who themselves have ADHD may benefit from targeted, more individualized parenting interventions that have an additional focus on the parents' planning and organizational skills (Johnston et al., 2012; Tarver et al., 2014).

Findings from studies have led to developing and proceeding with treatments and interventions and providing families with support. Several studies have addressed a need for non-pharmacological interventions to be more specially targeted towards NDD symptoms (Sonuga-Barke et al., 2013; Tarver et al., 2014). Individuals' functional independence and quality of life should be maximized throughout their development, and they should be helped in finding their areas of strength. According to Lai et al. (2014), the most effective interventions for ASD are behavioral and educational, but medication should also be considered, especially in persons with co-occurring symptoms. Similarly, Tarver et al., (2014, 2015) have reported that behavioral parenting interventions should be used as the first-line treatment of ADHD, although there is still a need for future trials of non-pharmacological interventions. Sonuga-Barke et al. (2013) also challenge future research to improve the efficacy of nonpharmacological interventions, while at the same time building a growing understanding of ADHD pathophysiology. Interventions should be better integrated with pharmacological approaches and focus on family-related functional outcomes. Parenting interventions can be perceived as a component of treatment targeting a wide range of outcomes and providing additional benefits, although they would not be effective in combating core ADHD symptoms (Tarver et al., 2014). Important targets for interventions include promoting the psychosocial wellbeing of parents and helping them to resolve the emotions associated with their child's diagnosis (Barlow et al., 2014; Wachtel & Carter, 2008).

According to Craig et al. (2016) and Schwartzman et al. (2021), the parents of children with different types of NDDs should be provided with interventions that empower them with knowledge and skills to reduce their stress and improve their quality of life. Findings from these studies suggest that children's emotional and behavioral problems are significant sources of parental stress. There are several intervention models targeted on specific symptoms of ASD (Bearss et al., 2015; Factor et al., 2019; Farmer & Reupert, 2013) or ADHD (Sonuga-Barke et al., 2013; Trillingsgaard et al., 2014). New findings demonstrate for example resilience-based interventions for parents with children with ASD (Schwartzman et al., 2021) and mindfulness-based interventions for parents with children with ADHD (Siebelink et al., 2021) as promising. A review by Barlow et al. (2014) revealed short-term evidence of the benefits of parenting programs on depression, anxiety, stress, anger, guilt, confidence, and satisfaction with the partner relationships. Other studies (Barlow et al., 2014; Dretzke et al., 2009; Michelson et al., 2013) have also reported that caregiver training and interventions have a general impact on family functioning and interpersonal relationships within the family. This suggests that parent and family involvement and the inclusion of family members in interventions would probably result in a greater effectivity and impact of treatments for the entire family (Ansari et al., 2016; Lai et al., 2014). This is in line with the findings of Rodriguez et al. (2019), which suggest that family-based interventions aimed at both parents and children with ASD bring understanding to the reciprocal link between parental stress and child functioning. Such interventions could include providing parents with training on how to cope with stress, and how to respond to demanding child behavior in a beneficial way.

Strictly manualized psychoeducational programs do not necessarily make room and/or give time for family members to express their dilemmas and questions, although it is well known that having a child with NDD can have various, and at times even serious impacts on different family members. Dialogical Family Guidance (DFG) was developed as a family intervention with the purpose of helping all family members to receive psychoeducation and increase their understanding of NDD/ESSENCE. DFG has been tailored for families with a child with NDD and aims to meet uniqueness of these families by using dialogue and the knowledge that parents have about their child and family (Cavonius-Rintahaka et al., 2020). The more systematic approach to combine psychoeducation, practical, and emotional guidance, along with dialogical elements, makes DFG a novel approach compared to other available interventions. DFG provides personalized support during a six-session semi-structured program, allowing new perspectives and insights to be found. The reflective dialogue approach used in DFG enables family members and professionals to initiate "a mutual learning process," in line with the concepts presented by Seikkula and Trimble (2005). Of particular note is that while it is important to teach parents effective parenting strategies, many parents simply need space to discuss their worries, thoughts, and feelings (Evans et al., 2015; Raitio et al., 2015).

A pilot study (Cavonius-Rintahaka et al., 2019) was performed to obtain knowledge about parents' experiences and hopes regarding the help they received from health professionals. Families taking part in the pilot study (29 mothers and 17 fathers) received ordinary clinical treatment for the child and were not provided with any family intervention. The results indicate a strong positive correlation between family functioning and family health ($r = 0.75$, $n = 46$, $p < 0.001$) and further reveal that managing as a parent in daily life, having good self-confidence as a parent, and how the relationship between parents works need attention when developing interventions for families with a child with NDD. In the study, the parents also expressed their need for dialogue, psychoeducation, and for concrete guidance. These findings have been taken into consideration in the development of DFG, and results from other studies have also been taken into account during the development and implementation process (Barlow & Stewart-Brown, 2000; Barlow et al., 2014, 2016; Bearss et al., 2015; Dretzke et al., 2009; Factor et al., 2019; Farmer & Reupert, 2013; Peasgood et al., 2016; Trillingsgaard et al., 2014).

Because DFG is a new family intervention, there is limited knowledge and only subjective opinions about aspects of its effects in clinical practice. It is therefore important to study the effects of DFG regarding family functioning, family health, and social support in daily life. It is particularly interesting to examine whether DFG meets the needs and expectations of families with a child with NDD to the extent expected. The aim of the present research is to study the effects of DFG based on parent reports regarding family functioning, family health, and social support.

