

# Nordic School of Public Health NHV

# Fathers involved in children with type 1 diabetes:

finding the balance between disease control and health promotion

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Fathers involved in children with type 1 diabetes: finding the balance between disease control and health promotion
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# **Abstract**

**Background:** Type I diabetes is a chronic disease that places great demands on the child and family. Parental involvement has been found to be essential for disease outcome. However, fathers' involvement has been less studied, even though high paternal involvement has been correlated with less disease impact on the family and higher quality of life among adolescents.

Aim: The overall aim of the study was to explore and analyze constructions of fathers' involvement in their child's everyday life with type 1 diabetes from an ecological and health promotion perspective. Four specific aims were applied: 1) explore and describe discourses in health care guidelines for children with type 1 diabetes in Nordic countries, focusing on parents' positioning (I), 2) analyze how Swedish pediatric diabetes teams perceived and discussed fathers' involvement in the care of their child with type 1 diabetes, and to discuss how the teams' attitudes toward the fathers' involvement developed during a focus group process (II), 3) explore and discuss how fathers involved in caring for their child with type 1 diabetes experience support from their pediatric diabetes team in everyday life with their child (III), and 4) analyze how involved fathers to children with type 1 diabetes understand their involvement in their child's daily life and to discuss their perceptions from a health promotion perspective (IV).

Material and methods: A qualitative and inductive approach was applied. Data were collected and analyzed during 2010-2012. The sample consisted of three pediatric guidelines originating from Norway, Denmark and Sweden (I), three Swedish pediatric diabetes teams (PDTs) (II), and 11 (III) and 16 (IV) fathers of children with type 1 diabetes who scored high involvement on the Parental Responsibility Questionnaire. Data were collected through repeated focus group discussions with the PDTs (II), online focus group discussions (III) and individual interviews (III, IV) with the fathers. Three analysis methods were applied: analysis of discourses (I), Constructivist Grounded Theory (II, III) and content analysis (IV).

Findings: The findings illuminated the complex interaction between the pediatric guidelines, the PDTs and the fathers. Fathers highly involved in their child's daily life experienced different levels of tension between the general recommendations and their personal experiences of living with a child with type 1 diabetes (III). The fathers regarded their involvement in their child's diabetes care as additional to their general parenting, and a fine balance was identified between a health promotion perspective and a controlling involvement. The common denominator between the highly involved fathers was their use of parental leave (IV). The PDTs initially perceived fathers' involvement as gendered and balanced on the mother's engagement, but as focus was set on fathers' engagement the PDTs increased their awareness of this and started to identify and encourage their engagement (II). At the macro-level, parents' voices were diminished in Nordic pediatric diabetes guidelines in favor of an expert discourse (I).

**Conclusions**: Fathers' involvement concerning a child with type 1diabetes is constructed in a complex way, based on an interaction between the fathers' perceptions of their additional involvement and the support provided by the PDTs; the PDTs' perceptions of the fathers' involvement; and how parents/fathers are constructed in pediatric diabetes guidelines. In order to promote the health and well-being of children with type 1 diabetes, fathers' involvement needs to be taken into account in the pediatric guidelines as well as in clinical practice.

**Key words:** children, fathers' involvement, health promotion, pediatric diabetes team, type 1 diabetes

# Sammanfattning

**Bakgrund:** Typ 1 diabetes är en kronisk sjukdom som ställer stora krav på barnet och dess familj. Föräldrarnas engagemang har visats vara grundläggande för hur sjukdomen hanteras. Även om fäders engagemang är ett mindre exploaterat område så visar studier att ett stort engagemang hos pappor minskar den negativa sjukdomseffekter på familjen och ökar livskvaliteten hos ungdomar med diabetes.

Syfte: Det övergripande syftet var att, ur ett ekologiskt och hälsofrämjande perspektiv, utforska och analysera konstruktioner av pappors engagemang i deras barns vardagsliv med typ 1 diabetes. Fyra specifika syften styrde delstudierna: 1) att utforska och beskriva diskuser in Nordiska länders riktlinjer för hälso- och sjukvård för barn med typ 1 diabetes med fokus på hur föräldrar positioneras (I), 2) att analysera hur svenska pediatriska diabetes team uppfattade och diskuterade pappors engagemang i vården av deras barn med typ 1 diabetes och att diskutera hur teamens uppfattning av pappors engagemang förändrades under de upprepade fokusgruppsdiskussionerna (II), 3) att utforska och diskutera hur pappor som är engagerade i sitt barn upplever stödet från det pediatriska diabetesteamet i vardaglivet med barnet med typ 1 diabetes (III) och 4) att analysera hur pappor till barn med typ 1 diabetes förstår sitt engagemang i barnets vardagsliv och att diskutera deras uppfattningar från ett hälsofrämjande perspektiv (IV).

Material och metoder: Avhandlingen har ett kvalitativt och induktivt perspektiv. Data insamlades och analyserades under tidsperioden 2010 – 2012. Urvalet bestod av tre pediatriska riktlinjer för barn med typ 1 diabetes från Norge, Danmark och Sverige (I), tre svenska pediatriska diabetesteam (II) och 11 (III) respektive 16 (IV) pappor till barn med typ 1 diabetes vars poäng på Parental Responsibility Questionnaire indikerade en hög grad av engagemang i barnets vardag. Data insamlades genom upprepade fokusgruppsdiskussioner med diabetesteamen (II), fokusgruppsdiskussioner på internet (III) och individuella intervjuer (III, IV) med papporna. Tre analysmetoder användes: diskursanalys (I) Constructivist Grounded Theory (II, III) och innehållsanalys (IV).

Resultat: Resultatet belyser den komplexa interaktionen mellan de pediatriska riktlinjerna för diabetesvården, de pediatriska diabetesteamen och papporna. Pappor som hade en hög grad av engagemang upplevde en spänning mellan generella rekommendationer angående diabetes och deras personliga erfarenhet av att leva med ett barn med typ 1 diabetes (III). Papporna betraktade sitt engagemang i sitt barns diabetesvård som ett tillägg till deras generella föräldraskap och en fin balans identifierades mellan ett hälsofrämjande perspektiv och ett kontrollerande engagemang. Den gemensamma nämnaren hos de i hög grad enagagerade papporna var deras uttag av föräldraledighet när barnet var litet (IV). De pediatriska diabetesteamen uppfattade inledningsvis pappornas engagemang som genusrelaterat och balanserat mot mammans engagemang. När diskussionen fokuserades på pappornas engagemang så ökade diabetesteamens medvetenhet om detsamma och teamen började identifiera och uppmuntra pappornas involvering (II). På makronivå befanns föräldrarnas perspektiv och röst nedtonad till förmån för en expert diskurs (I).

**Konklusion:** Pappors engagemang i sitt barn med typ 1 diabetes är komplext konstruerat. Det visar sig i interaktion mellan pappornas uppfattning om sitt engagemang som något extra utöver det generella föräldraskapet och stödet från diabetesteamet, hur teamen uppfattade pappornas engagemang och genom hur föräldrar positionerades i riktlinjerna för den pediatriska diabetesvården. För att främja hälsa och välbefinnande hos barn med typ 1 diabetes måste pappors engagemang beaktas i såväl de pediatriska riktlinjer samt i klinisk praktik.

