



Everyday life in families with a child with ADHD and public health nurses' conceptions of their role

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The highest and most beautiful things in life are not to be heard about,
nor read about, nor seen but, if one will, are to be lived.

Sören Kierkegaard

Abstract

Aim: The overall aim of this thesis was to describe and explore everyday life in families with a child with ADHD and public health nurses' role in relation to these families.

Methods: An explorative and descriptive design with qualitative and quantitative methods was used. In Study I, data was collected with individual interviews with nine parents, and analyzed using phenomenology. In Study II, data was collected with individual interviews with 17 family members, and analyzed with phenomenography. In Study III, data was collected with a questionnaire responded by 265 parents, and analyzed with statistics. In Study IV, data was collected with group- and individual interviews with 19 public health nurses, and analyzed with phenomenography.

Main findings: The families' everyday life was influenced by living in unpredictability, though they were striving for predictability. The experience of being a parent was described as contending and adapting every day, like windsurfing in unpredictable waters. The parents were balancing between maintaining self and parenthood (I). The family tried to safeguard a functioning family in managing everyday life and developing special skills, both within the family and the society. They fought for acceptance and inclusion, in relation to the social network and professionals. The siblings were both agitators and diplomats, and their social life was affected (II). Cooperation with professionals was cumbersome and a relationship built on openness, support, trust and guidance was essential for cooperation (I, II). Parents' sense of coherence, children's behavior, support from social networks and community health services had all an impact on family functioning. In families with children being medicated for ADHD, parents reported less behavioral problems in their child, better family functioning and more social support than parents with non-medicated children (III). The PHNs described their role as both a peripheral and a collaborating partner and they asked for guidelines and multidisciplinary collaboration (IV).

Conclusions: Everyday life in families with ADHD is both demanding and giving. Acceptance and support from the social network and supervision from professionals are essential. The public health nurse is in a unique position to support and supervise these families.

Keywords: ADHD, children, everyday life, family, family functioning, parents, public health nurse, support

Sammendrag

Hensikt: Den overordnede hensikten for avhandlingen var å beskrive og undersøke dagliglivet i familier med barn med ADHD, samt helsesøstres rolle knyttet til disse familiene.

Metode: Et eksplorativt og deskriptivt design, hvor kvalitative og kvantitativ metode ble benyttet. I studie I, ble datasamlingen gjennomført med individuelle intervjuer med ni foreldre, og analysert med fenomenologi. I studie II, ble datasamlingen gjennomført med individuelle intervjuer med 17 familie medlemmer, og analysert med fenomenografi. I studie III, datasamlingen var gjennomført med spørreskjema hvor 265 foreldre svarte, og analysert med statistikk. I studie IV, ble datasamlingen gjennomført med intervjuer i gruppe og individuelt med 19 helsesøstre, og analysert med fenomenografi.

Hovedfunn: Familiens dagligliv ble påvirket av å leve i uforutsigbarhet mens de strevde for forutsigbarhet. Opplevelsen av å være foreldre var beskrevet som å kjempe i, og å tilpasse seg, hverdagslivet, som å vindsurfe i uforutsigbare farvann. Foreldrene balanserte i mellom å opprettholde seg selv og foreldrerollen (I). Familien forsøkte å ivareta en fungerende familie ved å mestre dagliglivet og utvikle spesielle ferdigheter, både innad i familien og i samfunnet. De kjempet for å bli akseptert og inkludert, både knyttet til det sosiale nettverket og de profesjonelle. Søskene var både opprørere og diplomater, og deres sosiale liv var påvirket (II). Samarbeidet med profesjonelle var tungrodd og et samarbeid bygget på åpenhet, støtte, tillit og veiledning var essensielt (I, II). Foreldrenes opplevelse av sammenheng, barnets atferd, støtte fra det sosiale nettverket og kommunehelsetjenesten hadde innvirkning på familiefunksjonen. I familier hvor barnet var medisinerert for ADHD, rapporterte foreldrene mindre atferdsproblemer hos barnet, bedre familiefunksjon og mer sosial støtte enn de med ikke medisinererte barn (III). Helsesøstre beskrev sin rolle som både perifer og som en samarbeidspartner og de etterspurte retningslinjer og tverrfaglig samarbeid (IV).

Konklusjon: Dagliglivet i familier med ADHD er både krevende og givende. Aksept og støtte fra det sosiale nettverket og veiledning av profesjonelle er essensielt. Helsesøster er i en unik posisjon i forhold å støtte og veilede disse familiene.

Nøkkelord: ADHD, barn, dagligliv, familie, familiefunksjon, foreldre, helsesøster, støtte

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Original papers

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- III. Moen, Ø. L., Hedelin, B., Hall-Lord, M. L. (2014). Parental perception of family functioning in everyday life with a child with ADHD. Submitted
- IV. Moen, Ø. L., Hedelin, B., Hall-Lord, M. L. (2014). Public health nurses' conceptions of their role related to families with a child having attention-deficit/hyperactivity disorder. *Scandinavian Journal of Caring Sciences*. DOI: 10.1111/scs.12076

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Introduction

In Norway, children have one of the world's best living conditions, as from parents' report nine out of ten children have good or very good health (Department of Public Health, 2013). Youth studies in 2001 and 2004 showed that 90% of the boys and 86% of the girls reported their health as being good or very good (Norwegian Institute for Public Health, 2005), with similar results in 2009 (Norwegian Institute for Public Health, 2010). However, the prevalence of mental health problems has increased and been stated as one of the major issues in health promotion and sickness prevention. It is estimated that 15-20% of all children and youth suffer from decreased function in their everyday life because of symptoms of mental health problems such as anxiety, depression and behavioral disorders (Department of Public Health, 2013), including Attention Deficit Hyperactivity Disorder (ADHD). According to the increased mental health problems in children and youths, the focus and responsibility have changed for the public health nurse from a disease-oriented to a more care-oriented focus (Department of Public Health, 2013; Social and Health Services, 2004). The term children is used in this thesis and based on how children are defined by law in Norway from birth to the age of 18 (Norwegian Parliament, 1981), together with the definition from the United Nations Convention on the Right of the Child (United Nations High Commissioner for Human Rights, 1989).

I am an authorized nurse with a one-year postgraduate education in public health nursing (Helsesøster in Norwegian). In my practice as a public health nurse I have met families with restless children with the parents striving to find an explanation and help for their child's difficulties. My interaction with these parents, the child and the family to find the best solutions and interventions was interesting and challenging, sometimes leading to a feeling of mastery both for the family and myself, but also in some cases to a cumbersome experience of not reaching a common goal. In the school health service, I cared for pupils in the diagnosis process, including those with a diagnosis of ADHD. The many challenges they faced in managing themselves and their relations with peers, teachers and parents touched me. The parents' situation in this process engaged me in the work as a public health nurse in school. Ever since I asked myself what these families everyday lives were like and what the public health nurse's role may be when encountering these families, which have been the focus in this thesis.

Background

Prevalence of ADHD

One of the most common developmental conditions in childhood is ADHD, with a prevalence of approximately 5% of school-aged-children worldwide (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007). In Norway, approximately 2.9% of children between the ages of 6-12 years are diagnosed with ADHD (Surén, Bakken, Aase, Chin, Gunnes, Lie & Stoltenberg, 2012), including a difference in the prevalence of ADHD between counties from 1.2% to 3.5%. These differences questions whether the equality in health services in Norway is being met (Surén, Bakken, Lie, Øyen, Aaberg, Andersen, & Stoltenberg, 2013). The discrepancy between the prevalence in Norway and international estimates can be explained for example by the use of different diagnosis criteria (Polanczyk et al., 2007).

Children with ADHD

ADHD is characterized by behavioral symptoms of inattention, hyperactivity and impulsivity as a persistent pattern in different settings throughout one's life span (Barkley, 2006; Biederman, 2005). The inattention symptom of ADHD manifests itself in daydreaming, distractibility and difficulty in focusing on a single task for a prolonged period of time, which is also influenced by a shortcoming of the motivational component. The hyperactivity component is expressed as fidgeting, excessive talking and restlessness, while symptoms such as aggression and difficulties in impulse regulation may exert an influence on family life and social relations (Barkley, 2006).

ADHD causes difficulties in executive functions, which are best described as a collection of brain processes responsible for planning, organizing and, inhibiting inappropriate actions used to self-regulate behaviors and affect. They also have difficulties in to take an outside perspective of one-self and to motivate themselves (Barkley, 2006; Wu, Anderson, & Castiello, 2002). Executive functions help us to inhibit stimulating and interesting activities in favor of doing what needs to be done to adapt to our surroundings and needs (Kendall, Leo, Perrin, & Hatton, 2005).

The symptoms of ADHD and the difficulties in the executive functions influence the child's everyday life, with some of the worst case scenarios described by Barkley (2006) as being a failure to graduate school or engaging in criminal behavior. To have a diagnosis of ADHD, the child's difficulties must occur in multiple settings, and give severities beyond what can be handled without extra interventions at home and at school (Barkley, 2006;

Biederman, 2005; Diamantopoulou, Henricsson, & Rydell, 2005). Children diagnosed with ADHD are a heterogeneous group and their difficulties vary, with some having more problems in everyday life than others. Some have comorbidity such as Oppositional Defiant Disorder, mood disorders, compulsive behavior, depression and anxiety (Biederman, 2005; Blackman, Ostrander, & Herman, 2005). Poor sleep patterns are common, and although they appear not to need much sleep, daytime behavior is often worse when sleep is negatively affected (Sung, Hiscock, Sciberras, & Efron, 2008). Parents have reported problems in their children with ADHD related to emotional-behavioral role function, behavior, mental health and self-esteem and also a low health-related quality of life (Klassen, Miller, & Fine, 2004). However, early detection and appropriate treatment can alter this negative developmental trajectory (Ogden & Hagen, 2008).

Medications such as stimulants or antidepressants, cognitive behavioral therapy and parent management training are the most common interventions (Barkley, 2006). Parents medicating their children also face dilemmas like others' view on the use of the stimulant medication of children and the possible side effects (Hansen & Hansen, 2006; Harborne, Wolpert, & Clare, 2004; Jackson & Peters, 2008). The research on interventions primarily focuses on the child's difficulties and parents' management, while the inclusion of all family members is hardly mentioned.

The family unit

The family can be defined as “a self-identified group of two or more individuals whose association is characterized by special terms, who may or may not relate by bloodlines or law, but who function in such a way that they consider themselves to be a family” (Whall, 1986, p. 241). The family can be viewed at three levels: the individual level, the interpersonal level and the system level (Friedman, Bowden, & Jones, 2003). In the individual level, the family is a context of the individual and the family is the sum of its parts. In the interpersonal level, the family consists of dyads, triads and larger units. The system level focus is on the entire family, with its multiple systems, such as individuals, the family and larger systems, influencing the family. Friedman et al. (2003) describe that in family nursing, nurses work simultaneously with individuals, subsystems in the family, the family as a whole and the family-society relation. The interpersonal level using a holistic and interactional perspective is chosen in this thesis (Friedman et al., 2003).