Method

Participants

The original study design plan was to include fifty families in this study. This decision was connected to a calculation based on the realistic possibility of collecting target families who were attending the neuropsychiatric unit over a 2-year period of time. Seventy-nine ($N = 79$) families met the inclusion criteria during the data collection period (2016–2018). Of these, twenty-nine refused to participate, and their reasons for refusal included problems with schedules ($n = 17$), a long distance to the clinic ($n = 3$), parents feeling they had no need for/no interested in DFG ($n = 5$), other outpatient clinic visits coming up ($n = 3$), and language issues ($n = 1$). The recruitment period ended once fifty families had given their informed consent to the study during the data collection period. Both parents from each family were given the opportunity to attend. From these fifty families ($n = 50$), sixty parents participated in the study at baseline. Forty-two ($n = 42$) families and fifty-two parents ($n = 52$) completed both phases of the study (baseline T1 and 3 months follow-up T2).

The study participants were families with children referred to a neuropsychiatric unit at a university clinic that provides multidisciplinary assessments and rehabilitation plans through a team of child neurologists, child psychiatrists, (neuro-)psychologists, nurses, occupational therapists, language therapists, and social workers. Interventions and the rehabilitation of the child can be carried out either within the hospital, or at a clinic within the primary health care system.

Parents included in this study had a child with at least one diagnosis falling under the NDD umbrella (ADHD, ASD, tic disorders, speech and language disorders, specific learning disorders, specific developmental motoric or psychiatric disorders, delayed milestones) and aged between 4 and 16 years old. An additional criterion for inclusion in the study was that parents had adequate Finnish language skills and that they were the biological parents, caregivers, or stepparents of the child, and living with the child during ordinary day-to-day life.

The intervention group and comparison group consisted of a total of 52 parents at baseline. Of these, 30 parents were in the intervention group and 22 parents in the comparison group. The mean age of the parents at baseline was 38 years (SD 5), with the mean age of parents in the intervention group being 36.7 (SD 4.9) and the comparison group 38.7 (SD 5.3). In both groups, the median number of children was 2. The minimum and maximum number of children was 1 and 6 in the intervention group, and 1 and 5 in the comparison group (Table 1). There were no

Table 1 Baseline demographics of the parents taking part in intervention group ($n=30$) and comparison group ($n=22$)

	All participants		Intervention group		Comparison group		
Background variables	*n*	%	*n*	%	*n*	%	*p* value[1]
Gender							0.717
Father	18	34.6	11	36.7	7	31.8	
Mother	34	65.4	19	63.3	15	68.2	
Age (years)							0.376
< 38	25	48.1	16	53.3	9	40.9	
≥ 38	27	51.9	14	46.7	13	59.1	
Marital status							0.559
Married/cohabiting	38	73.1	21	70.0	17	77.3	
Do not live together	14	26.9	9	30.0	5	22.7	
Quality of the relationship between parents							0.613
Excellent/good	31	59.6	17	56.7	14	63.6	
Moderate/poor/very poor	21	40.4	13	43.3	8	36.4	
Basic education							0.175
Comprehensive school	16	30.8	7	23.3	9	40.9	
Matriculation examination	36	69.2	23	76.7	13	59.1	
Professional education							0.756
University degree	32	61.5	19	63.3	13	59.1	
College level degree or lower	20	38.5	11	36.7	9	40.9	
Number of children							0.618
1 child	10	19.2	7	23.3	3	13.6	
2 children	25	48.1	13	43.3	12	54.5	
≥ 3 children	17	32.7	10	33.3	7	31.8	
Other members of the family with neurodevelopmental disorders or diagnoses							0.284
Yes	15	31.9	10	38.5	5	23.8	
No	32	68.9	16	61.5	16	76.2	
Parents' self-reported health							0.959
Very good /good	40	76.9	23	76.7	17	77.3	
Moderate/poor/very poor	12	23.1	7	23.3	5	22.7	
Managing as a parent in daily life							0.516
Extremely well/quite well	28	53.8	15	50.0	13	59.1	
Moderate/rather/Extremely poor	24	46.2	15	50.0	9	40.9	
Having long-term illness or neuropsychiatric disorder							0.146
Yes	15	28.8	11	36.7	4	18.2	
No	37	71.2	19	63.3	18	81.8	

[1] Chi-square test

statistically significant differences in the background variables of the parents between the intervention group and the comparison group (Table 1).

The characteristics of the children in intervention and comparison groups were quite similar in both groups (Table 2). The mean age of the children was 6.1 (SD 1.5) in the intervention group and 7.1 in the comparison group (SD 2.6, Q_1 5, Q_3 in intervention group 7, Q_3 in comparison group 8). The minimum age of children in both groups was 4, and maximum age was 10 in the intervention group and 14 in the comparison group. The median age of the child when parents had first raised concern about the child's neuropsychiatric problems was 2.5 in the intervention group (Q_1 2, Q_3 3) and 3 in the comparison group (Q_1 1.7, Q_3 4). The mean number of children's hospital or clinic appointments before the first appointment at a university neuropsychiatry clinic was 3.9 in the intervention (SD 2.7) and 5.6 in the comparison group (SD 4.0). Most of the children had ADHD or ASD as their main diagnosis, but comorbidities were also common.