Nyckelord: barn, hälsofrämjande, pappors engagemang, pediatriska diabetes team, typ 1 diabetes

# **Original articles**

The thesis is based on the following studies, which are referred to in the text by their Roman numerals:

- I. Boman, A., Borup, I., Povlsen, L., & Dahlborg-Lyckhage, E. (2012). Parents' discursive resources: Analysis of discourses in Swedish, Danish and Norwegian health care guidelines for children with diabetes type 1. *Scandinavian Journal of Caring Sciences*, 26(2), 363-371.
- II. Boman, Å., Povlsen, L., Dahlborg-Lyckhage, & Borup, I. (2012). Swedish pediatric diabetes teams' perception of fathers' involvement: A Grounded Theory study (Accepted for publication in *Nursing & Health Sciences*).
- III. Boman, Å., Povlsen, L., Dahlborg-Lyckhage, Hanas, R., & Borup, I. (2012). Fathers' encounter of support from pediatric diabetes teams; the tension between general recommendations and personal experience (Accepted for publication in *Health & Social Care in the Community*).
- IV. Boman, Å., Povlsen, L., Dahlborg-Lyckhage, Hanas, R., & Borup, I. (2012). Fathers' involvement in their child's diabetes care seen from a health promotion perspective (Accepted for publication in *Journal of Family Nursing*).

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# **Preface**

My interest in children and their parents originates from my former profession as a pediatric nurse, with ten years' experience of clinical pediatric care. In my current profession as a lecturer I have educated nursing students, child health nurses and school nurses in pediatric nursing for 15 years. Working with children means that, as a professional, I must always relate to and cooperate with the child's relatives, most often the parents. My experience has been that there is a high degree of complexity in the relationship between health professionals and parents, and that many factors interfere with this interaction. A few years ago I read an article about children with diabetes, and one of the incidental findings caught my interest. The study showed a negative connection between the child's metabolic control and the father's education level. At the same time, a colleague was defending her thesis. The findings revealed that, in nurses' encounters with families, child health nurses mainly turned to the mothers and only addressed the fathers in exceptional cases. These two coincidences and a growing interest in gender issues led me to the area examined in the present thesis: fathers of children with diabetes, and their involvement in their child's life and care.

#### Introduction

#### **Public health**

Public health is the science of promoting health, preventing disease, and prolonging life for the whole population through the organized efforts of society (Winslow, 1920). The Ottawa Charter (WHO, 1986) states that health concerns individuals, while public health concerns the health of populations and societies. The Swedish National Committee of Public Health (SOU, 2000:91) defines public health as a multi-scientific area of knowledge with special focus on the influence of society's structure, environment and health care system on the health of the society's population and the efficiency of the health care system. A public health perspective means that the studied health issues are explained in a complex way using several determinants in different areas, for example socioeconomic, biological, gender and political. There has been an increased recognition over the last 30 years that disease, and health inequities, arise in large part from the conditions in which people are born, grow, live, work, and age. These conditions are referred to as the 'social determinants of health', a term encompassing the social, economic, political, cultural and environmental determinants of health (Tones & Green, 2004).

This thesis motivates its public health perspective by problematizing the research area in an ecological model in order to illustrate how social structures influence a population group: fathers. By widening the focus of diabetes management to include health resources in the child's everyday life, the complexity of everyday life is highlighted and a health promotion perspective is included.

# The Convention on the Rights of the Child

The United Nations General Assembly (1989) states the importance and obligation that all adults respect and promote the best interest of the child. In all decision-making, adults should consider how it might affect children, and the best interest of the child should always be the primary concern. Both parents are pointed out as essential to and responsible for the child's development, well-being and upbringing. It is the responsibility of governments to protect and assist families in fulfilling their substantial role as nurturers of children. The Convention on the Rights of the Child states that both parents are equally important to the child, and that a child has the right to stay in contact with both its mother and father. Children's right to good quality health care is also stated in the convention: all children should have access to the best health care possible, just as all children and their parents should have access to information to help them stay healthy (UN General Assembly, 1989).

# Children with type 1 diabetes

The Nordic countries have the highest incidences of type 1 diabetes among children worldwide. In a global ranking, Finland has the highest incidence rates and Sweden is fourth from the top. Norway and Denmark are ranked eighth and ninth, respectively, and Iceland 23<sup>rd</sup> (Craig, Hattersley, & Donaghue, 2009). In an incidence trend study on childhood type 1 diabetes in Europe, the prevalence under age 15 years is predicted to rise from 94,000 in 2005 to 160,000 in 2020, with an annual increase in incidence of 3.2% in Denmark, 2.7% in Finland, 1.3% in Norway and 3.3% in Sweden (Patterson et al., 2009). However, recent data from Sweden show that the rise in incidence may have leveled off (Berhan, Waernbaum, Lind, Möllsten, & Dahlquist, 2011).

Type 1 diabetes is a metabolic disease that manifests itself through increased serum glucose levels, affecting the child's metabolism. It is a chronic disease with widespread implications for the child's and the family's everyday life, as it requires a strict regimen with regard to food intake, physical activity and insulin injections (Sullivan-Bolyai, Rosenberg, & Bayard, 2006) . The child's metabolic control is measured based by glycated hemoglobin (HbA1c or A1C), the standard index of glycemic control over the preceding period of four to 12 weeks. The international recommended target HbA1c for all age groups of children is < 7.5% (DCCT percentage numbers) (Rewers et al., 2009), and in Sweden as close as possible to 6.9% (6.0% with previously used Swedish Mono S numbers, now expressed as 52 mmol/mol with IFCC numbers) without being disabled by hypoglycemia (Sjöblad,

2008). Parental involvement is a significant determinant of disease management outcome and metabolic control. Children develop and socialize within their family. They learn and adopt values, norms and strategies for everyday life, and the degree of parental involvement is therefore essential to disease management (Laffel et al., 2003). If the child and the family succeed in maintaining recommended HbA1c levels there is a decreased risk for future complications in the child, such as eye and kidney injuries (DCCT/EDIC research group, 2000). In Sweden, 56% in the age group 0-6 years, 34% in the age group 7-11 years, but only 24% of those aged 12-17 years have HbA1c levels below 57 mmol/mol (7.5% DCCT numbers), 35% of children with diabetes have HbA1c levels below the national target value, which indicates that a large group of children are at risk for future (Samuelsson, 2012).

All children and adolescents with type 1 diabetes in Sweden (Sjöblad, 2008), Norway (Njolstad, Bangstad, & Hodnekvam, 2010) and Denmark (Hertz et al., 2009) are treated by a pediatric diabetes team (PDT). This multidisciplinary team should consist of a pediatric diabetes nurse specialist, a pediatric endocrinologist or pediatrician specialized in diabetes, a dietician, a social worker, and/or a psychologist trained in pediatrics and with knowledge of childhood diabetes. The team should recognize the family and child as an integral part of the care team. The ultimate goal of the PDT's activity is to provide care that results in the child having normal growth and development, high quality of life and the lowest possible risk of acute and long-term diabetes complications. This is accomplished through the PDT's general aims, which are to provide the child and the family with professional, practical guidance and skilled training, consistent repeated diabetes education and self-management training, and up-to-date advice on insulin management and monitoring techniques. This should be done with an understanding of, and support for, the psychosocial needs of the family, assisting in the child's and the family's adjustment to and care of the disease (Pihoker, Forsander, Wolfsdorf, & Klingensmith, 2009).