The family structure has changed over the last few decades (Gage, Everett, & Bullock, 2006). More single-parent families and extended families, with stepparents and stepsiblings, are bringing up children. The family unit is comprised of individuals, but

with specific characteristics that reach beyond the individual members who interact on each other – positively or negatively. When one family member becomes impaired, it exerts an influence on all family members in one way or another (Wright & Leahey, 2009).

Parents are essential to family life, and good parenting has the potential to promote health, well-being and physical and emotional development, in addition to preventing ill health and social problems in subsequent generations (Gage et al., 2006). In this thesis the family unit is a part of the everyday life, in which the family lives together and raises the children.

Family functioning is important in managing everyday life and can be described as several dimensions that influence family life, such as problem-solving, communication, roles, affective responsiveness and involvement and behavior control (Miller, Ryan, Keitner, Bishop, & Epstein, 2000). The basic assumptions for family functioning are that all parts in the family are interrelated, and that one part of the family cannot be understood as being isolated from the rest of the members, even though they are individuals. Family functioning depends on the entire family, and not only on a family member or subgroups in the family and how they interact with each other. The interpersonal interaction in the family strongly shapes the behavior of family members (Miller et al., 2000), whereas the experiences and positions of each family member have an influence on the dyads, triads and larger units that interact with the family's functioning and health processes (Anderson & Tomlinson, 1992). Family functioning has been found to be the strongest association for the referral of children to the specialist health services (Reigstad, Jørgensen, Sund, & Wichstrøm, 2006).

Families with a child with ADHD

Families with children with ADHD encounter many challenges in the family unit and in society at large. Twin studies estimate a heritability of 76%, which is influenced by both biological- and family environmental factors (Faraone et al., 2005). This indicates that within a family there may be more than one family member who has this diagnosis.

Parents of children with ADHD have problems with child interaction (Seipp & Johnston, 2005), and experience emotional distress, stress and exhaustion (Harborne et al., 2004). Parent stress can rise sharply when the child does not respond to ordinary parental requests and behavioral advice (DuPaul, McGoey, Eckert, & VanBrakle, 2001). The mothers' parenting role and emotional distress have been identified (Gerdes et al., 2007; Kashdan et al., 2004; Lesesne, Visser, & White, 2003). Mothers have described caring for a child with ADHD as demanding and putting restrictions on their social life and time for

themselves (Peters & Jackson, 2009). Mother-teen conflicts and a greater degree of stress and conflicts within the families were reported with adolescents diagnosed with ADHD (Edwards, Barkley, Laneri, Fletcher, & Metevia, 2001). Moreover, inconsistent paternal discipline and a low involvement of the fathers have been associated with ADHD and may add more maternal stress, thereby highlighting the need for the involvement of fathers in the treatment of ADHD (Ellis & Nigg, 2009), and in everyday life.

Siblings of children with ADHD have reported emotional problems (Steinhausen et al., 2012) and feeling victimized by their sibling with ADHD (Kendall, 1999). Mikami and Pfiffner (2007) describe relationships with the child with ADHD as being marked by conflicts.

The family environment and parents' boundaries and limit settings are described as being associated with developmental and executive functions in children with ADHD (Schroeder & Kelley, 2009). Positive parenting in the developmental stage of early childhood may act as a protective factor against conduct problems (Scaramella & Leve, 2004). The children's disruptive behavioral symptoms exerted more of an influence on parenting practices than parental behavior did on children (Burke, Pardini, & Loeber, 2008). Families show less warmth, less engagement and poorer communication skills during challenging family interactions, due to e.g. playing games (Tripp, Schaughency, Langlands, & Mouat, 2007). Foley (2011) describes families with ADHD as having a higher level of family dysfunction, not only does family dysfunction affect the family unit as a whole, but it also has a profound effect on the child with ADHD in relation to an unhealthy environment, and decreased attention and memory.

Kendall and Shelton (2003) found four management styles in families with children with ADHD. "The chaotic family" was emotional unhealthy with multiple stressors, little external support, little internal structure, no coping strategies. "The ADHD-controlled family" was influenced by the ADHD symptoms which had become the centralizing component of family life, characterized by powerlessness and hopelessness. "The surviving family" attempted to figure out a way to survive as successfully as possible in spite of the disorder. "The reinvested family" had put their energy back into their lives and regained control of their lives. Parents' management styles may present the way in which parents emphasize the techniques they use to navigate everyday family life (Firmin & Phillips, 2009; Segal, 1998).

As the aforementioned studies have described mothers perceived their caregiver role to a child with ADHD as demanding and stressful (Peters & Jackson, 2009), with higher family conflicts also being reported (Kendall et al., 2005). Families with children with ADHD report a dysfunctional and unhealthy family environment (Foley, 2011). Moreover

the lack of adequate support from social network and the health-care system is highlighted and give the parents a feeling of being marginalized (Peters & Jackson, 2009).

Families in relation to the social network

Social networks are the ties and lasting relations between people (Sørensen, Sandanger, Dalgard, & Kleiner, 2008), with some networks being supportive and others having a destructive character (Umberson & Montez, 2010). Social support, a vital resource in the social network, may function as a catalyst when facing demanding life events (Antonovsky, 1987). Social support can be described using the main elements of emotional support, instrumental support, informational support and appraisal support (Barrera, 1986; Langford, Bowsher, Maloney, & Lillis, 1997). Emotional support includes friendship, trust, love, caring and empathy. Instrumental support includes concrete assistance through action or materials. Informational support includes suggestions and advice and a reduction of uncertainties. Appraisal support includes acceptance, acknowledgement and praise. According to Cobb (1976), emotional social support is comprised of a communication that leads to a belief in being esteemed and valued, cared for and loved, as well as belonging to a network with mutual obligations. Social support may enable individuals to use effective coping strategies to manage everyday life and adequate social support from others than family can protect people in crisis both in transitions in life and in a variety of pathological states (Cobb, 1976). The absence of social support may affect an individual's mental health negatively (Umberson & Montez, 2010).

When asking children about common perspectives on children with ADHD, they described them as angry and aggressive (Singh, 2011). Children's experiences of having ADHD are described as the feeling of being different from other children, in addition to a reduced ability to stop and think before they act (Shattell, Bartlett, & Rowe, 2008; Singh, 2011). Mothers describe the children with ADHD as being poorly understood, although others criticize the mothers as being too lenient with their child with ADHD, as a basis of the child's poor behavior (Peters & Jackson, 2009). Harborne et al. (2004) described mothers' feelings of blame and battles with both professionals and relatives. By contrast, Looyeh, Kamali and Shafieian (2012) describe how group therapy at school with girls with ADHD reduced symptoms and identified and reminded each other about appropriate behavior. The focus on social support as an external resource in families with children with ADHD has been scarce in research.

Public health nursing

Public health nurses (PHN) have a particular responsibility for children of all ages, youth and families (Norwegian Parliament, 2011), and their function is to promote health and to prevent disease, injury and harm (Ministry of Health and Care Services, 2003). They are also responsible for revealing early signs of special needs in children, and to follow-up and give support to those children and families. Furthermore, they also refer them to collaborative partners for treatment and follow-up (Ministry of Health and Care Services, 2003). A PHN meets all users of the child health clinic and school health service (Ministry of Health and Care Services, 2003), as almost all Norwegian families with children frequent the local child health clinics and school health services (Helseth, 2007). Regulations require a PHN to have routines for cooperation with GPs, personnel in kindergarten, schools, pedagogic psychological services (PPS), dental health services and specialist health services (Ministry of Health and Care Services, 2003). Clancy (2007) found that the laws, regulations and instructions for PHNs are very general and that the PHNs may be invisible in their methods. On the other hand, the consultations at the child health clinic and in the school health service is described as broad and open, and include topics that parents or children address and worry about. The relationship between the parents, child and the nurse may be both a trusting relationship and the maintenance of a professional distance to give appropriate advice and support (Clancy & Svensson, 2010). The public health nurses' open-door policy is an easily accessed nursing service and gives them a position to meet all children, adolescents and their families (Clancy, 2007). The public health challenges have changed during this century, with more people having a chronic illness and mental health disorders (Department of Public Health, 2013), such as ADHD.

In contrast to the cure-oriented model, the care-oriented model reflects on holistic health, thus resulting in the care of the whole person, including family, in which everyone has a potential for health (Hwu, Coates, & Boore, 2001). Health is a process from a salutogenic viewpoint, with a focus on what brings people close to the health pole, not as static or constant, but as more of a continuum between disease and health (Antonovsky, 1996). Life stressors which occur over time will become chronic stressors as a long-lasting life situation (Antonovsky, 1987), like living in a family with a child with ADHD. Health promotion is defined by World Health Organization (WHO) as, "The process of enabling people to increase control over, and to improve their health. Health is therefore seen as a resource for everyday life, not the objective of living" (WHO, 2009, p. 1). Nurses should focus on how to mobilize personal and environmental resources to achieve the potential for health (Hwu et al., 2001). This is more than simply focusing on disorders and medical issues, as it also extends to coping and achieving a feeling of health. The objective criteria for diagnosis and appropriate treatment may not give much room for the individual's

experience of health. To reach the salutogenic focus of health, the need for mapping the difficulties may enable people to handle their situation and focus on the resources (Antonovsky, 1987). The focus on families with a child with ADHD may be one of the core issues for the PHN with regard to the care-oriented model of health.

Rationale

ADHD is one of the most common behavioral disorders in children which influence the entire family and their social life. The public health nurse can be a resource to these children and their families. Previous research has been multifaceted regarding the children with ADHD and has focused on the child's difficulties, and interventions regarding the child and parent management mostly from a medical and psychological perspective. The mothers' caregiver role has been examined while the knowledge of fathers' and siblings' experiences is scarce. Nursing research in this area has mainly been conducted in America and Canada, whereas research focusing on everyday life in families with a child with ADHD from Scandinavia is limited. There is also a need to investigate the public health nurses' role in relation to these families.

General and specific aims

The overall aim of this thesis was to describe and explore everyday life in families with a child with ADHD and public health nurses' role in relation to these families.

The specific aims were to:

Gain a deeper understanding of the Norwegian parents' lived experiences of having a child with an ADHD diagnosis (I).

Describe parents-, siblings- and the child- with ADHD's experiences of everyday life in a family in which at least one child has ADHD (II).

Investigate family characteristics, family functioning, support and behavior of the child in families with a child with ADHD, from the parents' perspective. A further aim was to explore predictors of family functioning (III).

Explore the public health nurses' role in relation to families with a child who has ADHD (IV).