Table 2 Demographics of the children with NDD in families taking part in the study

	All children		Intervention group		Comparison group		
Background variables	*n*	%	*n*	%	*n*	%	*p* value
Gender							0.161[1]
Girl	10	19.2	8	26.7	2	9.1	
Boy	42	80.8	22	73.3	20	90.9	
Age (years)							0.523
< 7	31	59.6	19	63.3	12	54.5	
≥ 7	21	40.4	11	36.7	10	45.5	
Child's daytime activity							0.051
In daycare	40	76.9	26	86.7	14	63.6	
At school	12	23.1	4	13.3	8	36.4	
Diagnose of the child							-
Attention-deficit/hyperactivity disorder	14	26.9	9	30.0	5	22.7	
Autism spectrum disorder (e.g., Aspergers syndrome)	11	21.2	6	20.0	5	22.7	
Delayed milestone	10	19.2	8	26.7	2	9.1	
Speech and language disorders	6	11.5	4	13.3	2	9.1	
Specific learning disorder	4	7.7	-	-	4	18.2	
Other (motoric or psychiatric problems, unclear)	7	13.5	3	10.0	4	18.2	
First concern towards the child's neuropsychiatric problems							0.516
1–2 years	24	46.2	15	50.0	9	40.9	
> 2	28	53.8	15	50.0	13	59.1	
How the child's NDD problems affect his/her daily life							-
No symptom/hardly any symptoms	3	5.8	1	3.3	2	9.1	
Symptoms occasionally	5	9.6	2	6.7	3	13.6	
Symptoms often	22	42.3	15	50.0	7	31.8	
Symptoms disturbing all the time	22	42.3	12	40.0	10	45.5	
Earlier visit to the clinic/hospital							0.376
Yes	25	48.1	16	53.3	9	40.9	
No	27	51.9	14	46.7	13	59.1	

[1] Fisher's exact test, otherwise chi-square test

Procedure

Study design

Parents who attended the neuropsychiatric unit with their child for the first time during the data collection period were asked to take part in the study if they met the inclusion criteria. A research assistant nurse at the unit gave oral and written information to parents about the study, including information about the DFG family intervention.

Families who gave their consent to participate in the study filled in the baseline questionnaire and were alternately allocated into an intervention group or comparison group by a research assistant nurse. Families included in the intervention group were provided with DFG with an immediate starting point (baseline) simultaneous with ordinary clinical treatment, while the families in the comparison group only received ordinary clinical treatment. The randomization in this study meant that every second family was placed in an intervention group and every second family in the comparison group. However, the comparison group was given an opportunity to be provided with DFG after a 3-month waiting period. The parents could not choose which group they were assigned to, and the parent questionnaires completed at baseline did not affect which group the families were placed in. The ordinary clinical treatment at the unit was mainly focused on assessing children to clarify their diagnosis, and to plan the child's treatment and rehabilitation. Collaborating with parents is crucial when proceeding with a child's assessment and rehabilitation plan, but family interventions were not part of children's routine interventions at the unit. If needed, parents and siblings were also recommended to seek help from primary healthcare.

Data Collection

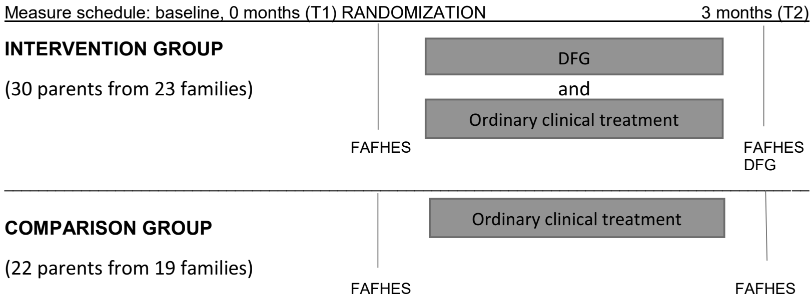
Baseline data (T1) were collected from both groups immediately after they had given their oral and written consent to participate in the study (Fig. 1). Randomization had already been completed in advance, and when giving their consent, the parents already knew whether they had been placed into the intervention group or the comparison group. The difference between the two groups was that the DFG intervention was immediately launched for the families in the intervention group, whereas those in the comparison group were told that they had to wait 3 months before gaining access to the intervention. However, the impact of the waiting list approach can cause different effects on outcomes and thus needs to be noticed (Cunningham et al., 2013; Mohr et al., 2009).

DFG is a family intervention tailored specifically for families with a child with NDD. The development process is based on clinical experience, practice, theory-based research, and a pilot study (Cavonius-Rintahaka et al., 2020). The aim of DFG is to help all the family members receive knowledge and gain an understanding of NDD/ESSENCE and to provide a reflective space for family members to discuss their worries, thoughts, and feelings. The DFG collaborative working process with family members lasts over six meetings (90 min per session) which take place within a 3-month period. The first intervention session begins with dialogue between the DFG therapist and parents, followed by an initial plan. The following five sessions are tailored together with the parents, depending on their needs, questions, daily demands, and hopes concerning the issues to be discussed during the common DFG process. Themes addressed by the parents are seen as the most important, although a DFG manual also includes suggested themes for each session and provides a structure for the DFG intervention process. The themes included in the manual are: Your family, What does NDD mean for your child, The child's development issues related to NDD, Demands in daily life, Resources in your family, Networks, Communication in your family, Relationships between family members, Sibling issues, Parents' reciprocal collaboration. The participants from the family (the child with NDD, siblings, and the parents) usually varied during the sessions, depending on the families' unique needs and the parents' wishes. Different combinations of family members participated in the six sessions.