The International Society for Pediatric and Adolescent Diabetes (ISPAD) has recommended processes of good clinical practice for the successful management of children and adolescents with diabetes. At the onset, the PDT should provide the family with practical care guidance and education in order to allow them to feel confident in providing diabetes self-care at home. The family and the child should initially, as well as henceforth, be provided with psychosocial support. During the first six months, frequent contact with the PDT is necessary to help the family manage the changing requirements of diabetes in their daily life; this is usually achieved through a combination of clinical appointments and telephone calls. Subsequently, ISPAD recommends that the diabetes care of children and adolescents be reviewed at outpatient clinics at least three or four times a year. These reviews should include assessments of physical parameters and changes in the child's developmental

performance. They should also include the child's leisure activities, potential ongoing psychosocial processes, and the child's and the family's diabetes-specific knowledge, appropriate to the age of the patient (Pihoker, Forsander, Wolfsdorf, & Klingensmith, 2009).

#### **Fathers**

Fatherhood is a social construction and institution that is intimately connected with the social production and reproduction of men, gendered families, and the gendered state (Hearn, 2002). Fatherhood discourses are determined by cultural and historical contexts. The father ideal has changed from that of being a moral teacher and disciplinarian to being a breadwinner and genderrole model, and again to today's nurturing and co-parenting father (Pleck, 2004). Contemporary family research points out how the institutional individualization, and the growing body of knowledge that the individual is subjected to, force the individual into a constantly reflexive approach. The individual has to choose and weight different options against each other in the construction of their own biography. Consequently, men's identity is no longer obviously related to work and career and they have to reflexively construct their life story with more dimensions than previously (Bäck-Wiklund, 2012). In Sweden, there has been a clear change in both policy and attitudes. Fathers are no longer expected to only take responsibility for family finances, but are instead expected to provide a new, more caring and egalitarian kind of parenting (Bergman & Hobson, 2002). Nevertheless, through representations of parental responsibility, the balance between work and family, and hegemonic masculinity, mothers continue to be positioned as primary caregivers (Wall & Arnold, 2007). The differences in paternity and maternity discourses result in a situation in which women who become mothers are obliged to enter into motherhood, while men can choose whether or not to be an active father (Bekkengen, 2006).

Considering the global standards, the Nordic countries have succeeded quite well in their quest to achieve equality between women and men as well as welfare and well-being among children. The Nordic societies are all officially pronounced advocates of equality between men and women. It is legislated that both sexes have not only the same rights and responsibilities in life, but also equal opportunities. Sweden, Denmark, Norway, Iceland and Finland have a common basic conception that the differences between the sexes in society are due to social and not biological factors (Gislason, 2010).

Regarding gender equality, the development of parental insurance is a specific attempt among the Nordic countries to encourage parents to share parental leave in order to solve childcare issues; all have adopted some form of initiative to induce fathers and mothers to share parental leave more

equally. The Nordic family model is characterized by shared parental responsibility for both economic issues and childcare (Leira, 2006).

The arguments for paternity leave are that children have a right to both parents and that paternal leave gives children better access to and contact with their fathers (Brandth & Gislason, 2010). Fathers' use of parental leave is encouraged by all five countries, but in different ways. Iceland, Norway and Sweden have introduced a quota, which means that part of the parental leave is a non-transferable period and is accessible only by one parent. Norway was the first country in a global context to establish a father quota; Denmark introduced but then withdrew the quota after a couple of years. Sweden has increased the time from one to two months, and in Finland the father quota is six weeks. Iceland takes the lead in the pursuit of equality through its 3+3+3 parental leave model: three months' parental leave for mothers, three for fathers and three for the parents to decide how to share.

In the Nordic countries, Icelandic fathers take the proportionally highest paternity leave, followed by Swedish fathers. This is explained as a direct effect of paternal leave quotas. The overall trend is that fathers in all the Nordic countries take parental leave and those who do not are to be considered the exception (Duvander & Lammi-Taskula, 2010). However, it has been argued that a discrepancy exists between the structural and practiced levels, as the increase in fathers' parental leave is modest in spite of the expanded structural and economic conditions (Bekkengen, 2006).

Paternal involvement is defined as engagement, accessibility and responsibility (Lamb & Tamis-Lemonda, 2004). Responsibility is identified as participation in key decisions and tasks such as making appointments, selecting childcare, arranging after-school care, and caring for sick children. Accessibility entails being present and available to the child, and engagement refers to having direct contact and shared interactions with the child as well as providing care (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000).

The father's involvement has been found to play an important role in the child's development. For example, committed and involved fathers support the development of children's independence and competence (Paquette, 2004). If the father is involved in the child's everyday life, it is common that the mother is as well. This gives the child access to two dedicated parents, which means a higher level of stimulation and greater opportunities to develop social skills (Flouri, 2008). It has also been concluded that a father's regular engagement in the child predicts a range of positive developmental outcomes, although it is not possible to say exactly what constitutes fathers' engagement (Sarkadi, Kristiansson, Oberklaid, & Bremberg, 2008). Fathers' engagement enhances cognitive development and reduces the frequency of behavioral problems in boys as well as psychological problems in young

women, and there is "enough evidence to support the intuitive assumption that fathers are good for their children" (Sarkadi et al., 2008, p.157). A father also influences his child's health, directly or indirectly, through his socio-economic status. Because men generally have better economic conditions than women, it may affect the child's opportunities for health and well-being if they support their child economically (WHO, 2007). Both Sarkadi et al. (2008) and WHO (2007) recommend that professionals working with young children and their families request and actively encourage fathers' engagement from an early stage.

#### Fathers of children with diabetes

Because it has been concluded that fathers' involvement in the care of their child with long-term medical condition has a positive impact on the child's well-being and family function (Swallow, Macfadyen, Santacroce, & Lambert, 2011), knowledge about how fathers contribute to their children's development and well-being is fundamental in the clinical treatment of children with type 1 diabetes. A father's perception of his life situation, his coping and adaptation to circumstances, his knowledge about the disease and his communication behavior will all have an impact on how well the child's illness is treated in everyday life and therefore on how well the child's metabolic control is maintained (Dashiff, Morrison, & Rowe, 2008).

When it comes to mothers of children with type 1 diabetes, there is a growing understanding of how care of the child, the parenting function and management of the disease are related to each other (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai, Rosenberg, & Bayard, 2006). Fathers have been underrepresented in pediatric research, and when they have been included their responses have not been analyzed separately, thus making it difficult to understand their contribution to parenting (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Furthermore, research has been limited in examining the father's role independent of the mother's in areas of type 1 diabetes (Hansen, Weissbrod, Schwartz, & Taylor, 2012). Consequently, there is less research and knowledge about fathers' experiences and the role and influence of their acceptance and management of type 1 diabetes (Dashiff, Morrison, & Rowe, 2008). It is known that the father's adaptation to living conditions is correlated with the child's metabolic control, and that poor adjustment is a determinant of inferior metabolic control (Forsander et al., 1998). The father's experience of family functioning is linked to the child's metabolic control, just as his experience of stress in the family is an essential factor in determining how the child will accept and manage the disease (Auslander, Bubb, Rogge, & Santiago, 1993). High paternal involvement correlates with less disease impact on the family and higher quality of life among adolescents, whereas poor metabolic control is associated with the father perceiving the family as dysfunctional (Gavin & Wysocki, 2006). Dashiff (2008) concludes that fathers' contributions to the family seem to be associated with improved disease management outcomes.

In the absence of any effective means to prevent or cure type 1 diabetes, there is a need to ensure appropriate planning of services and resources to guarantee high-quality care for the increased number of children who currently have diabetes, and for those who will be diagnosed with diabetes in the future (Patterson et al., 2009). One such resource is the child's father.