Methods

Study design

The thesis is designed according to the naturalistic paradigm. A paradigm reflects the general perspective of the world and how reality is understood (Kuhn, 1996). In the naturalistic paradigm, reality is not a fixed entity, but instead is a construction made by the people within a context and created through an interactive process, and different constructs are possible (Polit & Beck, 2012). Inquiry within the naturalistic paradigm involves qualitative data collection and analysis, but there is nothing against the use of descriptive and inferential statistics for the purpose of discovery, explanation and validation (Cody, 2013; Sandelowski, Davis, & Harris, 1989). An explorative and descriptive design with qualitative and quantitative approaches was used in this thesis. The qualitative studies are inductive, while the quantitative study aims to further investigate aspects of the findings from the qualitative studies in a larger sample. An overview of the designs and methods is presented in Table 1.

Table 1 An overview of the four studies in this thesis

Study	Design	Participants/ sample	Data collection	Data analysis
I	Descriptive Qualitative	9 parents	Individual interviews	Phenomenology
II	Descriptive Explorative Qualitative	17 family members	Individual interviews	Phenomenography
III	Cross-sectional Quantitative	354 mothers, 194 fathers	Survey	Statistics
IV	Descriptive Explorative Qualitative	19 public health nurses	Group and individual interviews	Phenomenography

Phenomenology (I)

Phenomenology is considered to be both a philosophical discipline and research method. Phenomenology seeks a deeper understanding of the essence of a phenomenon in the life-world (Husserl, 1995). Life-world can grow and shrink, and represents all possible human lived experiences from an inside perspective (Bengtsson, 2005). Ontologically, the world is lived by human beings, and cannot be separated from them (Lavery, 2008), which means that phenomena can be studied as life experiences. Epistemologically, the knowledge conceived is the structure of lived experiences. Methodically, phenomenology is an attempt to unfold the meanings as they are lived in everyday life, and research will elucidate structures of experience as they appear in consciousness, which means to make the invisible visible (Lavery, 2008). The lived experiences are what we take for granted, and can only be reached through the subject's descriptions. Husserl's (1995) goal was to reach pure descriptions of the phenomenon by setting theories, personal knowledge, subjective experiences, expectations, and established opinions into brackets, "epoché", to be able to observe the world in a purely objective way. While Colaizzi (1978) claims that the researcher's presupposition is necessary to conduct a research project, and that presuppositions can never be entirely eliminated but must be "bridled" (Dahlberg & Dahlberg, 2004) to uncover the phenomenon. During the analyzation process, the researcher interprets the data material to elucidate the most invariant meaning as an essential structure (Colaizzi, 1978; Todres, 2005). The goal is to produce a description of the phenomenon as unbiased as possible, without giving it meanings not supported by the lived experiences described by the participants (Colaizzi, 1978; Strandmark & Hedelin, 2002).

Phenomenography (II and IV)

Phenomenography is a qualitative and empirical research approach used, to identify the similarities and differences of how various phenomena in-, and aspects of, the world around us are experienced, conceptualized, understood, perceived and apprehended (Barnard, McCosker, & Gerber, 1999; Marton & Booth, 1997). The most essential feature of phenomenography is the descriptions of the different ways in which people experience the world around them on a collective level (Marton & Booth, 1997). Ontologically, the assumptions of the world emphasize human thinking as a man-world relationship, and that the only world we can communicate is the world that we experience – a non-dualistic view (Marton & Booth, 1997; Sjöström & Dahlgren, 2002). The first-order perspective is statements made about the world or the phenomenon, what something really is, things taken for granted (Marton, 1981; Marton & Booth, 1997). Phenomenography focuses on the second-order perspective, how the world is experienced. From an epistemological

viewpoint, the knowledge conceived consists of a limited number of qualitatively different conceptions of a phenomenon that can be described and understood by others (Marton & Booth, 1997; Sjöström & Dahlgren, 2002). The conceptions vary not only between people, but also within the same person over time, because the phenomenon's different aspects are conceived in relation to both context and time (Barnard, McCosker, & Gerber, 1999).

Cross-sectional study (III)

Cross-sectional studies with a descriptive and correlational quantitative design are often used in population studies (Altman, 1991; Tabachnick & Fidell, 2013). The purpose of cross-sectional studies is to describe the relationship between variables under investigation at a fixed point in time, and not to look for causal knowledge. Examining findings from qualitative studies in a larger sample gives the possibility to generalize the findings to a larger population and transfer the results to other situations and people (Polit & Beck, 2012).

Participants

Study I, II and III

The participants were parents of children with ADHD, who were also members of the Norwegian ADHD Association (I, II, III) In Study II, other family members were also included. Parents in seven families were recruited by the leader in a local association (I, II). Inclusion criteria were that the child should have been diagnosed before the age of 12 and had the diagnosis for more than one year. The children had to be between the ages of eight to 17 (I, II) and up to 16 (III). The parents asked their children for participation (II). One family and three children (II) in the participating families (I) declined to participate (II). In Table 2 the families in Study I and II are presented.

Table 2 Families participating in Study I and II

Family	1	2	3	4	5	6	7
Parents	Mother ^{1, 2}	Mother ¹	Mother ^{1, 2}	Mother ^{1, 2}	Mother ^{1, 2}	Mother ²	Mother ¹ ☐
		Father ^{1, 2}			Father ^{1, 2}	Father ^{1, 2}	Step father ¹ ☐
Children with ADHD	Son ²	Daughter ²	Son ²	Son☐	Son ²	Son☐	Son☐
Siblings	Son ²	Son ²	Daughter ²		Son ²	Son☐	

¹ participated in Study I

² participated in Study II

☐ declined participation in Study II

In Study III, a sample of 400 mothers and 200 fathers were randomly chosen, selected from the study population (Figure 1). The sample size was calculated to be sufficient by consulting a statistician, and assuming a drop-out rate of approximately 50% (Tabachnick & Fidell, 2013). Fifty-two were parents excluded due to duplicates, wrong address and do not have a child with ADHD. The sample included 354 mothers and 194 fathers. From the group of fathers, 35 mothers responded instead of the fathers. There were no statistically significant differences between those 35 mothers and the other participating mothers (n=182) concerning the variables included in the study. Those mothers were therefore included resulting in a response rate of 48.2%, from mothers 82.2% and from fathers 17.8%. One questionnaire from a father was excluded because of an over 50% internal dropout, with the remaining 264 participants including 217 mothers and 47 fathers.

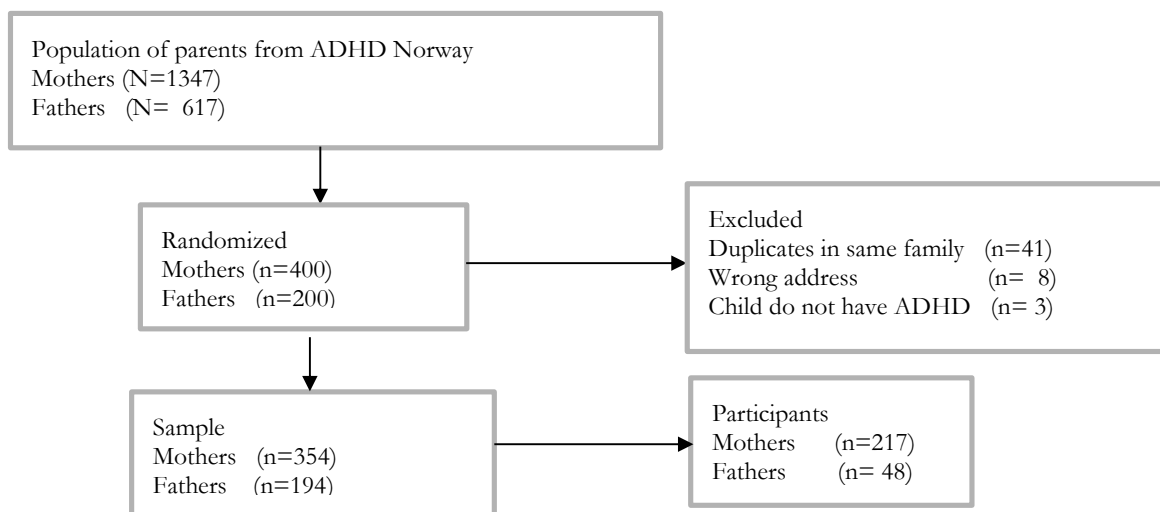


Figure 1 Overview of participants in Study III

An overview of the participants' characteristics is shown in Table 3. The participants were mothers, fathers, stepparents, foster parents (I-III) and children with ADHD (II) and their siblings (II). The parents' ages varied from 28 to 62, with a mean age of 41.6 (I-III). The children's age varied from eight to 17, with a mean age of 12.1 (II).

Table 3 Description of the participants

	STUDY I n=9	STUDY II n=17	STUDY III n=264	%
Gender (parents and children)				
Men	4	3	47	17.8
Women	5	6	217	82.2
Boys	-	6	-	-
Girls	-	2	-	-
Age (parents and children)				
Children				
8-17	-	8	-	-
Parents				
28-39	1	1	100	37.9
40-52	2	2	152	57.6
53-62	6	8	12	4.5
Family member (parents and children)				
Mother	5	6	-	-
Father	4	3	-	-
Child with ADHD	-	4	-	-
Sibling	-	4	-	-
Marital status (parents)				
Cohabitants/married	6	4	223	84.5
Single/divorced/widow/widower	3	5	41	15.5
Education (parents)				
Compulsory-/upper secondary school	4	5	126	47.7
Collage/university	5	4	134	50.8
Missing	-	-	4	1.5
Place of residence (family)				
Rural	7	12	132	50
Urban	2	5	132	50

Drop-out analysis (III)

The response rate was 48.2% and a drop-out analysis was conducted between the responding and non-responding group. Information about the age of the child with ADHD, the place of residence and the parents' gender was given from the ADHD association. No statistically significant differences between the groups were found.

Study IV

The leading PHN in 13 municipalities were asked for the participation of PHNs. Seven declined participation due to other ongoing projects or a lack of resources. Six leading PHNs agreed and a strategic sample of 23 PHNs gave their consent to participate, although four dropped out because of illness. The PHNs differed in age (from 27 to 62 years), postgraduate education (six had more than one degree) and job experience (from newly graduated to 30 years). They worked in both rural and urban municipalities, which varied in terms of geographical extent and number of residents.

Data collection

Procedure (I - IV)

Qualitative interviews took place during spring 2006 (I), spring 2010 (II) and spring 2012 (IV) in the parents' home or in a public office (I, II) and in the PHN's workplace (IV). In Study I, the interviews had a narrative style, to understand the phenomenon deeply (cf. Todres, 2005), in which the interviewer (author) invited a parent to talk freely about his/her experiences related to being a parent of a child with ADHD. In Study II, the interview was based on the participant's experiences to illuminate variations of descriptions of the phenomenon (cf. Marton & Booth, 1997). The children (II) were given the opportunity to draw during the interviews, though none of the children wanted to (cf. Björkman, Almqvist, Sigstedt, & Enskär, 2012; Lewis & Porter, 2004; Piaget, 1929). In Study IV six group interviews, with two to four participants and one individual interview, were conducted. During the first two interviews, an observer was present to give feedback to the moderator (author) regarding her ability to include all the participants and to encourage discussion regarding the phenomenon. The moderator (author) is used to working with groups, and sufficiently attended the participants why the observer withdraws. The interviews were recorded and transcribed verbatim by the author (I, II, IV). The quantitative data collection took place during spring 2013 (III) and a questionnaire was sent by postage mail from the Norwegian ADHD association. The sample was given a number linked to the members list, blinded for the research group, and only the employee at the association had the linking information. Two reminders were sent.