The DFG structure is based on three guidance areas: psychoeducation (didactic element), practical guidance for daily life (skill-based practice), and emotional guidance. The practical guidance includes issues concerning daily life situations, helping parents find new solutions to the repetitive demands that emerge in the home environment. This is a skill-based practice that engages parents to a concrete level of how to behave and operate with the child. If needed, parents are guided on how to practice in their home environment and are provided with ideas about recommended changes that aim to make their everyday life run more smoothly. This emerging knowledge can be discussed together during the following intervention sessions. The emotional guidance includes sharing and listening to other families` stories and unique experiences, giving the participating families a space where every family member feels they are an equal, important, special, and unique individual. Alongside psychoeducation and guidance, the DFG therapist is interested in identifying the challenges and needs of all family members.

The DFG therapist and family members collaborate and seek effective parent strategies, skills to strengthen family members' relationships, and to engage in a dialogue to meet their individual goals. During the sessions, the DFG therapists gain knowledge about issues including the family system, family strengths, parenthood, the parents' relationship, family crises, and sibling reactions within the family. Parents share information regarding their daily demands, everyday lives, and the questions they have. When inviting family members to an open dialogue, professionals bring attention to these issues. Dialogue is an active process of speaking and listening. It is essential for professionals to be present in the moment, avoid speaking too much, or drawing conclusions too quickly. Every treatment meeting is unique and can be a shared emotional and healing experience. Supporting dialogue in a conversation encourages the participants to express their emotions and promotes a collective feeling of trust. Dialogue also leads to finding a shared language, and

Fig. 1 Study design and data collection



new ways of understanding problems can emerge (Seikkula & Trimble, 2005).

We believe that professionals need to find a balance between psychoeducation and having the sensitivity to make sure that the voices of each family member are heard. DFG differs from many other interventions in that it involves collaborating with all family members, not only the child with NDD or the parents. According to parents with children with NDD, personalized support for the entire family is an important aspect when addressing family health (Cavonius-Rintahaka et al., 2019).

Both medical and nursing knowledge are required to understand the complexity of NDD (Thapar et al., 2017) and ESSENCE (Gillberg, 2010). The DFG therapist possesses the competence required to transform this knowledge concerning NDD symptoms into practical guidance for families, in order to help them in their daily lives. DFG involves using traditional theory-based elements stemming from family therapy as an open dialogue (Seikkula & Trimble, 2005), reflection (Weingarten, 2016), and systems therapy (Haefner, 2014).

Health care professionals, including registered nurses and social workers, participated in a three-day training program before being allowed to deliver DFG to families taking part in this study. Motivation and a willingness to attend were important factors when selecting professionals for this training. All professionals had a minimum of 3 years working history in neuropsychiatry. Supervision and consultation for the professionals was regularly made available during the study by the researcher. Individual qualifications and competence need to be given attention when studying the effect of interventions (Firth et al., 2020). In this study, these factors were considered during the recruitment and implementation phases, although the professionals attending the DFG training were nurses and social workers, not psychotherapists. While the researcher was the one providing the professionals with the DFG training, she was not in direct contact with the families and did not deliver DFG to the study participants.

Measures

The FAFHES instrument (Astedt-Kurki et al., 2002, 2004, 2009) was originally developed for patients with cardiac disease and their family members, and previous research has investigated the associations between social support for the family of adult cardiac patients and family functioning and perceived family health. FAFHES provides a reliable and valid instrument (Astedt-Kurki et al., 2009) and has been used in different contexts in various studies (Hakio et al., 2015; Lepistö et al., 2017). The FAFHES instrument was modified and tested in a pilot study and has been deemed applicable for families with children with NDD (Cavonius-Rintahaka et al., 2019).

The FAFHES instrument contains three dimensions: family functioning (19 items), family health (23 items), and social support provided by professionals (21 items). All the items are measured on a Likert scale ranging from 1 to 6 (I disagree totally, I disagree, I disagree somewhat, I agree somewhat, I agree, I agree totally). Family functioning, family health, and social support were seen as poor if the median was 1.00–2.7, moderate if it was 2.8–4.5, and good if it was 4.6–6.0 (Lepistö et al., 2017).

The DFG instrument was developed for this study to obtain information and parents' experiences about the DFG family intervention. The instrument contains 14 items. Questions concerning the number of sessions and the time spent on them were included as "Is six sessions the right number of sessions?" (Yes/No) and "How many sessions are suitable for DFG, according to you?" (1 = 1, 2 = 2……6 = 6). Questions about the content and recommendation of DFG sessions included: "Did you get practical tips for daily life?" (1 = yes absolutely…0.5 = not at all) and "Would you recommend DFG to other parents?" (1 = yes absolutely…0.4 = no). One open-ended question was included in the DFG instrument: "*Could you describe your experiences, comments and/or ideas about how to improve DFG?*". Parents filled out the instrument after completing the DFG process (six meetings).

A session checklist was used to monitor adherence to the identified themes and functions as a fidelity test to ensure that the therapist is delivering the program according to standards in line with the manual and their DFG training. The checklist also helped the professionals navigate through DFG, giving them structure, and reminding them to bring up certain important themes with the families. Professionals working with families during DFG sessions filled in the checklist after every finalized DFG process.

Demographic data were collected at the baseline stage of the study. The demographic data for parents were obtained in the first section of the FAFHES parent questionnaire including gender, age, marital status, quality of relationship between parents (extremely good, good, average, poor, extremely poor), basic education, professional education, number of children, other members of the family having NDD or related diagnoses, parents' self-reported health (extremely good, good, average, poor, extremely poor), and managing as a parent in daily life (extremely good, good, average, poor, extremely poor). The demographic data of children concerned their gender, age, the child's daytime activity, diagnosis on referral, parents' first concerns regarding the child's neuropsychiatric problems, the effect of the child's NDD on his/her daily life, and the child's earlier visits to the clinic. In addition to parent questionnaires, official medical reports were used to include the diagnosis of the children in the baseline demographics. The diagnoses of the children were defined by medical doctors and pre-established (diagnosis already on referral) or established during the study at the neuropsychiatric clinic. Potential additional diagnoses received after the study period were not included. Both parents from the same family had the opportunity to fill out their own FAFHES and DFG instrument, which were completed when visiting the unit.