# **Theoretical frame**

# **Health promotion**

Health promotion, also known as the New Public Health, is defined as the process of enabling people to improve and increase their control over their health (WHO, 1986). Health promotion has its roots in the Ottawa Charter, where health is defined as a resource for health integrated with everyday life. The charter recognizes and legitimizes the extension of health domains, and proposes health policies in all sectors of society (WHO, 1986). From a health promotion perspective, people are viewed as social actors and agents, and the focus is on their empowerment (Kickbusch, 2007), encompassing both individual and structural approaches to health (Tones & Green, 2004).

The health promotion perspective employed in the present thesis starts by making the father – a potential existing health resource in the child's everyday life – explicit. A review of fatherhood and health outcomes in Europe has revealed that increased active involvement in fatherhood not only leads to beneficial health effects for the men themselves, but also for their partners and their children (WHO, 2007). Several major studies have addressed the effects of increased paternal involvement on children's development. The results have been consistent: children of highly involved fathers are characterized by increased cognitive competence, increased empathy, less sexstereotyped beliefs, and more internal locus of control. This is explained not by the sex of the parent, but by the quality of his/her relationship with the child and the other parent. Fathers and mothers seem to influence their children in more similar than dissimilar ways, regardless of sex. Why fathers' involvement has specific health and developmental outcomes is therefore explained by the child's likely access to two highly involved parents, the fathers' explicit desire to have a close relationship with the child, and the quality of family cohesiveness in which both parents experience the relationship as good (Lamb & Tamis-Lemonda, 2004).

According to the health promotion perspective taken here, the father is viewed as an important actor and health determinant in a child's everyday life. When the father is recognized as caregiver on an equal footing with the mother, the prospects for the child to develop improve (Sarkadi et al., 2008).

Having a health promotion perspective involves focusing on what promotes health rather than on what cures illness, the aim being to prevent problems before they occur (Rootman, 2001). For health care professionals, the task is to provide support and options that enable people to make sound choices, to point out the key determinants of health, and to make people aware of these determinants and to use them (Eriksson & Lindstrom, 2008). In the present thesis, this is reflected by focusing on how fathers are supported and how they understand their involvement in their child's daily life.

Some of the core concepts in health promotion are sustainability, empowerment and participation (Rootman, 2001). Sustainability means permanency in health efforts and their outcomes. Here, it is illuminated by the assumption that the child is taught to manage his/her diabetes in a sustainable manner by both parents in the home environment. Empowerment and participation are promoted by encouraging fathers to be actively involved in their child's daily life and diabetes care.

The health promotion perspective of the thesis does not take its standpoint in the sex of the parent, even though fathers are obviously focused on. The health promoting benchmark is based on the assumption that the child has two parents who are equivalent and that each of them promotes the child's health and development, regardless of their biological sex.

# The ecology of human development

The ecology of human development is a unified but highly differentiated conceptual scheme for describing and interrelating structures and processes in both the immediate and more remote environment (Bronfenbrenner, 1979). In this model, development is viewed as a sustainable change in which a person perceives and interacts with his/her environment.

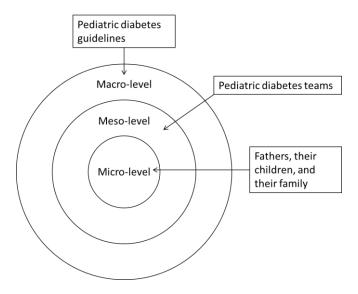


Figure 1. The thesis placed in an ecological model

The ecological environment is conceived of as a set of nested structures, each inside the next and in reciprocal interaction. The innermost level, known as the micro-system, contains the developing person and his/her closest settings. In the thesis this is illustrated by the father, the child with diabetes, and the family (Figure 1). The next level is the meso-system, defined as settings outside the inner circle in which the developing person might participate, here concretized by the PDTs and the pediatric clinics. The exo-system is defined as settings that the developing person never enters but in which events occur that affect what happens in the immediate environment. Examples of the exo-system are parents' workplaces, when the focus is set on child development. In the thesis, the exo-system is not concretized. The outer frame, the macro-system, consists of the overarching patterns of ideology, the organization of social institutions common to a particular culture or subculture, and legislation (Bronfenbrenner, 1979). Here, the latter system consists of gender systems and guidelines for children with type 1 diabetes.

In the ecology of human development model, there is a reciprocal interaction between and within the systems. In the micro-system, the basic unit of analysis is the dyad, a two-person system with mutual dynamic possibilities. If one member of the pair undergoes a process of development the other does so too, here exemplified by the father-child relationship. The capacity of the dyad to serve as a developmental environment is dependent on the presence and participation of third parties, the meso- and exo-systems. Third parties are essential to the functioning of dyads as an effective context for human development. Bronfenbrenner (1979, p. 5) expresses this as follows: "If third parties are absent, or if they play a disruptive rather than a supportive role, the developmental process, considered as a system, breaks down; like a three-legged chair". Finally, the macro-system

determines the specific properties of exo-, meso- and micro-systems that occur in everyday life and steer the courses of behavior and development.

#### Social constructionism

The present thesis has a social constructionist perspective, assuming that the contemporary gendered care for a child's health is constructed in social relations and in cultural and historical contexts.

Social constructionism refers to constructing knowledge about reality rather than constructing reality itself (Shadish, 1995). The key assumptions of social constructionism involve taking a critical stance on taken-for-granted knowledge. How the world is perceived depends on the cultural and historical context, and all knowledge is sustained through social processes in which knowledge and social action interact. The world is constructed as people communicate and there is no single version of reality (Burr, 2003). Danermark (2001) argues that there is a reality, independent of our knowledge of it, but also that this reality is not something immediately fixed and empirically accessible. Reality contains a dimension, not immediately observable, where the mechanisms can be found which produce the empirical observable events. According to Danermark, our knowledge of reality is also something that is always conceptually mediated and thus more or less truth-like (Danermark, 2001).

There is an ontological division identified within social constructionism: the relativistic standpoint and the realism approach. Representatives of the relativistic view claim that discursive constructions are entirely independent on the material world, and that it is language itself that provides the tools for constructing a reality beyond words. On the other hand the realism standpoint, which is taken here, advocates that our knowledge of the world is necessarily mediated by – and therefore also constructed through – language, while maintaining that there are underlying structures that generate phenomena, versions of which we then construct through language (Willig, 2008). If everything is discursively constructed, as the relativistic standpoint claims, then there are no grounds for critical evaluation between different views of the studied phenomenon, here fathers' involvement.

A discourse is a practice that systematically forms the objects to which it refers; it is "knowledge formations, entities that provide an effective and limited lens for producing knowledge about a topic" (Foucault, 2002, p.49). Discourses make it possible to see the world in a certain way, as they produce our knowledge of the world (Burr, 2003). The term discourse refers to the manner in which individuals and institutions communicate through written texts and spoken interaction (Horsfall & Cleary, 2000). The available forms of language place limits on what is possible for the object in the

discourse to say, think, and do. This incorporates practice into the concept of discourse. Discourses may or may not be put into practice, without threatening their hegemonic position (Talja, 1999).

Discourses construct the phenomena of the world, as they determine which aspects will be brought into focus. Different discourses construct the world in different ways; every discourse portrays the object as if it has a very different nature from other objects. From a social constructionist perspective, the things people say and write are not manifestations of some inner, essential condition; they are rather expressions of discourses, and originate in the discursive culture these people inhabit (Burr, 2003). Some discourses are dominant, or hegemonic – they are so entrenched that they are invisible, taken for granted and not scrutinized. The hegemonic discourse has the power to proclaim knowledge as well as the truth (Arribas-Ayllon & Walkerdine, 2008). By talking about something in a specific way, we produce a particular form of knowledge that is highly interrelated with power; the one with interpretive privilege is also able to set the agenda.