Interviews (I, II and IV)

In Study I, the initial question was, “Could you please tell me about your experiences as a parent from the time you first noticed something different with your child up to the present?” When the parents expressed that they had told what they wanted to, the author asked questions in their own words to acquire a deeper understanding related to the phenomenon and topics they had described. In Study II, an interview guide was used with themes related to family life, social network and the help system. The initial question was, “You are living in a family with ADHD, what does that mean to you and your family?” Follow-up questions using “How?” and “Can you tell more?” were used to explore variations and to obtain rich descriptions of the phenomenon. The children were encouraged to start to talk about their everyday life and the interviewer shunted the children in the direction of the phenomenon (Docherty & Sandelowski, 1999). The children varied in age, and the author attempted to adapt to the child in both language and approach (cf. Barnard et al., 1999). The author is used to talking with children and adolescents as a public health nurse and was aware of the power balance in the interview (cf. Marton & Booth, 1997).

In Study IV, an interview guide was used with the following themes; the PHN’s role related to families with a child with ADHD and the PHN’s role in collaboration with other professionals. Follow-up questions were used to get rich and varied discussions and descriptions.

Questionnaire (III)

The questionnaire contained questions regarding characteristics of the parents, children and families, and two questions about support from the health services. Furthermore, the Sense of Coherence scale (SOC), the Family Assessment Device (FAD), the Strengths and Difficulties Questionnaire (SDQ) and the Social Cohesion and Support Index (SCS) were included.

Characteristics of parents included questions regarding age, gender, marital status (spouse/cohabitant, divorced/single, widow/widower), education (compulsory school, upper secondary school, collage/university), and own ADHD-diagnosis (yes/do not know/no).

Characteristics of the child with ADHD included questions regarding age, gender, and medication for ADHD (yes/no).

Characteristics of the family included questions concerning the number of members in the household, the number of children below the age of 18 living at home, and place of residence (urban/rural).

Two questions asking for ***support from the health services*** in the community- and specialist services were included. The response rate ranged from 1=not at all to 7=to a high degree.

Sense of Coherence-13 scale (SOC-13) was conducted by Antonovsky (1993). The scale measures meaningfulness, comprehensibility and manageability. The short version contains 13 items and the items have a seven-point scale, with the only the anchors defined. The sum score is computed by adding all items, ranging from 13 (weakest SOC) to 91 (strongest SOC).

Family Assessment Device (FAD) was used to measure the general family climate and functioning (Epstein, Baldwin, & Bishop, 1983). In this thesis the subscale General Functioning was used regarding family relationship, communication and problem solving (Miller, Kabacoff, Epstein, Bishop, Keitner, Baldwin, & Spuy, 1994). The instrument contains 12 statements, including six statements regarding healthy functioning in the family and six statements describing unhealthy functioning in the family. The statements are answered on a four-point scale, ranging from 1=totally agree to 4=do not agree at all, with the lower the mean score, the greater family functioning.

Strengths and Difficulties Questionnaire (SDQ) rates the child's behavior and covers five dimensions: Emotional problems, conduct problems, hyperactivity, peer-problems and pro-social behavior (Goodman, Ford, Simmons, Gatward, & Meltzer, 2000). The parent's version was used in this study. The instrument contains 25 statements, with three response alternatives, "not true", "somewhat true" and "certainly true", which are rated 0-2 for negatively worded items and inversely 2-0 for positively worded items. The sum score ranges from 0 to 50, with the lower the score the better.

Social Cohesion and Support Index (SCS) measures individual experience of social support and integration in social networks, which was conducted and related to Cobb's (1976) three classifications of information (Sørensen, Bøe, Ingebrigtsen, & Sandanger, 1996). The index has four questions answered on a five point scale, with five being high perceived social support. The results are presented in a mean score of the four items.

Data analysis

Phenomenology (I)

A phenomenological approach was chosen to obtain a deeper understanding of parents' lived experiences of having a child with an ADHD diagnosis. The data were analyzed according to the steps by Colaizzi (1978). All the transcribed interviews were read repeatedly to acquire a feeling for them and a sense of the whole. Significant statements related to the phenomenon and the aim of the study, were extracted from each interview. The meaning from each significant statement was formulated and a leap was taken from what the participants said to what they meant. In this step, the researchers were challenged to go beyond what was given in the original data to discover hidden meanings and interpret the data, but at the same time, they should stay with the data. The aggregated formulated meanings were grouped into clusters of themes, which then were organized in main themes and subthemes and compared with the transcripts to validate them. The results were integrated into an exhaustive unequivocal description of the investigated phenomenon, a description of the fundamental structure called the essential structure. The findings were subsequently validated by returning them to the participants (cf. Colaizzi, 1978).

Phenomenography (II and IV)

A phenomenographic approach was chosen to gain variations in descriptions of the parents', siblings' and children's with ADHD experiences of everyday life in a family in which at least one child has ADHD, and to explore the public health nurses' conceptions of their role in relation to families with a child who has ADHD. The data were analyzed as a pool of meanings with all the transcripts together (II, IV) (Marton & Booth, 1997), and the steps by Dahlgren and Fallsberg (1991) were followed. The transcriptions were carefully read through by all the researchers to become acquainted with them in detail while establishing an overall impression (familiarization). Significant statements were selected to give a short but representative version of the entire dialogue concerning the phenomenon (condensation). The condensations were compared to find the sources of similarities and differences (comparison). Conceptions that appeared to be similar were put together, compared and discussed to belong to different groups, with each group mutually exclusive (grouping). A preliminary attempt was made to describe the overall picture of the similarities within each group of conceptions (articulating). The various categories were denoted by constructing a suitable linguistic expression (labeling). The obtained descriptive categories were subsequently compared with regard to similarities and differences (contrasting). Additionally, steps from comparison to articulation were

repeated in an iterative procedure to ensure that both the similarities within, and the differences between, categories were discerned and formulated in a distinct way. Analytic closure was reached when noting new emerged from reading and rereading the transcripts and condensations (cf. Green & Bowden, 2006). The findings were presented in an outcome space (Marton & Booth, 1997). The different descriptive categories were related to each other in a horizontal structure (II, IV) in which the categories are equal and at the same level (Uljens, 1989).

Statistical analysis (III)

Statistical analyses were performed using IBM Statistics, Statistical Package for Social Sciences (SPSS), version 20. Concerning statistical methods, parametric tests were considered appropriate (Field, 2013). Sum scores from ordinal level instruments were considered as continuous and given in a normal distribution of the data, and the sample size was sufficient (Field, 2013; Tabachnick & Fidell, 2013). Descriptive statistics with frequencies, percentages, means and standard deviations were used. Comparisons between subgroups were conducted using independent sample t-test, Pearson's Chi-square test and One-way analysis of variance (ANOVA) (Field, 2013). The homogeneity of variance was tested using Levene's test. A post hoc test, Tukey HSD, was used to find out where the difference among the groups occurred. Following this a standard multiple regression analysis was performed (Field, 2013). All tests were two-tailed with a p -value $<.05$. Lastly the internal consistency was measured through the use of Cronbach's alpha (Cronbach, 1951).

Ethical Considerations

Study I and IV were approved by the Norwegian Social Science Data Services and Study II and III were approved by the Regional Ethical Committee for Medical and Health Research. During the entire research process the researchers followed research ethical principles such as autonomy, beneficence, nonmaleficence and justice (Northern Nurses' Federation, 2003).

Ethical considerations regarding *autonomy* were applied with regard to the confidentiality, integrity and voluntariness of the participants (Northern Nurses' Federation, 2003). The participants received an information letter (I, II, III, IV), including one specially adjusted for the children (II). They gave their written informed consent (I, II, IV), with one parent consenting for the child up to the age of 16, and the child assenting (II). In Study III, they consented by returning the questionnaire. Regarding confidentiality (I, II, IV), any information given by the participants was not made accessible to others than the research

group. Anonymity was given (III) with no opportunity for the researchers to link the participants to the data, just a fictitious number. The participants were also informed that they could withdraw from the qualitative studies before publication.

Beneficences, as the opportunity to share their knowledge with other families and PHNs (I, II, IV), were described in the information letter, but also the disadvantages such as discomfort in answering questions and telling their story or answering questionnaires (III) containing questions and conceptions of their child and family situation. *Nonmaleficence*, regarding the researchers safeguarding the participants during the interview, allowed children to have their parent present and not ask integrity-offensive questions (Fog, 2004). The risk of harm was perceived as minimal and the researcher encouraged the participants to contact their GP or the researcher, who could help them in making contact with the community health service if they felt in need for help. Nonetheless, no one made contact with the researcher.

Regarding *justice* the children's right to have a voice and to freely express their conceptions of family life was highlighted (II) (Grover, 2004; United Nations High Commissioner for Human Rights, 1989), and therefore individual interviews were conducted. Being a public health nurse, the researcher was familiar with talking to children. The children may have been vulnerable, and some of the children wanted their mother present during the whole- or parts of the interview. In this way, the children's feelings of security were highlighted, even though they may not have spoken freely about their family life with their mother present.

Trustworthiness (I, II, IV)

To ensure quality in qualitative research, there are several considerations to take into account from designing to publishing, which in this thesis is described with regard to credibility, fittingness, auditability and confirmability, based on Sandelowski (1986). In order to receive *credibility*, pilot interviews were performed, which confirmed that the initial questions (I, II, IV) and interview guide (IV) were relevant to the aim of the studies. In terms of variations in job experience as a PHN, as well as working in rural or urban municipalities which yielded different ways of experiencing the role of being a PHN (cf. Marton & Booth, 1997), and strengthened the credibility of the study. Group interviews are unique insofar as giving the opportunity to discuss diversity in, and achieving various conceptions about, a phenomenon (Hyrkäs & Paunonen-Ilmonen, 2001), and reflections may be brought to a meta level (Walsh & Bowden, 2000). A limitation of the study is that some managers in the municipalities declined to participate due to a lack of resources or because of too many other ongoing projects.

Fittingness (Sandelowski, 1986) refers to whether the findings may be transferable to other settings and groups. To promote fittingness, the participants, both the parents, the families and the PHNs were selected because they could illuminate the phenomenon being studied (Sandelowski, 1986). The parents (I, II) were both mothers and fathers, who were single, married or cohabitating, had different education levels and lived in urban and rural areas. In this way, the findings are well-grounded, and represent both the typical and atypical (Colaizzi, 1978; Marton & Booth, 1997).