Data Analyses

Statistical analysis was carried out using IBM SPSS Statistics for Windows version 27. The total scores for the three FAFHES variables were calculated by summing the score for all the items in the variable and dividing the sum by the number of items. The internal consistency of the scale was evaluated using Cronbach's alpha coefficients, with results ranging from 0.86 to 0.96. The Kolmogorov–Smirnov test was applied to verify that the FAFHES sum variables were normally distributed. The distribution of FAFHES in the intervention group and comparison group was checked using the Shapiro–Wilk test. Nearly all had a normal distribution, except for the social support of comparison group at T1.

The chi-square test or Fisher's exact test was used to determine whether a difference exists between the intervention group and comparison group and the demographic variables. While some categories of demographic variables were small, the relationship between dependent variables (FAFHES) and demographic variables was analyzed using the Mann–Whitney U test or the Kruskal–Wallis H test with Bonferroni correction. A repeated measures analysis of variance (ANOVA) was used to examine the effect of time between the intervention and comparison group. The level of significance (p) was set as ≤ 0.05.

The parents also produced qualitative data by reporting their perceptions in writing more freely in response to one open-ended question: "Could you describe your experiences, comments and/or ideas about how to improve DFG?". The responses to this additional open-ended question from the DFG instrument were analyzed using content analysis (Graneheim et al., 2017). The content analysis followed a procedure using inductive content analysis, and therefore the variables were not identified in advance. The qualitative analysis began by reading parents' written responses, and frequent references to questions addressed in this study were highlighted. This was followed by an identification of similar sentences. Similar references were classified as a "subcategory" (grouping and combining similar or related answers). These subcategories were named relating to the actual content and present parents' opinions and hopes formulated to the upcoming themes. The last step in the content analysis was to create "main categories" based on "subcategories" by analyzing similarities and differences relating to the content. The results are presented as five main categories.

The researcher monitored the DFG session checklists, filled by the professionals after every finalized DFG process.

Results

Associations Between Background Variables and FAFHES at Baseline

At baseline, those parents who felt that the quality of the relationship between parents was good or excellent (Md 4.9, Q_1 4.4, Q_3 5.2) had better family functioning (U 135.5, $p < 0.001$) than those parents who felt that the quality of the relationship was moderate, poor, or very poor (Md 3.8, Q_1 3.6, Q_3 4.5). Similarly, the parents who felt that the quality of the relationship between the parents was good or excellent (Md 4.3, Q_1 3.8, Q_3 4.7) had better family health (U 123.5, $p < 0.001$) than those parents who felt that the quality of the relationship was moderate, poor, or very poor (Md 3.7, Q_1 3.4, Q_3 3.8).

At baseline, the parents who reported managing extremely well or quite well as a parent in their daily life (Md 5.0, Q_1 4.6, Q_3 5.4) had better family functioning (U 93.5, $p < 0.001$) than those parents who reported managing moderately or rather or extremely poorly as parent in their daily life (Md 3.8, Q_1 3.7, Q_3 4.4). Similarly, those parents who reported managing extremely well or quite well as a parent in their daily life (Md 4.4, Q_1 3.8, Q_3 4.7) had better family health (U 137.5, $p = 0.000$) than those parents who reported managing moderately or rather or extremely poorly as parent in daily life (Md 3.7, Q_1 3.3, Q_3 3.9).

The Effect of DFG on Family Functioning, Family Health, and Social Support

There was a significant within-subjects effect of time on family health ($F(1, 50) = 10.2$, $p = 0.002$, effect size $= 0.169$) and social support ($F(1, 50) = 52.8$, $p < 0.001$, effect size $= 0.513$), indicating that family health and social support increased in both groups over time. However, there was a significant between-subjects effect of group ($F(1, 50) = 6.1$, $p = 0.017$, effect size 0.108) and interaction between time and group ($F(1, 50) = 5.6$, $p = 0.022$, effect size $= 0.100$) on social support, indicating that there was difference between groups and that social support increased more in the intervention group than in the control group (Table 3).

Participant's Perception of DFG

Parents filled out the DFG instrument during the last DFG session. Most parents (96%) taking part in this study felt that DFG was provided at an appropriate time for them, although some were provided with it immediately after the child's appointment at the clinic, and others after waiting for a 3-month period. In the intervention and comparison

Table 3 ANOVA results for FAFHES

	Intervention group		Comparison group		Within-subjects effects						m		
Outcome measure	**Baseline**	**3 month**	**Baseline**	**3 month**	**Time**			**Time*Group**			**Group**		
FAFHES	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	F	**Sig**	η^2_p	F	**Sig**	η^2_p	F	**Sig**	η^2_p
Family Functioning	4.44 (0.74)	4.39 (0.77)	4.63 (0.82)	4.60 (0.78)	0.538	0.467	0.011	0.016	0.900	0.000	0.916	0.343	0.018
Family Health	3.89 (0.52)	4.13 (0.60)	4.24 (0.63)	4.30 (0.65)	10.188	**0.002**	0.169	3.504	0.067	0.065	2.718	0.105	0.052
Social Support	4.10 (0.68)	5.17 (0.55)	3.93 (0.99)	4.48 (0.77)	52.757	**<0.001**	0.513	5.550	**0.022**	0.100	6.074	**0.017**	0.108

η^2_{p} =partial eta square

group, the parents felt that the optimal time for starting the DFG intervention would be immediately or 1 month after the child's first visit to the clinic. Six sessions are usual for DFG, and this was seen as adequate for most (86%) parents. All the parents (100%) felt that all of the family members had been taken into consideration during the DFG sessions. Parents felt (yes absolutely, or yes 96%) that they had received advice and practical guidance, and that the DFG had helped them to manage better with their child with NDD (very much or much 89%). The parents taking part in this study also recommended (yes absolutely, or yes 100%) DFG as a suitable intervention to be delivered to other families (Table 4).