However, no discourse lasts forever; they all depend on the historical context in which they exist. Given that there will always be a number of discourses, the prevailing discourse is continually the subject of contestation and resistance (Willig, 2008). The implicit power in one discourse is only apparent from the resistance in another competitive discourse (Burr, 2003).

#### Gender

The basic gender assumption made here is that men and women are more alike than different in all that is essential to humankind. They are regarded as equal and not supplemental, as the latter standpoint indicates that there are gendered differences in the skills and competencies of men and women. Human beings are born into different biological sexes, but it is through social relations that they are fostered to become boys, girls, women and men (Hirdman, 2003). Applying this notion to the thesis means that the underlying assumption is that the father and mother are viewed as equal caregivers to their child, and that caregiving is not an inherent female quality.

Gender is discursively constructed. Being a man or a woman is not a pre-determined state. It is rather a 'becoming', a condition under active social construction. The classic phrase "One is not born, but rather becomes, a woman" (Beauvoir, 1964, p.301) is also relevant to men: one is not born masculine, but has to become a man (Connell, 2002). Gender construction takes place at different but equivalent, interacting levels. At the institutional level, where the construction of men and women is carried out within the family, education and profession, different male and female characteristics are attributed depending on the context. Masculinity and femininity are also recognized by cultural symbols, normatively agreed upon by both sexes and articulated in doctrines

at the societal level. Finally, gender is also constructed in the individual's subjective identity, and the different levels interact reciprocally (Wallach Scott, 2010).

Masculinities are necessarily plural because they are related to different positions within a power structure, that is, a gender order that segregates men in accordance with how far they are from the hegemonic norm: white, heterosexual and professionally successful (Aboim, 2010). The dominance of hegemonic masculinity is achieved through culture, institutions and persuasion, and is not based on force (Connell & Messerschmidt, 2005). Men are positioned, and position themselves, through discursive practices in relation to masculinity (Connell, 1995). Hegemonic masculinity features by cultural consent, discursive centrality, institutionalization and the marginalization of alternatives, and presumes the subordination of non-hegemonic masculinities. One of the most important characteristics of hegemonic masculinity is that few perform it but all relate to it, directly or indirectly (Bekkengen, 2002). Hegemonic masculinity works in part through the production of exemplars of masculinity, e.g. professional sports stars, symbols that have authority despite the fact that most men do not fully live up to them (Connell & Messerschmidt, 2005). Hence, the majority of men construct complicit masculinity because they are not particularly powerful; nor do they influence the dominant cultural symbols of manhood. On the other hand, most men do not explicitly defy the codes of masculinity. However, men with complicit masculinity are not to be viewed as passive subjects between the men who are most powerful and those who directly challenge hegemonic masculinity. In their being, they are doing gender (Aboim, 2010).

#### A child-oriented masculinity

Arguments have been made for an emerging new masculinity: child-oriented masculinity (Bekkengen, 2006). In the Nordic countries, recent decades have seen the emergence of an increased focus on children's well-being, according to which new demands on parenthood have occurred that have influenced the norms of what a man should be like. This has given rise to a child-oriented masculinity, based on the best interest of the child discourse and the father-child relationship. Children are considered not only the mother's responsibility, but also as part of the father's commitment beyond simply providing for them. The relationship with the child is also regarded as benefitting fathers' development and growth as human beings (Brandth & Gislason, 2010).

Child-oriented masculinity may be stronger at the discursive level than in practice (Bekkengen, 2006). The reason for this is that men can choose to put the child-oriented masculinity into practice or not; e.g. at a discursive level, fathers' parental leave is represented as optional, not mandatory. Men can choose not to take parental leave and still remain good fathers (Wall & Arnold, 2007). The discrepancy between the discursive and the practice levels is revealed in the fact that there has been

a modest increase in fathers taking parental leave in relation to society's structural support (Bergman & Hobson, 2002). On the other hand, men who take long parental leave are also those who practice the child-oriented discourse (Bekkengen, 2006).

There is an ongoing discussion on how child-oriented masculinity is positioned in relation to other masculinities. On the one hand, there are indications that men who practice the child-oriented discourse encounter resistance from other men (Bekkengen, 2002). This could indicate that child-oriented masculinity is not highly ranked. On the other hand, having a child orientation is discursively positively portrayed, and being child-oriented is interconnected with being a modern man. Additional support for child-oriented masculinity becoming hegemonic is found in the combination of its strong positive discursive position and the fact that relatively few men practice it.

#### Aim

The overall aim of the thesis was to explore and analyze constructions of fathers' involvement in their child's everyday life with type 1 diabetes in an ecological context.

The specific aims of the four studies included were to:

- explore and describe discourses in health care guidelines for children with type 1 diabetes in
   Nordic countries, focusing on parents' positioning (I).
- analyze how Swedish pediatric diabetes teams perceived and discussed fathers' involvement in the care of their child with type 1 diabetes, and to discuss how the teams' attitudes toward the fathers' involvement developed during the focus group process (II).
- explore and discuss how fathers involved in caring for their child with type 1 diabetes experienced support from their Swedish pediatric diabetes team in everyday life with their child (III).
- analyze how involved fathers of children with type 1 diabetes understood their involvement in their child's daily life and to discuss their perceptions from a health promotion perspective (IV).

#### Material and methods

### Research design

The research design was guided by the overall aim of the thesis. The use of a qualitative approach was motivated by the explorative nature of the research focus and the less explored area of fathers of children with type 1 diabetes and their involvement in their child's everyday life and diabetes care (Dashiff, Morrison, & Rowe, 2008). The design was also reasonable, given the focus on social structures interfering with social behavior as well as on the PDTs' and fathers' experiences and meaning construction. The strength of a qualitative approach is its ability to deepen our understanding of the studied phenomenon. The qualitative research design is rooted in the empirical data through the intention to use an inductive approach, and has the power to illuminate the people behind the numbers (Patton, 2002). In order to highlight the complexity of fathers' involvement and to reflect different structural systems of reciprocal influence on involvement, the specific aims were positioned in an ecological context (Figure 2). At the macro-level, discourses embedded in guidelines were analyzed in order to describe how they were likely to influence parents' involvement in their child's everyday life and diabetes care (I). Fathers' experiences of PDTs' support (III) and fathers' perception of their involvement in their child's daily life and diabetes care (IV) reflect the interaction between the meso- and micro-levels. Finally, the PDTs' perceptions of fathers' involvement and the development of PDTs' attitudes toward the fathers' involvement during the research process (II) illustrate the meso-level.

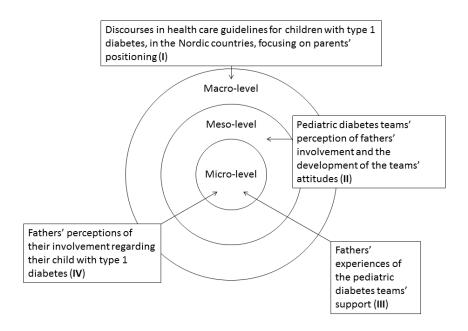


Figure 2. The thesis positioned in an ecological context

The reciprocal interaction between the levels in the ecological model is in accordance with the basic assumption of public health, that lifestyles and living conditions determine health status (Smith, Tang, & Nutbeam, 2006). Further strengthening the link between public health and the ecological model is the fact that the latter illustrates how policies, programs and services (macro-level) determine conditions for healthy lifestyles (micro-level) and for creating supportive environments (meso-level).