During the analytic process, the researchers ensured that the categories were logically related to the phenomenon under study (I, II, IV) and mutually exclusive (II, IV) (Marton & Booth, 1997; Sjöström & Dahlgren, 2002). Colaizzi (1978) was followed (I), and themes and main themes were illuminated in the analytical process to obtain structure and *auditability* (cf. Sandelowski, 1986). The text (II, IV) was analysed according to the steps by Dahlgren and Fallsberg (1991) and presented in an outcome space (II, IV) (Marton & Booth, 1997). Additionally, an analysis form was used (I, II, IV) that made it possible for others to follow the steps of the analysis and to help ensure that the categories were mutually exclusive and represented the variations of conceptions (II, IV) (cf. Sandelowski, 1986).

To gain *confirmability* (Sandelowski, 1986), the researchers had critical reflections throughout the entire research process. The research group had different professional competencies as nurses, which have strengthened the confirmability, thus bridling the presupposition (Dahlberg & Dahlberg, 2004) and reflecting the participants' voice. Quotations were used (I, II, IV) to strengthen the confirmability of the themes and categories (Sandelowski, 1986).

Validity and reliability (III)

In the quantitative study (III), the choice of instruments is based on findings from two qualitative studies (I, II). Regarding the questionnaires, the question of validity as a quality criterion refers to an instrument measuring what it is intended to measure (Polit & Beck, 2012).

Reliability is the degree of consistency or dependability with which an instrument measures a certain attribute, and comprises stability, internal consistency and equivalence (Polit & Beck, 2012).

SOC-13 was constructed by Antonovsky (1987), and has been tested for validity and reliability in other studies (Eriksson & Lindström, 2005). Test-retest over several years

showed stability with some increase with age. The internal consistency measured with Cronbach's alpha ranged from 0.70 to 0.92 in other studies (Eriksson & Lindström, 2005). In this study the Cronbach's alpha was 0.86. The instrument has been used in Norway (Langeland, Wahl, Kristoffersen, Nortvedt, & Hanestad, 2007; Weimand, Hedelin, Sällström, & Hall-Lord, 2010).

FAD General Functioning subscale was constructed by Epstein et al. (1983) and has been tested for validity and reliability in other studies (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). Concurrent validity was tested with two other instruments (Byles, Byrne, Boyle, & Offord, 1988). The internal consistency measured with Cronbach's alpha ranged between 0.82 - 0.86 (Cunningham, McHolm, Boyle, & Patel, 2004; Kabacoff et al., 1990) and in this study the Cronbach's alpha was 0.90. *FAD* has been used in other Norwegian studies (Nrugham, Larsson, & Sund, 2008; Reigstad, Jørgensen, Sund, & Wichstrøm, 2010).

SDQ was constructed by Goodman (1997) and tested for validity and reliability by Goodman and Scott (1999). The questionnaire has been compared with other instruments with the same theoretical foundation, with satisfying correlation (Goodman, 2001; Heyerdahl, 2003). The test-retest had a satisfactory stability within six months (Heyerdahl, 2003). The internal consistency measured by Cronbach's alpha ranged from 0.76 to 0.87 in other studies (Heyerdahl, 2003), and was 0.79 in this study. The questionnaire has been used in both clinical practice and in research, as well as in Norwegian epidemiological studies (Heyerdahl, 2003).

SCS was constructed by Sørensen et al. (1996) and tested for validity and reliability (Klepp, Mastekaasa, Sørensen, Sandanger, & Kleiner, 2007; Sørensen, Mastekaasa, Sandanger, Kleiner, Moum, Klepp, Bøe, 2002), with a Cronbach's alpha of 0.66 (Sørensen, Klungsyre, Kleiner, & Klepp, 2011). In this study, the Cronbach's alpha was 0.78. The scale has been used in Norwegian population studies (Sørensen et al., 2002).

The questionnaire as a whole was pilot tested for clarity with ten parents in the Norwegian ADHD association. They commented that the questions were relevant and the questionnaire was considered to not be offensive. Hence, no adjustments were made.

Main findings

Everyday life in families with a child with ADHD (I, II)

The experiences of being a parent to a child with ADHD were described with the following metaphor *Contending and adapting everyday - windsurfing in unpredictable waters* (I). The life of a parent with a child who has ADHD is sometimes like balancing on a windsurfing board, insofar as trying to maintain oneself as both a person and a parent. The unpredictable winds and waves, managing everyday life in the family, struggling to adapt to the social network or contend with professionals may drive parents into deeper waters or assist them safely to shore. Life for the parents was focused on how to handle a child with aggressive, outrageous behavior and poor impulse control, which led to problems in peer relationships, school achievement and family life. Having a child with ADHD was experienced as a complex and difficult situation that required an inner force to meet the daily challenges related to making and sustaining the efforts best suited to the interest of the child. As the parents grew with this role, their ability to balance on the windsurfing board seemed to improve, although they had to go against the wind and be prepared for stormy waters.

The two main themes (I) *Maintaining self and parenthood* and *Interacting with the Social Network* are interrelated and the strength needed by parents to balance in between these issues. The challenges faced by the parents are dependent on what is most striking in the family situation at the time. The social network and professionals may support the parents to manage their role as parents of a child with ADHD or make it more burdensome.

Maintaining self and parenthood describes times when the parents had to use a great deal of effort to put their individual needs aside in order to focus on their role as parents, which was perceived as frustrating. The subtheme “despair and sorrow” describes how the mothers tended to worry, whereas the fathers adopted a wait and see strategy. The tools that came with the parenting role were felt to be unsuitable for the task of bringing up a child with ADHD. In connection with a child receiving the ADHD diagnosis, the parents described a kind of grieving process and a sense of loneliness.

The subtheme “coping and hope” describes how to better understand what ADHD entails and prepare for new challenges in the child’s development, in addition to seeking more information. In having control and managing their family situation, they found life more rewarding.

Interacting with the social network describes how the network and professionals felt cumbersome to relate to, and as such, became a burden. The subtheme “being a parent in

the eyes of others” describes how other adults often appeared to be intolerant and doubted the parents’ ability to bring up the child, with the parents questioning their own abilities and power of judgment, thus contributing to making the role as a parent even more difficult. In other situations, they experienced acceptance, openness and received support in their role as parents from friends, relatives, and professionals. Support from others lead to having a renewed sense of confidence and a restored inner strength.

The subtheme “dealing with people who are supposed to help” describes how the follow-up from health personnel or teachers, was perceived as negative because it seemed as if professionals in the community were reluctant to take responsibility, which was felt as insulting and frustrating. When professionals entered into a dialog with the parents and opened up to allow for a better understanding, directness and clarification, cooperation was improved.

The family members strive to ensure that the family is a good place to live and grow up in (II), which is described in the descriptive category *Safeguarding a functional family*. The parents and the siblings are sensitive to the needs of the child with ADHD, and attempt to adapt to avoid conflicts with the child.

The conception “managing daily life” describes how structure and routines in the family are regarded as a prerequisite for ensuring that family life provides a sense of security and control. Boundaries are described as necessary for survival as a family, and in relation to the child with ADHD, parents must set strict boundaries, with little room for negotiation and with clear consequences. Conflicts arise more quickly between parents who have ADHD themselves and their children because these parents experience that they are unable to overlook trivial matters, while the children are sensitive to how a parent with ADHD handles his/her own aggression. Medication is perceived, both by the parents and the child with ADHD, to create a filter that facilitates concentration and helps to avoid unimportant impressions, thereby leading to less hyperactivity and aggression. Children with ADHD use a lot of energy on self-control and the maintenance of a façade when not medicated. The relationship between siblings and the child with ADHD is often dominated by quarrels that may end in extreme outcomes. Siblings describe being overlooked because the child with ADHD has laid such a strong claim to his/her place in the family and having a respite, is seen as being absolutely essential for both siblings and parents.

The conception “developing special skills” describes the result of- and is discerned as a process in everyday life. Some family members use experience exchange in their decision making with regard to the challenges ADHD causes, which is also perceived in peer work in the ADHD association. The support to other families with children with ADHD is

described as giving. The parents tell how their role as parents has been strengthened as a result of their participation in parent training, for example using few words and clear messages. The parents develop their own strategies to help the child with homework because the advice they get from school is experienced as not being competent.

“Becoming an adult” is a conception linked to challenges that the transition to adult life make. The parents describe a delicate balance between control and allowing the child with ADHD to become independent. The transition of the child with ADHD to the adult mental health services is described as frightening because confidentiality reduces the parents’ involvement. The children themselves are more relaxed concerning their future.

The descriptive category *Fighting for acceptance and inclusion* (II) deals with how the family members interact with the surroundings to make the child with ADHD a part of society.

The conception “sharing or being alone with responsibility” describes a dilemma that the parents face while waiting too long before applying for help in a difficult family situation or not fighting hard enough at the start to be heard and obtaining help, which made them experience being alone with their responsibility. The parents have perceived that teachers blame them, when a child with ADHD shows unrestrained behaviour at school, which is thought to be degrading and offensive and can be conceived as an indication that they have failed in their role as parents. The support of the specialist healthcare services in providing a suitable treatment regime is experienced as a relief for both the children and parents.

The conception “interacting socially” describes the conflicts that arise when the child with ADHD has difficulty in conforming to social codes or when others do not understand the child. The parents stress the importance of the child with ADHD’s need for positive reinforcement from other children. Being the victim of bullying, exclusion and having few or no friends are described by the children with ADHD. The support of a social network is considered as being vital for acceptance and inclusion, both by the parents and children. Learning strategies to live with ADHD in a social context is regarded as being of importance for the child with ADHD’s development, with changes in behavior and routines viewed as a demanding and intensive process that takes quite a bit of time. Other people’s respect for strategies is also seen as important. The ability to feel proud of oneself with an ADHD diagnosis is also stressed, but in order to achieve this, the child must be accepted and included.

Family function, behavior of the child, sense of coherence and social support (III)

The parents rated the family functioning (FAD) with a mean score of 1.98 (SD 0.52), and the mean score of their child's behavior (SDQ) as 23.39 (SD 6.30). The parents' sense of coherence (SOC) mean score as 62.85 (SD 10.9) and the mean score of social support (SCS) was 3.90 (SD 0.78).

Subgroup comparisons

Independent-sample t-tests were run to compare men and women with regard to their characteristics. Only one statistically significant difference was found, namely that the men were older than the women ($t=3.98$; $p=.000$). Comparisons were also made between groups concerning the parents' marital status, education level, the child with ADHD's gender and medication, and the families' place of residence in relation to SOC, SCS, SDQ and FAD. Marital status showed one statistically significant difference ($t=2.67$; $p=.009$) in SOC, with married/cohabitants having a stronger SOC ($m=63.48$, $SD=11.23$) compared to single parents ($m=59.45$, $SD=8.24$). Parents who lived in urban areas rated their children with a statistically significantly lower SDQ score ($m=22.27$, $SD=6.09$) compared to those living in rural areas ($m=24.56$, $SD=6.37$), ($t=2.93$; $p=.004$).