Qualitative Data Results

The one open-ended question in the DFG questionnaire constitutes the qualitative data results, which are presented as five main categories, including subcategories. The first main category "Practical guidance for daily life" included subcategories of "Experience of getting practical guidance" and "New procedure models for daily life". This included parents' expressions such as "We experienced DFG very positively. We received answers and solutions on how to deal everyday difficulties" and "We got a lot of practical ideas to take home."

The **second** main category of "Being heard" included the subcategories of "Good parent and family discussions during the DFG sessions" and "Experience of professionals listening to parents." Parents felt that they had been given full attention and expressed it with sentences such as: "It felt great that we were listened to, whenever we had the need to talk," "The atmosphere was wonderful, allowing us to be ourselves and it felt genuine," "Our concerns were heard and now we have survival strategies."

The third main category "Getting information" included the subcategories of "Experience of getting information as parents" and "Experience of getting new understanding as parents." Quotes from parents included: "This was a good experience, which helped us understand the child's situation better…" and "We got a lot of new ideas, information about the NDD symptoms, and support."

The fourth main category "Positive feedback about own parenthood" included the subcategory of "Experience of getting positive feedback as parents." This category was explained by comments such as "The positive feedback strengthened our self-esteem as parents" and "It is nice to get feedback about your own parenthood. You do not get it very often, at least not as much as in DFG."

The fifth main category of "DFG was a needed and rewarding experience" included subcategories of "DFG is a positive experience, getting attention as a family." Quotes from parents included: "We experienced DFG as a positive and relaxing experience" and "All six meetings were good and helpful."

Improvement ideas presented by the parents were, for example, that DFG could include more than six sessions, and that evening sessions would be appreciated. A few parents also hoped that the DFG therapists would make home visits and offer help in their home environment.

The analyses of the checklists used in this study verify that all (100%) DFG programs have been implemented to families according to protocol and the requirement of the manual.

Discussion

The aim of this research was to study the effects of the DFG intervention based on parents' reports regarding family functioning, family health, and social support, using FAFHES and DFG instruments. These randomized families were compared between intervention group and comparison group. Surprisingly, families in both groups reported family functioning, family health, and social support as moderate or good already at baseline. Referring to previous studies made in these target families (Caicedo, 2014; Craig et al., 2016; Duarte et al., 2005), getting such relatively good findings concerning parents` experiences of family functioning and family health already at the baseline was unexpected.

Table 4 Participants' ($n=29$) assessment taking part of on the last DFG session

DFG instrument	Intervention group	
	n	%
Who gave the information about DFG		
Doctor	6	20.7
Nurse	23	79.3
Was the DFG at appropriate time for your family		
Yes	28	96.6
No	1	3.4
When is the right time for DFG		
At once	18	64.3
After 1 month	9	32.1
After 2–4 months	1	3.6
How many DFG sessions did you have		
1–5	1	3.4
6 (ordinary for DFG)	28	96.6
Is six DFG sessions adequate		
Yes	25	86.2
No	4	13.8
What is adequate number of DFG sessions		
4–5	-	-
6	25	86.2
7 or more	4	13.8
Did you have DFG sessions outside the clinic		
Yes	2	6.9
No (usual in DFG)	27	93.1
Are DFG sessions outside clinic needed		
Yes	9	32.1
No	19	67.9
What is best time for one DFG session		
45 min	1	3.4
60 min	3	10.3
90 min (ordinary for one DFG session)	25	86.2
Who were delivering DFG sessions for your family		
Nurse	26	89.7
Social worker	3	10.3
Were all family members taken into consideration		
Yes	29	100
No	-	-
Do you recommend DFG sessions to other families		
Yes, absolutely	26	89.7
Yes	3	10.3
Did you get practical advice and tips		
Yes, absolutely	16	55.2
Yes	12	41.4
Maybe	1	3.4
How much did DFG help you to manage with your child		
Very much	11	37.9
Much	15	51.7
A little	3	10.3

The results of this study indicate that there were greater improvements in social support for the DFG group, but no between group differences in relation to family health. This finding can be associated with the fact that the children with NDD in these families were university hospital treatment patients during this study. Moreover, the children in this study were quite young, and there were no parent reports of children having behavioral problems, nor ODD. Families taking part in this study were receiving ongoing care (ordinary clinical treatment) for their child, and this could explain the proportionally good baseline reports for both groups.

Although the families expressed moderate or good values already at baseline, there were still some positive changes in both groups concerning the experience of family health and social support compared to baseline. The main result of this study was that family health and social support increased in both groups, but in the intervention group, the change towards better health and support increased more compared to the comparison group. According to Johnston et al. (2012), there are many factors in the family environment, family relationship, and family psychology/dynamics that influence these target families.