The four studies are explorative, descriptive and analytic, motivated by the relatively unexplored research area. A quasi-intervention was integrated into the design of Study II, as data collection was repeated three times with each PDT. This was done both to influence the PDTs' attitudes toward fathers' involvement and to gain an understanding of how their attitudes developed during the data collection process. The characteristics of the four studies are presented in Table 1.

Table 1. Characteristics of Studies I-IV

Study	I	II	III	IV
Year (data collection)	2010	2010 - 2011	2011	2011 - 2012
<b>Design</b> Qualitative, inductive Quasi-intervention	X	X X	x	X
Data sources and participants Guidelines Pediatric diabetes teams/repetitions Fathers of children with diabetes	n = 3	n = 3/3	n = 11	n = 16
Data collection Guidelines obtained from Norwegian, Swedish and Danish pediatric diabetes teams Repeated focus group discussions Online focus group discussion Individual semi-structured interviews	X	X	X X	X
Data analysis Analysis of discourses Constructionist Grounded Theory Content analysis	X	X	x	x

# **Settings**

Study I was performed in a Nordic context and included guidelines for children with type 1 diabetes in use in Norway, Denmark and Sweden. The guidelines were collected in May to June 2010. Studies II-IV were conducted in Sweden (Study II performed May 2010–January 2011, Study III January 2011–August 2011 and Study IV February 2011–February 2012).

# Samples

The sample in Study I consists of three pediatric diabetes guidelines, originating from Sweden, Norway and Denmark. The guidelines differed in length (from 18 to 233 pages) as well as in authors' professions, from solely pediatricians to a combination of pediatricians, diabetes nurses, dieticians and chiropodists. They also differed in the number of authors, from four to 33. The total of 46 authors of the guidelines consisted of 40 pediatricians or specialists in pediatric medicine, four dieticians, one diabetes nurse, and one chiropodist. An overview of the characteristics of the included guidelines is provided in Paper I.

In Study II the sample consisted of three PDTs from three pediatric diabetes clinics in Sweden, recruited at a regional PDT meeting where the four studies were presented. The three clinics have their patient base in varied socio-economic areas: one with an average income well above, and the other two just below, the national mean. The clinics also vary in their number of patients, from about 75 to 170.

Different professions were represented in each PDT. Common to all teams were a pediatric nurse, a pediatrician and a dietician. Two teams had been expanded with social workers, and one with a psychologist. The average professional experience of pediatric diabetes care was 18 years. The representation of the different professions in the different teams is illustrated in Table 1 in Paper II.

In Studies III and IV, fathers of children with type 1 diabetes were recruited from the three pediatric diabetes clinics represented in Paper II. Fathers who attended the diabetes clinics with their children were asked consecutively by the pediatric nurses to participate, and were informed in writing (Appendix I). The inclusion criteria for asking were: fathers visiting the clinic with their child (alone or together with the mother), more than one year since disease onset, and in cases in which the parents were separated, fathers having at least 50% custody of the child with diabetes.

Twenty-nine fathers responded, five of whom declined to participate (Figure 3). According to the qualitative design (Patton, 2002) an attempt was made to achieve variation in the fathers' socioeconomic background, the child's age, the duration of the disease and the number of children. A printed demographic questionnaire was sent by post to the remaining 24 fathers (Appendix II). Since

variation was considered to have been obtained by the responding fathers, no more participants were approached. The mailing included the Parental Responsibility Questionnaire (PRQ), an instrument developed to assess mothers' and fathers' levels of engagement in their child's everyday life (Appendix II) that has been used and validated in the Swedish context (Chuang, Lamb & Hwang 2004). The PRQ is constructed as a seven-point Likert scale, with lower scores indicating that the father is the more involved parent and scores at the upper end pointing to mothers being primarily responsible for the child's everyday life. Scoring close to 4 indicates that both parents are equally involved. The questionnaire is sensitive to the child's age but gender-neutral. The PRQ was used to identify the most involved fathers in the sample, as the studies focused on incitements for fathers to become engaged in their child's everyday life and how these fathers experienced the support from the PDTs. A postage-paid reply envelope was included, and after one written reminder 20 responses had been collected. The fathers were rated, based the PRQ, in descending order of their engagement in their child's everyday life. Because a Grounded Theory (GT) design was used in Study III, the sample size was not predefined (Charmaz, 2006). The sample of Study III turned out to consist of 11 fathers, ranking from 1 to 4.86 on the PRQ and ranging in age from 37 to 51 years. Their children's ages ranged from four to 15 years, and their diabetes duration from two to eight years. Seven of the fathers cohabited with the mother. Their highest educational level was evenly distributed between upper secondary school and higher education. A further description of the participating fathers' characteristics is presented in Paper III.

The sample in Study IV was set to 16 fathers, as four of the original participating fathers declined to participate due to time constraints (Figure 3). These fathers scored 1 to 4.29 on the PRQ, and their number of children ranged from two to five. Their children's diabetes duration ranged from one to 15 years. Half the fathers were cohabiting with the child's mother, and 14 had been on parental leave with their children. The fathers' ages ranged from 33 to 51 years. Examples of their professional status are disability pensioner, CEO, military officer, teacher, salesman, sport agent and truck driver. The characteristics of the 16 participating fathers are presented further in Paper IV.

Eight fathers participated in both Studies III and IV.

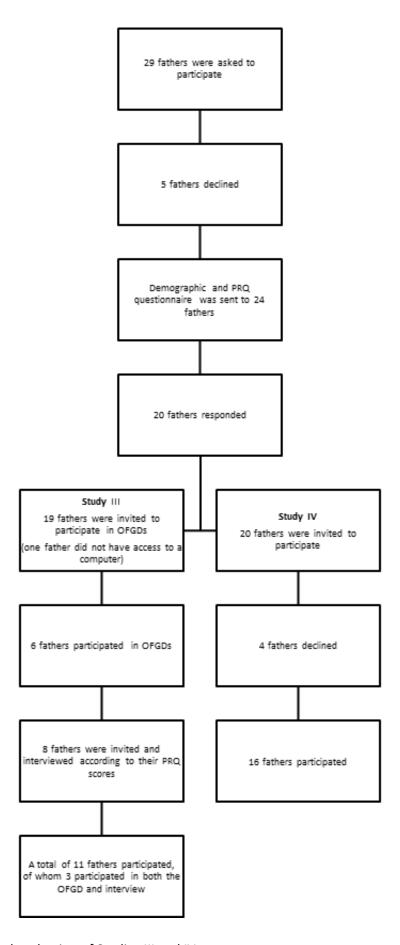


Figure 3. The sample selection of Studies III and IV

#### Data collection

In order to identify and collect guidelines from the Nordic countries, personal contact was established via email with leading pediatric diabetes professionals in Norway, Denmark, Finland, Iceland and Sweden. The contacts were mediated by a member of the executive committee of ISPAD. It turned out that Finland had general guidelines for type 1 and type 2 diabetes, without specification of pediatric diabetes care, and was therefore excluded (personal communication with National Health and Welfare, Diabetes Prevention Unit, Finland, 20 May 2010). It was also discovered that the Icelandic guidelines were not available in English. This resulted in the inclusion of guidelines from Norway, Denmark and Sweden, all written in their respective native language but understandable to the researcher.

The data collection for Study II was conducted through repeated focus group discussions (RFGD) with the PDTs. The focus group discussion method was chosen because it is a collective rather than individualistic research method (Patton, 2002), and it was assumed that the teams had an aggregated approach to the families and thereby the fathers. The focus group discussion is a useful method for gathering exploratory data in a relatively unexplored area, and it is descriptive and process-oriented. It is an appropriate method when it is desirable to encourage research participants to explore the issues of importance to them, the PDTs' perceptions of fathers' involvement in their own vocabulary, generating their own questions and pursuing their own priorities (Kitzinger, 1995). Because knowledge is constructed in social practice, and the world is constructed in people's communication (Burr, 2003), it is appropriate to collect data by letting people discuss the studied area.