There were statistically significant differences between parents who had a child medicated for ADHD and parents with a non-medicated child (Table 4).

Table 4 Comparing families with child on medication for ADHD and not

	Medicated children	Non-medicated children	t-test ⁴	<i>p-value</i>
	n= 221	n= 39		
	Mean (SD)	Mean (SD)		
SCS ¹	3.95 (.75)	3.64 (.92)	2.34	.02
SDQ ²	23.04 (6.28)	25.97 (5.64)	2.66	.008
FAD ³	1.95 (.50)	2.14 (.53)	2.06	.04

¹Social Cohesion and Support Index, scores ranging from 1 (lowest) to 5 (highest)

²Strengths and Difficulties Questionnaire, scores ranging from 0 (most favorable) to 50 (less favorable)

³Family assessment device, scores ranging from 1 (most favorable) to 4 (less favorable)

⁴Independent sample t-test

The parents in families where the child was medicated for ADHD reported more social support (SCS) and rated their child's behavior (SDQ) as less problematic and family functioning (FAD) as better than parents in families where the child was non-medicated.

The one-way between-groups analysis of variance was conducted to explore the impact of parents with ADHD on SOC, SCS, SDQ and FAD. There were statistically significant differences between the parents with ADHD and the other parents with regard to SOC and FAD (Table 5).

Table 5 Significant differences between the parents with ADHD and the other parents

	n	Mean (SD)	95% CI	F ³	p-value
SOC ¹				13.51	.000
Yes	39	56.10 (8.30)	53.41 - 58.79		
Do not know	44	60.16 (10.60)	56.94 - 63.38		
No	174	65.03 (10.77)	63.43 - 66.64		
FAD ⁴				3.79	.024
Yes	40	2.17 (.517)	2.00 - 2.33		
Do not know	45	2.01 (.498)	1.86 - 2.16		
No	179	1.92 (.516)	1.85 - 2.00		

¹ Sense of Coherence, sum score could range from 13 (weakest) to 91 (strongest)

² Family Assessment Device, scores could range from 1 (most favorable) to 4 (least favorable)

³ One-way Analysis of Variance (ANOVA)

Those parents with ADHD rated a significantly weaker sense of coherence (SOC) and poorer family functioning (FAD) compared to those reporting not to have ADHD.

Regression analysis

The standard multiple regression analysis showed that the combination of independent variables explained 46.2%, of the variation on the dependent variable, FAD. The independent variables which gave significant contributions are shown in Table 6.

Table 6 The dependent variable FAD¹ and independent variables contributed significantly

Independent variables	B	Std. error	Beta	t-value	p-value
Parent age	.014	.004	.163	3.274	.001
SOC ²	-.017	.003	-.361	-6.338	.000
SCS ³	-.163	.038	-.246	-4.312	.000
SDQ ⁴	.018	.004	.217	4.252	.000
Support from community health services	.042	.015	-.139	2.718	.007

¹Family assessment device, dependent variable, scores could range from 1 (most favorable) to 4 (least favorable)

²Sense of coherence, sum score could range from 13 (weakest) to 91 (strongest)

³Social cohesion and support index, scores could range from 1 (lowest) to 5 (highest)

⁴Strengths and difficulties questionnaire, sum score could range from 0 (most favorable) to 50 (least favorable)

⁵Support from community health services, scores could range from 1 (lowest) to 7 (highest)

The parents' sense of coherence described most of the variation followed by support from the social network and the child's behavior. SOC, SCS and support from

community health services had a positive effect on FAD, thereby showing that a strong sense of coherence and support predicted a better family functioning.

The public health nurses' conceptions of their role (IV)

In order to give the family guidance in their contact with the support services, and to map their individual needs, the PHN focused on helping the family, the parents and the children, and on establishing a good relationship as described in the descriptive category *Supporting the family unit*. A conception the PHNs highlight is, "To strengthen the parental role". Trust, continuity and dialogue between the parents and the PHN are described as important approaches. Parents need support to acquire the strength to follow up both the medication and other interventions. Some parents seek reassurance in their role, and others may under-communicate their anxiety. According to the PHNs' the supervision of parents, both individually and within a group, are used as interventions to strengthen parents in their role.

"To meet the child in everyday challenges" is a conception where the PHNs describe their contact with the child in the school health service. The PHNs perceive it as more important for the child to receive the help needed to cope with everyday life than to reach a diagnosis. Their role is to be a reliable and available adult who sees and listens to the child without putting demands on him/her. Having the courage to rely on observations and personal intuition is regarded as essential for the PHNs. The conversations with the child are described as focusing on the child's coping with everyday life and strengthening the child's resources. Some PHNs conceive that they are able to guide in psychosocial matters, while others are of the view that such issues are not their tasks.

"To have a family-focused approach" is a conception describing that some PHNs are offering support and supervision to the entire family in order to retain an overall perspective, including the mapping of resources to reinforce the family in coping, while others are more concerned about the parents. Conversations with siblings appeared to be somewhat rare and understood as an unfulfilled need.

Understanding the child is a descriptive category in which the PHNs explained their previous uncertainty about their own competence about children with ADHD, but that they have become more confident about communicating this competence and about focusing on interventions at an early point in time.

"To use professional competence" is a conception describing the PHN's concerns when the child does not follow the phases of development, but their worry is perceived as

difficult to express. As normality is perceived as narrower than previously in society, some PHNs ask themselves if that is why there is a need for a diagnosis for some children. Some describe waiting to intervene and follow-up, while others perceive that they have available interventions to offer. Lastly, some PHNs perceive that they do not have proper procedures for these children and they want clear policies.

“To choose the time and arena for observation” is a conception regarded as essential. Observation of the child at the PHN’s office is not perceived as suitable, so moving the consultation to the playroom and observing the child at play is perceived as giving. In addition, home visits are experienced to represent a good arena for observing. Observation in the classroom or schoolyard is conceived of as providing varied and rich information since the child is interacting with other children. An observation team in the nursery school, in which staff from the PPS, the nursery school, the child welfare service and the public health centre participate, is regarded as yielding valuable information because of complementary understandings.

Multidisciplinary collaboration is a descriptive category describing different levels of collaboration called for by the PHNs, which is a significant initiative in the follow-up and early interventions.

The conception “to work together” involves different collaborative partners, and is perceived as important but informal, while the role of the PHN is unclear. A joint organization is viewed as bringing collaborative partners together, and those who are not part of a joint organization want such a change. Collaboration with the GP is regarded as difficult but important, as the GP is often assigned to follow-up medication. The PHN is seeking collaborations with the Children and adolescents’ psychiatric service, which is described by some as infrequent and with poor exchange and others as a good collaboration.

“To be an active partner” is a conception describing the PHNs’ choice to include themselves as a collaborating partner. The PHN ask for feedback from collaborators about those families where the child has been diagnosed with ADHD, whereas parents expect the PHN to know.

Summary of the findings

The families' everyday life is influenced by living in unpredictability, though they are striving for predictability. Life inside the family unit and their relation to society are interrelated. *Inside the family unit*, the parents are experiencing an interchange between maintaining the self and parenthood with a child with ADHD. The parents experience despair and sorrow in their battle for their child, but they also describe coping and hope for the future. The parents try to manage their child with ADHD and the everyday demands. In safeguarding a functioning family, the family members are tuning themselves in on the child with ADHD's shifting mood and the use of strict boundaries to develop special skills to live with ADHD, both within the family and in the society. Parents who have ADHD themselves seem to be more vulnerable and report a weaker sense of coherence and poorer family functioning than other parents. Medication has both advantages, like less behavioral problems in the children and better family functioning, and disadvantages like dilemmas of using central stimulating medication to a child and side effects. Siblings are influenced by living in a family with a child with ADHD, and are experienced as both agitators and diplomats, with some describing being overlooked and coming into strong opposition against their parents. The parents', sense of coherence and the child's behavior are important in family functioning.

In relation to society the family is interacting with the social network and fighting for acceptance and inclusion. In the upbringing, the child with ADHD needs feedback from grownups and friends, but the children with ADHD describe having few or no friends. To be accepted and included are essential. The child's behavior problems decrease and social support increase if the child is on medication. In the sharing of responsibility and follow-up from personnel in the help systems, some parents describe teachers and health professionals as delaying the process leading to a diagnosis. Perceived support from the community health services predicts family functioning positively. A relationship with professionals built on openness, trust, support and guidance, all of which are essential for cooperation. The PHNs describe their role in relation to these families as both a peripheral and essential collaborating partner. The choice of arena and time are crucial for observing and understanding of the child. To reveal early signs of difficulties in the child, supporting and supervising the family as a whole or the individuals within the family, referral and follow-up of the child and family are the PHN's responsibility. The collaboration with other professionals depends on the personnel's motivation, and those not having a joint organization around families are asking for reorganization.

Methodological considerations

This thesis is grounded in the naturalistic paradigm and the knowledge generated is dominated by the participants' view of the world and their lived experiences. The design is descriptive and explorative, and both qualitative and quantitative methods are used. The methodological considerations are discussed in relation to trustworthiness in the qualitative studies and validity and reliability in the quantitative study.

Trustworthiness of the qualitative studies (I, II, IV)

The participants (I, II, III) were members of the ADHD Association, and may be the most articulate, accessible and high status parents, with the resources and motivation it takes to become the member of an association, and may therefore represent the elite (cf. Sandelowski, 1986). Nevertheless, these parents have the voice and ability to give rich descriptions of different perspectives of the phenomenon. As a member of the association, they had participated in groups with other parents and shared experiences, which may have helped them to reflect over their everyday life and develop their ability to narrate their story. The participants represented a varied group of parents, according to marital status, gender, educational level and place of residence, and they had children of different ages (I, II) which may strengthen the fittingness (cf. Sandelowski, 1986).

In Study II, the participating children were set to the age of seven according to “the concrete operational stage” (Piaget, 1929), in which children's abilities to perform logical operations in their thoughts are developed, as well as when the child has the ability to give rich descriptions and reflect on their everyday life. The age of 17 was set as a limit according to legacy, while the child is considered as a grown-up at the age of 18. The number of participants (II, IV) was found to be sufficient due to a phenomenographic study (Larsson & Holmström, 2007).

During the interviews in Study I, the mothers narrated and gave rich stories of their everyday life compared to the fathers. This corresponds with Kvale (2006), who asked if the qualitative interview suits women more than men. In the interview in Study II, follow-up questions were used that made it possible to identify the variations of experiences according to the phenomenon (cf. Marton & Booth, 1997). This approach may suit the fathers better, insofar as asking them to tell more and describe the variation in their experiences. However, despite using fewer words than the mothers, the fathers contributed with deep descriptions in the interviews (I, II).