The quality of the relationship between the parents was connected to family functioning and family health. Those families with excellent or good parental relationships also had better family functioning and family health. This result is in line with several studies (Craig et al., 2016; Duarte et al., 2005; Hartley & Schultz, 2015; Hartley et al., 2010) reporting that the nature of NDD symptoms reflects and influences the whole family, including marital problems. Naturally, the stressful and demanding nature of NDD symptoms may elicit marital miscommunication and inconsistencies in parenting, or a low frustration tolerance between parents. Marital dysfunction was not profoundly examined in this study, but according to Hartley et al. (2010), the risk of divorce is significantly high in parents of children with autism and reminds us of the need to pay attention to the relationship of the parents during family interventions.

Obviously, the families in this study have children with a different range of NDD disorders. A child's behavior can evoke negative reactions between family members and result in dysfunctional parenting practices. Repetitive unsuccessful parental efforts to control the child's behavior can decrease the parent's self-esteem, emotional well-being, and negatively affect their parenting identity. The parents in this study expressed that positive feedback about their own parenthood was important and that DFG was a rewarding experience as a parent. It appears that getting positive feedback from professionals about one's parenthood and parental skills has strengthening impacts on parenthood identity. Also, the experience of getting practical guidance, having good discussions, and being heard during the DFG sessions seemed to be meaningful for parents.

Coping as parent in daily life was connected to family functioning, family health, and social support. The parents in the intervention group received advice and practical guidance to help them in their daily lives, and this helped them manage better with their child with NDD. This is in line with the study by Craig et al. (2016) which indicated that increasing parents' knowledge and skills can reduce stress and offer parents empowerment. Having enough knowledge as a parent can foster a sense of independence and give confidence in managing something that they had previously found to be difficult.

Based on several studies (Biederman & Faraone, 2005; Chen et al., 2017; Hudziak et al., 2005; Tick et al., 2016a), due to a high heritability rate, there is an increased prevalence of the same kinds of symptoms or even diagnoses in parents and siblings of children with NDD. In this study, approximately one-third of the parents agreed that more than one family member had neurodevelopmental disorders, and several parents answered positively to the question concerning parents having long-term illness or a neuropsychiatric disorder themselves. According to Rucklidge et al. (2007), men and women with ADHD, regardless of gender, struggle significantly with their own psychosocial functioning.

The role of parental attributions in children's responses to treatment is essential. A study by Caicedo (2014) claims that families need interventions to improve health and functioning for both the parents and the children. In this study, nearly all the parents reported that all of the family members had been taken into consideration, and a family system perspective had been put into practice. Ansari et al. (2016) have also confirmed that relationships among individuals within the family are known to have a unique influence over the overall family system and that professionals can help parents in establishing positive thinking towards the child.

Nearly all the parents, including those in the comparison group, felt that the DFG intervention had been well-timed and that DFG should be delivered to families very quickly after the child's initial appointment at the clinic. It could be that families have already had the experience of struggling for several years, and a 3-month wait for DFG does not cause much of a problem in comparison. According to Moen et al. (2015), social support and support from community health services are strongly positively associated with family functioning. Thus, the knowledge of an upcoming DFG intervention can probably provide families with comfort and alleviate their feelings of stress to some degree.

It is well-known that the family environment is an important factor in the development of every child, and family dysfunction may serve as a risk factor that poses a bad influence on the child's development and presentations of NDD symptoms. It can be that a dialogic approach offers help to identify aspects of parenting that are demanding in families' daily life. The use of open dialogue (Seikkula & Trimble, 2005) throughout the DFG intervention process allows professionals to confirm families' emotions, expectations, and disappointments. With the help of dialogue, family members get an opportunity to process and share their experiences, combined with psychoeducation and guidance in practical issues. This study supports the findings of Evans et al. (2015) that parents need space to discuss their worries and reflect on their thoughts and feelings. This can be considered as an important factor in family interventions. However, because only parents' perceptions were studied, the results of this study need to be seen as rather preliminary, and they can only be considered to determine the parents' perceptions of the acceptability and usefulness of DFG. Furthermore, as this study only provides limited information about the objective effects of DFG, there is a need for research using more objective, observational measures to further ascertain the effects of this intervention. Nevertheless, this study helped to reveal many interesting aspects and factors, and these could be evaluated in more detail by using a structured parental interview in addition to the FAFHES instrument.

Limitations and Future Research

The FAFHES instrument has been tested in studies since 2002 (Astedt-Kurki et al., 2002, 2009) and has been found to be a reliable tool in terms of construct validity and internal consistency, as well as to have good psychometric properties with a Cronbach's alpha for family functioning 0.92, family health 0.80, and social support 0.98 (Astedt-Kurki et al., 2009). These values are in line with the values from the modified FAFHES instrument used in this study as at T1, family functioning was 0.90, family health 0.86, and social support 0.95, and at T2 family functioning 0.92, family health 0.88, and social support 0.95. Although the instrument was modified and tested in a pilot study and was deemed applicable for families of children with NDD (Cavonius-Rintahaka et al., 2019), it needs to be noted that the modified FAFHES instrument has been used only in these two studies.

However, because only parents' perceptions were studied, the results of this study need to be seen as rather preliminary, and they can only be considered to determine the parents' perceptions of the acceptability and usefulness of DFG.

Furthermore, as this study only provides limited information about the objective effects of DFG, there is a need for research using more objective, observational measures to further ascertain the effects of this intervention. The most important area of future research is to examine the effects of DFG using objective child and parent outcome measures. Until then, the effects of DFG cannot be estimated reliably. Other limitations are the reliance on parental report measures and the fact that the comparison group was aware that they would receive the intervention at a later stage. Nevertheless, this study helped to reveal many interesting aspects and factors, and these could be evaluated in more detail by using a structured parental interview in addition to the FAFHES instrument.