Repeating focus group discussions allows the research area to be explored more deeply, and as knowledge is constructed and reconstructed through interaction, the participants may increase their understanding of the studied phenomenon. This means that a quasi-intervention may be conducted by virtue of the repeated discussions, as the studied area becomes more explicit and accessible to the participants (Ljunggren, Johansson, Wang, & Pettersson, 2009). The RFGDs within the three PDTs were conducted at the clinics, during work hours, and were repeated three times each. More detailed practical process information is presented in Paper II. The data collection was not carried out in chronological order, since there was no intention to compare the different teams' perception of fathers' involvement but rather a development process within each team. The process of the performance meant that Team A was interviewed twice before Team B's and C's first focus group discussion. The reason for this procedure was both pragmatic and based on the research method, GT, in which a purposive and theoretical sampling procedure was performed simultaneously with the analysis process regardless of which team contributed the data (Charmaz, 2006). This means that

categories emerging from one team's session were deepened and broadened during the RFGD with the next team.

The moderator used open-ended, semi-structured questions, suitable for inductive approaches (Patton, 2002) as well as focus group discussions (Kitzinger, 1995). Initially a semi-structural interview guide was used, in order to keep the interactions focused while allowing the professionals' perspectives and experiences to emerge. Throughout the RFGD the guide developed according to the purposive and theoretical sampling. To capture how the PDTs experienced fathers' involvement, they were asked to share recent situations in which they had met fathers with different degrees of engagement. The narratives were further explored through probing questions from the moderator and through the participants discussing the different situations to which most of them could relate.

In Study III, data were initially collected through online focus group discussions (OFGDs) and interviews. The OFGD has been found to be a method that produces many unique and useful ideas and that is geographically independent, just as the contributions from the participants are likely to be equally distributed (Underhill & Olmsted, 2003). The primary intention was to use OFGDs as the only data collection method. Nineteen of the 20 fathers were divided into four groups; one father did not have access to a computer, and was therefore excluded.

Four virtual group rooms were created in Fronter, a platform used for Internet communication. The Internet group rooms were separated from each other, and access was only permitted to the selected fathers and the researcher. For further information on how the procedure was performed, see Paper III.

After five days, five of the nineteen fathers had participated in the OFGDs and a reminder was sent by email, resulting in one additional participant. One group asked for more time; the extended time resulted in one additional post from yet another father.

Given the large attrition in the sample in Study III, data collection was continued through individual interviews. Interviewing can be carried out in order to determine what is in and on someone else's mind, to gather their story (Patton, 2002).

The fathers were ranked by their PRQ scores, and the descending list was used to determine the order in which they should be invited. The eight fathers with the highest scored involvement were interviewed; no one declined to participate. Three of the six fathers who had participated in the OFGDs were included in the interview group based on their PRQ scores. Further information on the interview procedure is provided in Paper III.

The open-ended questions were listed in a semi-structured interview guide to ensure that the same basic lines of inquiry were pursued with each father (Patton, 2002). This interview guide also developed throughout the data collection. Explorative questions focused on values, and emotions were used to ask the fathers to share their experiences of the meetings with the PDTs, followed by probing questions. Examples of questions are 'Tell about a situation when you felt supported/not supported by your PDT', 'Describe your experiences of your PDT', 'What is your opinion of the support from your PDT', 'What would you like to see happen?' and 'How do you feel about the support?'.

Individual interviews were also used as a data collection method in Study IV, again justified by the wish to gather the fathers' stories (Patton, 2002). Five of the 16 interviews were conducted by telephone, and the rest face-to-face. All interviews started with socio-demographic questions and 'small talk', aimed at socializing and creating a friendly atmosphere to make the fathers feel comfortable (Kvale & Brinkmann, 2008). In the face-to-face situations, this pre-conversation lasted longer than in those performed by telephone; consequently, the latter sessions were shorter. These interviews followed an interview guide with semi-structured and open-ended questions. The questions were classified as experiential, behavioral and valuing. The fathers were initially asked to narrate an ordinary day with their child, followed by probing questions like 'What do you think about being involved in your child's daily life?' in order to deepen and develop how the fathers perceived and understood their involvement (Patton, 2002). The fathers were also asked to further develop why and how they were engaged in their child's daily life.

# **Analyses**

The four studies included in the thesis differ in terms of their macro-, meso- and micro-perspectives as well as their specific aims. Accordingly, different methods of analysis have been applied.

Given that the focus of the analysis of discourses is on the use of language to create, sustain or challenge constructed realities in particular situations (Horsfall & Cleary, 2000), it is an appropriate method to explore how parents are socially constructed in the guidelines. Further, the focus in the analysis of discourses is on revealing discourses and examining how they operate to make statements accepted as meaningful and valid (Willig, 2008), which is in accordance with the aim to explore discourses in the pediatric diabetes guidelines. Additionally, because the focus is also on how discourses transform and produce social reality – how the subject is positioned and what effect the discourse has on the subject's possibilities to act, talk and experience the world (Talja, 1999) – it is an appropriate method for exploring parents' positioning in the documents.

There are several ways to conduct analysis of discourses, and there is no single rigorous method that must be used. Willig (2008) developed a six-step model for carrying out the analysis of discourses in a Foucauldian sense, in that it focuses on the availability of discursive resources within a culture and its implications for those who live in it. The use of this approach was justified by the focus in Study I, which was on how the discourses in the guidelines facilitated and limited, enabled and constrained what could be said, by whom, where and when (Parker, 1992).

Initially, it was found in the analysis phase that the term father was rarely used in the Swedish guidelines and did not occur at all in the Norwegian and Danish ones. Instead, the concepts parents and family were applied in all three guidelines. Hence, the aim of Study I was adjusted to focus on parents and family. A more detailed description of the analysis procedure and Willig's method is provided in Paper I.

Grounded Theory is an inductive, comparative, interactive, and iterative method with the purpose of generating theory derived from, and anchored in, data (Charmaz, 2006). GT is also characterized by its aim to discover social processes, through simultaneous data collection and analysis, whereby both processes and products are shaped by the data through constant comparison, theoretical sampling and memo writing (Eaves, 2001).

GT was used in Studies II and III, as the aims of the two studies were exploratory in nature and focused on research areas that have received limited attention. The analysis method was also motivated by the two studies' focus on social processes (Wuest, 2007): the professionals' perception of fathers' involvement and the fathers' experiences of the support from the PDTs. Constructionist Grounded Theory, as described by Charmaz (2006), guided the analysis. The approach was chosen for its basic assumption that people construct and maintain meaningful worlds through dialectical processes in which they confer meaning on their realities, in contrast to classic GT (Glaser & Strauss, 2006) in which the researcher is supposed to be an objective viewer. According to Charmaz (2006), a constructionist approach considers that both data and analysis are constructed through shared experiences and relationships. Consequently, the researcher cannot take an objective observational position; the 'discovered' reality is a construction of the interaction between researcher and data. This is in accordance with and supports the quasi-intervention conducted in Study II, during which findings were constructed on the basis of the PDTs' and the researcher's shared experiences.