The choice of individual interviews with family members (II) was made to strengthen the credibility and regarding justice for the children. It is important that children receive the opportunity to freely express their views and be heard (United Nations High Commissioner for Human Rights, 1989). The children, both children with ADHD and their siblings, talked freely about their everyday life experiences, and some expressed that it was good to be in focus for the conversation. To conduct family interviews may cause the family members to avoid certain experiences, or the most powerful person in the family becomes the voice for them all (cf. Ahlström, Skärsäter, & Danielson, 2009).

The interviews (IV) were conducted in groups of PHNs, and provided a rich amount of data when discussing the phenomenon. The variation of conceptions between group members and the reflections may be brought to a meta-level (Green & Bowden, 2006), while group interviews may be limited if power differentials exist between the participants (Jayasekara, 2012). However, the participants reflected together and became acquainted with their colleagues' conceptions of their role as a PHN in relation to these families, and the fact that all had experience with families with a child with ADHD strengthened credibility. Group dynamics can also assist people in expressing and clarifying their views in ways that are less likely than in an individual interview. The PHNs illuminated issues in their work, which was conceived of as important knowledge for other PHNs and may benefit the families.

The participants subsequently read the findings and recognized them as their own experiences (I), which strengthen credibility (cf. Colaizzi, 1978). On the other hand, the findings represent the essence of the phenomenon under study, and the interviews have been analyzed by the research group, moving away from the individual lived experiences to a more invariant meaning. In phenomenography (II, IV), the participants are not asked to confirm the finding (Marton & Booth, 1997).

To secure trustworthiness, the author wrote down notes based on self-reflection during the entire research process, in order to become aware of own biases and assumptions as a protection from imposing a pre-understanding of the study (Colaizzi, 1978). The research group had different professional competence as nurses, which may have strengthened trustworthiness.

Validity and reliability of the quantitative study (III)

To avoid selection bias (cf. Polit & Beck, 2012), the sample was randomly selected from the members of the Norwegian ADHD association. The sample was comprised of members of an association, they lived in rural and urban areas and represented all counties in Norway. Though, generalizability must be made with caution. Hence, the knowledge revealed could be important to non-members other families.

Due to two reminders and information about the study on the association's web-site, the response rate was only 48.2%. A low response rate was expected, though it may represent a risk of bias (Polit & Beck, 2012). Other studies with similar groups also had a low response rate (Ford & Rechel, 2012; Weimand et al., 2010). The reason for not responding is not known, but those who did not respond may have been under more strain. The drop-out analysis with the known parameters of place of residence, the parents' gender and the age of the child with ADHD was conducted between responding and non-responding groups and no significant differences were found.

There were more mothers (82.2%) than fathers (17.8%) who responded which reflects the size of the population. Moreover, some mothers responded instead of the fathers, and those mothers were compared with the other responding mothers concerning the included variables. Since there were no statistical differences between the groups, mothers who responded instead of the fathers were included. In another ADHD study, an overrepresentation of mothers has been shown (Cussen, Sciberras, Ukoumunne, & Efron, 2012).

Well-known instruments tested for validity and reliability were used in this thesis. With regard to reliability (Polit & Beck, 2012), the internal consistency measured with Cronbach's alpha, exhibited good values, and were comparable to previous studies.

Concerning statistical analysis, parametric tests were considered appropriate (Field, 2013). As the assumption of normal distribution and the homogeneity of the variance were met, the sum and mean scores from the instruments were considered continuous. The sample size was also considered appropriate according to the analysis. Since multiple tests were performed, a Bonferroni correction could have been performed, thus adjusting the α -level (Field, 2013). Deciding on a stricter level of significance might reduce the risk of type 1 error (falsely rejecting the null hypothesis), but increase the risk of type 2 error (thereby rejecting the effect there really is).

Discussion of the findings

The overall aim of this thesis was to describe and explore everyday life in families with a child with ADHD, in addition to the public health nurses' role in relation to these families. The main findings describe how the families were living in unpredictability while striving for predictability. Their everyday life was influenced by the behavior of the child with ADHD, the interaction between parents, siblings and the child, their fight for acceptance and support from their social network and professionals. Family functioning was associated with the parents' sense of coherence, the child's behavior and social support. The findings are discussed according to everyday life inside the family unit and in relation to society, even though they are interrelated arenas. The public health nurses describe their role related to these families both a peripheral and essential collaborative partner.

Inside family unit

Everyday life in a family with a child with ADHD is influenced by the child's behavior (I, II) managing the parental role (I, II), the siblings interaction with each other (I, II) and the family functioning (I, II). The parent's age, sense of coherence, the child's behavior, support from the social network and the community health services revealed a statistically significant impact on family functioning (III).

The parents described how they struggled to manage and raise their child with ADHD and how they searched for tools to assist in the upbringing (I, II). They rated their child's behavior with more difficulties, (SDQ 23.4), than children aged 10 to 19 in a Norwegian population survey (SDQ of 10.7) (Van Roy, Grøholt, Heyerdahl, & Clench-Aas, 2006). To manage the situation, some parents used principles from the Parent Management Training-Oregon Model (PMTO), with few words and clear messages. The PMTO was described as being valuable in the interaction with the child (I, II), and Hagen, Ogden and Bjørnebekk (2011) found that interventions with the PMTO gave greater effective discipline and family functioning after a one-year follow up in a similar sample. Family-directed interventions may improve the management of ADHD (Cussen, et al., 2012), whereas the PMTO may also have had some positive effects on other family members (II). This kind of interventions ought to be offered to families with children with behavioral problems.

The parents with ADHD handling of aggression influence the interaction with their children (II). Parents with ADHD reported a weaker sense of coherence and poorer family functioning (III). Those parents may display symptoms similar to their children

without being diagnosed and treated for ADHD symptoms, which could contribute to poorer family functioning (Cussen et al., 2012). Other studies have found that parents with children with ADHD use less positive parenting behavior (Edwards et al., 2001; Foley, 2011; Tripp et al., 2007). The usual tools in the parent role were not useful and did not match parenting a child with ADHD (I). There is no direct path to better family functioning, although the identification and recognition of mental health problems in parents is essential. Kendall and Shelton (2003) found different management styles in families with children with ADHD. The families (I, II) seemed to reflect all types of management styles, with the exception of “the chaotic family”. Nonetheless, this process is not linear, and the families can oscillate between different management styles. When they meet new challenges such as the child’s puberty, they may go to another management style, and when they overcome the obstacles, they reinforce the family again.

The ability to adapt to life events and a willingness to continue to strive when life is demanding may be seen as the creative factor in sense of coherence (Antonovsky, 1987), with family functioning being strongly influenced by the parents’ sense of coherence (III). Parents with a strong sense of coherence may have an advantage. García-Moya, Rivera, Moreno, Lindström and Jiménez-Iglesias (2012) highlighted the importance of dynamics and security in the family in the development of sense of coherence, while a study by Edbom, Malmberg, Lichtenstein, Granlund and Larsson (2010) found that a strong sense of coherence was associated with less ADHD symptoms in early adulthood. Interventions to improve children’s development of a strong sense of coherence, which involves the family supporting communication and parental knowledge, should be important (García-Moya et al., 2012). To see the child behind the ADHD diagnosis and the child’s abilities, and not only the demands in life, were stressed by the parents (I, II), and everyday life may play an important role in providing meaningful experiences and developing a strong sense of coherence (Antonovsky, 1987; García-Moya et al., 2012). The three dimensions of sense of coherence, comprehensibility, meaningfulness and manageability (Antonovsky, 1987), can be used as a framework in family interventions. Comprehensibility addresses the families need for support, information and supervision regarding the child with ADHD, as a perception of environmental events to be ordered and structured more than being chaotic. Meaningfulness involves that the family’s resources are in balance with the demands faced. The parents described hope for the future of their child (I), which may be connected to meaningfulness. Manageability encompasses the use of flexible coping strategies. The PHN as a facilitator in the access to appropriate services and the supervision of parents may increase the families’ coping in their everyday life. The dilemma raised by the PHNs is the use of many interventions in the community, which may delay the child’s diagnosis (IV). By contrast, the use of low-threshold- and early interventions should not hold back a referral to a specialist for

assessment. The dialogue with all family members to map their resources and needs is a central clue.

The findings showed that the use of medication was described as a dilemma, but also as a valuable treatment combined with other interventions (I, II) supported by other studies (Hansen & Hansen, 2006; Jackson & Peters, 2008). There are several concerns, such as the ethical issues associated with the long-term use of stimulant medication in young children, modifying their behavior and the nature of short- or long-term side effects (Daley, 2006; LMI, 2014). Parents have reported changes in personality in their child such as a zombie-effect in the use of medication (Jackson & Peters, 2008). Medication helped to facilitate concentration and to avoid unimportant impressions (II). The medication of the child has given less problems in family functioning and less behavioral problems in the child (III). The use of medication can reduce the severity of some behavioral problems while improving the social interaction with peers and others around them, and the use of psychosocial interventions is a valuable complement to stimulants (Daley, 2006). In Norway, the medication must be subscribed by a specialist in child and adolescents' psychiatric services, and the child's medication is followed-up by the families GP (LMI, 2014). In this flux of dilemmas regarding medication, parents may need someone to discuss these issues with, and the public health nurse and the family's GP should take responsibility for this and for the follow-up of medication.

The siblings described their relationship with the child with ADHD as complicated (II). The arousal of conflicts, attempting to tune in on the moods of the child with ADHD, the experience of being left in the shadow of the child who needs most of the parents' attention (I, II) and the negative effect of their social life, such as not feeling free to invite friends at home (II), are described as being cumbersome. Kendall (1999) describes the amount of severity in violence and aggression as affecting siblings as being victimized and overlooked by the parents. Those siblings are having more emotional problems than other siblings (Steinhausen et al., 2012), as well as more conflicts (Mikami & Pfiffner, 2007). The public health nurses described dialogues with siblings as important but scarce (IV). Group interventions with siblings of children with disability, such as ADHD, have been positively evaluated (Granat, Nordgren, Rein, & Sonnander, 2012). Siblings of children with ADHD described that they had taken a less nurturing role, perceiving the child as being less dominant. The role-playing in the group intervention provided the siblings with knowledge on how to solve problems in relationship and establish confidence in their right to set limits toward the child with ADHD and improving knowledge of the difficulties of ADHD. Interventions that conceive knowledge may give the siblings tools to use in their everyday life in the relationship with the child with ADHD. The cooperation between the community health services and volunteer organizations is asked for in the latest guidelines in Norway by the Department of Public

Health (2013), and it is important to develop cooperation according to these guidelines.