All families included were clients of the same neuropsychiatric outpatient clinic at a university hospital, and therefore the results do not include any comparison between other outpatient clinics or hospitals. The parents in this study are representative concerning the focus group, because they all have a child with at least one NDD diagnosis. Moreover, the children became patients receiving ordinary care at the university hospital during this study, and the families were involved in the child's assessment and treatment plan at the baseline measure. Nevertheless, families drawn from several different clinics could provide wider knowledge about families with diverse baseline experiences.

Several studies reveal that families of children with NDD experience multiple challenges causing stress, burden, exhaustion, and emotional problems. However, the families included in this study were an atypical representation of parents with children with NDD, because surprisingly, all the families reported moderate or good family functioning, family health and social support at baseline. Hospital involvement can explain why the parents reported their level of family functioning to be at least moderate already at the baseline. These are limitations that need to be taken into consideration when reading the results, as the relatively good baseline family functioning and family health values most likely affect the 3-month follow-up values. Accordingly, this study may be seen as having limited capacity to produce knowledge about the effects of DFG only concerning families with relatively good baseline values for family functioning and family health.

In this study, randomization was carried out in an atypical way, as every second family that gave their consent to the study was placed in the intervention group and every second family to comparison group by a research assistant nurse. Using a random number generator would have been a more common form of randomization. According to Mohr et al. (2009), there is little agreement or consistency concerning the design and construction of control conditions, and yet it is known that different types of control conditions can produce significantly different effects on outcomes. Families in the comparison group were at the same time waiting for 3 months to initiate their DFG intervention. This can be considered as a limitation, as the knowledge of getting DFG later can affect parents' experiences and collected comparison group data. However, this was also an ethical decision, because it seemed important to give all families meeting the inclusion criteria in this study an opportunity to be provided with DFG.

The treatment used in this study (DFG) was manualized, its implementation monitored, a checklist was used during DFG by professionals, and the intervention was carried out by trained and supervised professionals (Cavonius-Rintahaka et al., 2020). The professionals worked in pairs when delivering the intervention. In this way, the DFG interventions provided to families were aimed to be homogeneous in quality and delivered in-line with the laid-out DFG intervention structure. The professionals received their DFG education from the same educator, and this made the training equal for implementers. These procedures can be seen as factors improving the intervention quality and reducing any variability among professionals. On the other hand, the impact of the professionals' implementing DFG cannot be completely ignored. According to Firth et al. (2020), interactions with professionals and differences between individual professionals make the study vulnerable, and differences in the skill levels of therapists are always possible. These therapist-related effects between those implementing DFG and family outcomes should be considered in the future delivery of DFG, and research conducted within this context. This may have implications on the application of research evidence, and the outcome and delivery of DFG.

In this study, although the children were taking part in the DFG sessions, they did not fill in their own questionnaires and the children's opinions are not featured in the results. The results therefore involve only the parents' perceptions, and the children's voices have not been heard, which is an issue regarding follow-up research. More research is needed using objective, observational measures to further ascertain the effects of this intervention. Furthermore, there is a need for knowledge about DFG's effectivity in families with low family functioning and family health at the baseline, and studies on whether this treatment is effective with other diagnostic, or disease groups would be of interest.

Support given during a 3-month period to the entire family can already increase families' experiences of family health and social support. Managing in daily life as a parent and the relationship between parents was associated with family functioning and family health**.** Responses from the DFG parent questionnaire report that practical guidance, information, dialogue between professionals and parents, and positive feedback on one's parenthood can be strengthening factors. According to the parents, the advice and practical guidance given in the intervention had helped them manage better with their child with NDD. Based on the parents' reports, it can be assumed that in addition to the information provided, it is important to offer parents an opportunity to engage in a dialogue about their experiences and the emotions they face in their daily life with the child. This study provides preliminary evidence that shows that parents can have positive perceptions of DFG. But as the results only present parents' perceptions of the acceptability and usefulness of DFG, larger-scale and more rigorous research is warranted to further ascertain the effects of this intervention.

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Author Contribution DCR: prepared the material, collected the data, analyzed the qualitative data, assisted with the quantitative data analyses, executed the study, and wrote the paper. MR: collaborated with design, analyzed the quantitative data, and wrote parts of the paper, collaborated with editing of the final manuscript. CG: contributed to study conception, design of the study and collaborated with editing of the final manuscript. EB: contributed to study conception, collaborated with design, and with editing of the final manuscript. ALA: contributed to study conception and design of the study, material preparations, analyzing and writing of the paper. All authors read and approved the final manuscript for submission.

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Availability of Data and Materials The datasets used and analyzed during the current study are available from the corresponding author on reasonable request. To protect the confidentiality of the participants, the data are not publicly available due to privacy/ethical restrictions.

Declarations

Ethics Approval and Consent to Participate The ethical standards of the American Psychiatric Association and the Declaration of Helsinki were followed in this study (World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects, 2013). The study was granted ethics committee approval before the onset of the study (2012, 2013, 2015) from the Helsinki University Hospital ethical committee of psychiatry (nr:106/13/03/03/2012) and research approval from the University Hospital board was received in 2012, 2013, and 2015. This study was retrospectively registered with ClinicalTrials.gov with the identifier: NCT04892992 on May 18, 2021. All the procedures performed in the study are in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments. Informed consent to participate in this study was obtained both orally and in writing from participants (parents in the families) included in the study. The researcher was not involved in any way directly with the families and did not deliver DFG to the families taking part in this study, to maintain objectivity in this research process.

Conflict of Interest The authors declare no competing interests.

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