In relation to society

Social support (SCS) was a positive predictive factor on family functioning (FAD) (III), and the need for feedback from other children, families, teachers and friends was highlighted as important for the child's socialization in society (II). Moreover, a renewed sense of confidence and restored inner strength was described when the parents experienced acceptance and support from family and friends (I). Social support was found to be essential to family management in families with a child with ADHD (Brown, Howcroft, & Muthen, 2010), in addition to interact positively on mental health (Sørensen et al., 2008). Although mental health was not mentioned by the informants (I, II), and therefore not investigated in Study III, the positive correlation between sense of coherence and mental health has been found in other studies showing people with a strong sense of coherence also reporting good mental health (Eriksson & Lindström, 2006). External resources, such as social relations, may help promote the balance in the demands of life (Antonovsky, 1987), while the PHNs may support parents and children in encouraging the family's connectedness with social network.

Parents and children described difficulties in peer relations (I, II), both when other children and parents did not respect the child's strategies in handling their own aggression and in the child's difficulties in understanding social codes. Hurt, Hoza and Pelham Jr, (2007) ask if fathers may provide as role models for positive social interactions between boys and peers in both gender-appropriate behavior and conflict resolution. An association was found between the feeling of family loneliness and problems with peers, and when the children withdraw from family interactions in general, this may reduce their opportunities to acquire and practice social skills. Shattell et al. (2008) discuss whether children with ADHD's aggression and impulsivity may exert an influence on their ability to follow the rules of social interaction. The child's opportunity to learn to avoid conflicts, to be patient and to develop empathy may go through one good friend (Mikami, 2010). Having one good friend may be more important than being in a group of risk-taking peers (cf. Umberson & Montez, 2010), which is what the parents feared the most because the child was easily influenced (II).

Children with ADHD described themselves to be somewhat different than other children (II), including being more creative or antisocial, but also wanting to be like everybody else, which was also described by Shattell et al. (2008) and Neophytou and Webber (2005). The oldest adolescents in this thesis tended to accept the diagnosis, though they could also see the positive effects of the diagnosis. Help from friends, teachers, music and

physical activity may also have a good influence on children with ADHD (Singh, 2011). The key mechanism in social support is social norms and being liked by peers (Umberson & Montez, 2010), although the oldest adolescents may have matured and become more sure of themselves (II).

The parents from rural areas rated their children as having more severities than parents from urban areas (III). A child in rural areas may be more visible compared to those living at urban areas with a larger amount of people, and less social support was reported from parents of non-medicated children (III). Others' opinions of the child with ADHD may represent the dark side of social relationships, implying stress and an undermining of health (Umberson & Montez, 2010).

The parents described putting their own life on hold, setting studies and work aside because of their strained family situation (I, II), which was also supported by another study (Nes et al., 2013). Being employed may provide benefits such as appreciation and social inclusion, management and personal growth. Rather than being a recipient of assistance, the opportunity for nurturance in a relationship may influence SOC in a positive direction (Langeland & Wahl, 2009). Many parents have the nurturance role in their family, but being the provider in other social relationships may be positive, as for example work and companionship in the ADHD association (I, II).

The parents described their frustration in their struggle in raising their child and the pieces falling into place in a picture when the child is having the diagnosis (I, II). Other people, such as relatives (I, II) and teachers in the community (I, II) questioned whether ADHD is a diagnosis. The PHNs claimed that the concept of normality is narrower than previously (IV), which questioned whether the society claims the need for a diagnosis. Since the medication of the child leads to better family functioning and less behavioral problems in their child (III), the diagnosis may have made a difference in everyday life. To reveal early signs of special needs and the assessment of early interventions may point out who have the diagnosis and who does not (Ogden & Hagen, 2008). Larsson et al. (2009) found that some children did not fulfill the criteria for an ADHD diagnosis one year after the Webster-Stratton program. These parent management interventions require multidisciplinary collaboration and the special training of personnel and the PHN is the first encounter and become the trusted follower throughout the course of diagnosis and care.

The public health nurses' role

Poor family functioning predicted less perceived support from the community health services (III). The PHNs described the importance of supporting the family unit and supervising parents in both individuals and groups to help strengthen the parents in their parental role (IV). The PHNs have a responsibility to identify children and families with special needs, and the question is how to identify those with special needs.

The use of conversations with children and adolescents in the school health service was described by the PHNs, some of whom asked for helping tools and clear policies in order to make observations more systematic and informative in their contact with families with children with a possible ADHD diagnosis (IV). In the school health service, a health and lifestyle tool in health dialogues has been used (Golsäter, Sidenvall, Lingfors, & Enskär, 2011). The use of health dialogues or working tools such as genograms and ecomaps has been proven to be useful in identifying and following up children and families with special needs (Clausson & Berg, 2008). Golsäter, Sidenvall, Lingfors and Enskär (2010) described health dialogues between school health nurses and pupils, which aimed to gain knowledge about and insight into, individual health problems, and to give advice. Health dialogues are dominated by close-ended questions and the nurses as taking the initiative and being the most active partner. The pupil's psychosocial health was less discussed than the physical lifestyle (Golsäter, Lingfors, Sidenvall, & Enskär, 2012), as the use of close-ended questions may hinder the PHNs in their supervision of both parents and children (Tveiten, Ellefsen, & Severinsson, 2005). Some of the PHNs said that conversations with children were not their responsibility, while others focused on the children's and families' everyday life (IV). Family counselling was described as an intervention with a professional moderator as a neutral third party, which could increase the families' sense of control over their life circumstances (II).

Supervision requires a dialogue in which the parents, children and the PHNs are the experts. The parents and children are experts on their family life and their experience of living with ADHD, and the PHNs are experts in child development (Tveiten & Severinsson, 2005). Parents and PHNs described a trusting relationship that might lead to a mutual understanding of the family and the PHN in terms of thoughts, attitudes, experiences and feelings (I, IV). In building a trusting relationship, the PHNs may hesitate to communicate the worry regarding the child's development, so consequently they may wait and see and delay interventions (IV) (Tveiten & Severinsson, 2006). In a trusting relationship, in which the PHN accepts the parents as experts on their child, the PHN should communicate the difficulties in the child that may help the parents to see their child's special needs, and consent to the interventions of the child.

The PHNs focusing on everyday life instead of the child's diagnosis (IV) which reflects a holistic view of health, such as the care-oriented model (Hwu et al., 2001), and mirrors the PHNs' broad role in health promotion. The concept of the family used in family nursing (Friedman et al., 2003) may be approached in different ways in the PHNs' work. Sometimes, the focus is on all family members in interventions, with the family in the foreground and the family as an interactional system. When having the parent-child relationship in focus, the PHNs is working with the family as a subsystem of clients. In the school health service, the PHN may work primarily with the child, and thereby with the family as a context or the family as a sum of its parts. In general, most nursing is individually focused with the client in the foreground, with the family members as separate rather than interacting units. In the PHN's work with the social environment, the family with a child with ADHD is viewed as a part of society that is in the foreground. Which focus the PHNs have on the family may depend on and change according to the situation. In interventions such as parent management training and family intervention sessions, the PHN sees the family as either a subsystem or as a client. The interventions regarding a child with ADHD require multidisciplinary collaboration.

The role of the PHNs is often described as unclear in the multidisciplinary collaboration, and the choice the PHNs make in being an active partner or not was stressed (IV). The tacit knowledge (Clancy & Svensson, 2010), and the concerns the PHNs have but which is not easily expressed (IV), may be conceptualized when communicating their concerns with parents and collaborative partners. Clancy, Gressnes and Svensson (2012) stated that PHNs reported that the most missed collaborative partner in relationships with children, young people and families was the mental health professionals, whereas second was the child protective worker. Some communities have a joint organization, with PHNs, child protective workers, nursery school teachers and mental health professionals in the same unit (IV). Communities also have interventions comparable to PMTO (cf. Ogden & Hagen, 2008) or the Webster-Stratton Program (cf. Webster-Stratton & Reid, 2010) anchored in the collaborating team (IV). Within a joint organization, the PHNs were more secure about their own competence and who their cooperative partners were, having both a common mind set and complementary knowledge was also given (IV). The collaborative discussions may be easier and the role of the PHN's clearer in the multidisciplinary work within a joint organization. On the other hand, the personnel's motivation was also described as a component in collaboration (IV). Further intervention studies, with a focus on organizations' influence on the PHN's role and families with children with ADHD are also needed.

Conclusions and implications for practice

Conclusions

- ✓ Being a parent to a child with ADHD is a demanding situation, one that is both complex and intense, but also rewarding. They must demonstrate an inner strength to manage parental issues.
- ✓ Siblings describe how family life influences them in family relationships, both positively and negatively, and how their social life is negatively influenced.
- ✓ Parents and children with ADHD highlight the importance of developing special skills to live with ADHD, focusing on possibilities and not only difficulties.
- ✓ Parents with ADHD and families with non-medicated children with ADHD seem vulnerable.
- ✓ Support from both the social network and support from the health services may strengthen the parents' feelings of meaningfulness, comprehensibility and manageability, and increase family functioning.
- ✓ Public health nurses' role in relation to families with a child with ADHD is varying. Some are uncertain about their competence and have difficulties in expressing their worries concerning the child. Some act as collaborative partners with both the family and other professionals.
- ✓ The public health nurse is in a unique position to identify those families with high demands.

Implications for practice

- ✓ The increase in parents' understanding of the difficulties of ADHD symptoms should make them more prepared to face the challenges in everyday life, and being more likely to consent to interventions.
- ✓ Interventions need to be established regarding families with high demands before family problems become too severe, and the child reaches a possible diagnosis.
- ✓ Joint organization and guidelines may provide multidisciplinary collaboration and benefit families.
- ✓ The public health nurses working in child health clinics and schools have responsibility and opportunity to promote and prevent health problems and thereby to identify and follow-up families with high demands.

Further research

- Studies should be carried out that focus on possible internal and external factors influencing family functioning, such as parents' mental health and family sense of coherence and social relations.
- Studies should be carried out with all family members.
- Longitudinal studies are necessary regarding families' everyday life and family functioning.
- Studies to develop instruments used to reveal early signs of behavioral problems are needed.
- Intervention studies should be carried out on the impact of multidisciplinary collaboration concerning these families.

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Everyday life in families with a child with ADHD and public health nurses' conceptions of their role

ADHD is one of the most common behavioral disorders diagnosed in children. These children have difficulties regarding the regulation of emotions, maintaining attention and impulse control, all of which influence family and social life. The aim of this study was to describe and explore the everyday life of families with a child with ADHD and public health nurses' role in relation to these families. The parents were contending with- and adapting to the parental role and social network. The family attempted to safeguard a functioning family in managing their everyday life, tuning themselves in on the child's shifting moods, using strict boundaries and developing special skills. The family fought for acceptance and inclusion when interacting with their social network and professionals. Parents with ADHD and families with non-medicated children reported more problems in family functioning. Characteristics in parents and the child with ADHD, as well as support from the social network and community health services, all influenced family functioning. The PHNs described their role as both a peripheral and collaborating partner, asking for guidelines and multidisciplinary collaboration. The public health nurse is in a unique position to support and supervise these families.

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