In Study IV, content analysis was chosen as the analytical method based on the purpose to provide a description of the fathers' perceptions of their involvement concerning their child with diabetes, and to illuminate this by building a hierarchal model (Elo & Kyngäs, 2008). Content analysis involves the reduction and sense-making of qualitative data in order to identify core consistencies and meanings

(Patton, 2002). Several approaches to content analysis are identified. In the present study, a conventional content analysis was conducted because an inductive design was used (Hsieh & Shannon, 2005). Latent as well as manifest content analysis was used to capture the fathers' understandings of their involvement and to combine these understandings into a larger whole (Graneheim & Lundman, 2004). Three steps guided the analysis phase. First, the preparation phase was conducted, whereby units of analysis were chosen and an attempt was made to comprehend the whole. This was followed by coding, grouping, categorizing and abstracting data in the organization phase. Finally a conceptual map was drawn, referred to as the results phase (Elo & Kyngäs, 2008). A detailed description of the analysis process, further illuminated by examples of the analysis processes, is provided in Paper IV.

#### **Trustworthiness**

Qualitative methods are founded on an understanding of research as a systematic and reflective process for the development of knowledge that can be contested and shared, implying ambitions of transferability beyond the study setting. Accordingly, the researcher "must use strategies for: questioning findings and interpretations instead of taking them for granted; assessing their internal and external validity, instead of judging them obvious or universal; thinking about the effect of context and bias, without believing that knowledge is untouched by the human mind; and displaying and discussing the processes of analysis, instead of believing that manuals grant trustworthiness" (Malterud 2001, p. 483).

Larsson argues for quality criteria in qualitative research that concern quality in the work as a whole, in terms of the researcher's perspective consciousness as well as the internal logic and ethical values. Further criteria affecting the quality of the results are richness of meaning, structure and theory development. Five criteria for validity are proposed: discourse criteria, heuristic value, empirical anchorage, consistency and a pragmatic criterion (Larsson, 1993).

In discourse analysis the trustworthiness of the findings depends on the verifiability of the researcher's interpretations, which must be based on the research data in a consistent and identifiable way (Talja, 1999). The excerpts are not descriptions of the object of research; they are the object of research. They constitute the basis for the researcher's argumentation and provide linguistic support for the interpretations (Potter & Wetherell, 1987). Because the aim of discourse analysis is to produce interpretations that are intrinsically macro-sociological, the quantity of data does not have to be large. The amount of data is therefore not a quality criterion in the analysis of discourses, as every single data source may suffice to indicate what kinds of interpretations are possible (Talja, 1999). All knowledge — even research-based — is constructed in discourses.

Consequently, even knowledge produced in the analysis of discourses reflects the discourse the researcher inhabits and, thus, a high degree of transparency of underlying assumptions must be sought in order to establish credibility (Winther Jorgensen & Phillips, 2000).

According to Charmaz (2006), the quality of a GT study is based on credibility, originality, resonance and usefulness. Credibility concerns whether the data are sufficient to address the claims, whether the analysis process was comparative, whether the categories cover the empirical observations, and whether there is sufficient support for the claims. The requirement of originality focuses on the freshness of the categories and on how the grounded theory challenges, extends or refines current ideas, concepts and practices. Resonance is established by exploring whether the grounded theory makes sense to the participants and whether the analysis offers them deeper insight into their lives. Finally, usefulness stands for transferability and implications for practice (Charmaz, 2006).

Because the emerged GT depends on the researcher's view and cannot stand outside it (Charmaz, 2006), reflexivity becomes crucial to the quality of the claims. Objectivity is achieved by ensuring transparency of the researcher's view through all steps of the research process (Malterud, 2001).

Quality in qualitative content analysis is sought through credibility, dependability and transferability (Graneheim & Lundman, 2004). Credibility focuses on how well the data and the analysis address the intended focus, how well-selected the most suitable meaning units are, and how well the categories and the theme cover the data. Dependability reflects how well the researcher takes into account temporal changes in data. It is important to question the same areas for all participants, but at the same time interviewing is an evolving process during which interviewers acquire new insights into the studied phenomena. The third and final part of trustworthiness, transferability, concerns the extent to which the findings are transferable to another context. Based on a clear and transparent description of the entire process, the researcher claims transferability of the findings. In the thesis the following steps have been taken throughout the design, data collection and analysis process in order to validate the findings and achieve trustworthiness:

Throughout the entire process the researcher has kept a diary in order to document processes in the research, processes and feelings within the researcher, and emerging thoughts and ideas. In Studies II and III, memos were continuously written in the simultaneous data collection and analysis process.

To achieve transparency in perspective consciousness, the researcher's background and theoretical perspectives have been described (I, II, III).

By using focus group discussion for data collection, data quality was enhanced through the interactions among the professionals on the team (II). Participants in focus groups tend to impose checks and balances on each other, which weeds out false or extreme views (Patton, 2002).

A validated instrument measuring fathers' involvement in their child's daily life, the PRQ, was used to sample the informants (III, IV). Variation in the fathers' socio-economic backgrounds was sought in order to increase transferability (III, IV).

Initially, the participants in the RFGDs tended to describe their perceptions of fathers' involvement in a normative way. To overcome normative descriptions, a narrative approach was used (II, III, IV). Credibility was also sought by repeatedly summarizing the perception of what the participants expressed and seeking their confirmation during the interviews and focus group discussions (II, III, IV).

An established and validated analysis model was applied in the analysis of discourses in order to achieve credibility (I). The model has built-in face validity: in Step 2, underlying discourses are revealed and their relevance and plausibility are examined and discussed in subsequent steps.

Credibility was pursued by constantly comparing data from the RFGDs, the interviews and the emerging categories, so that links between the data and the analyses would become evident. Furthermore, the emerging categories were constantly discussed and developed to ensure that they covered the data (II, III). Originality was sought by letting the findings challenge, extend and refine current concepts such as health promotion, gender structures and eco-cultural pathways (II, III). The findings were presented to and recognized by both the PDTs and the fathers, thus achieving resonance (II, III).

The analysis process in the content analysis was made transparent by illustrating how meaning units, condensations and abstractions were conducted (IV).

Text excerpts have been used to exemplify the different steps, just as evaluation and discussion have been continuously woven into the findings (I). Citations from participants are used to exemplify and to help the reader judge the strength of the links between data and abstractions (II, III, IV).

In order to achieve a high degree of trustworthiness, the process of writing the drafts has been essential (I, II, III, IV). Through alternation between the data, the analytic steps and the writing of the draft, the emerging findings achieved a higher level of abstraction and were at the same time empirically strengthened.

The validity of the findings was also reinforced by regular review and discussions with supervisors and colleagues (I, II, III, IV).

Malterud (2001) argues that the researcher's background and position will affect what is chosen to investigate, the perspective of the investigation, which methods are judged to be adequate, which findings are considered to be most appropriate, and the framing of the conclusions. Hence, validity in qualitative research is highly dependent on the transparency of the researcher's reflexivity, preconceptions and theoretical frames of reference.

My pre-understanding of the studied area is based on my background as a pediatric nurse with professional experience of neonatal care, medical care for children aged 2-18 years, and school health nursing. In the latter part of my professional life I have taught, on an advanced level, child health nurses within the Public Health and Health Promotion Program. My experience of pediatric diabetes care is limited to the children I have met during their initial hospital stay in conjunction with the onset of the disease. As a pediatric nurse I have extensive experience of meeting and interacting with families, including fathers.

#### **Ethical considerations**

Ethics in science concern doing good and not causing any harm (World Medical Association, 2011). When doing research on human beings there are four guiding ethical principles: the requirement for information, the requirement for consent, the requirement for confidentiality, and the requirement for utilization (Vetenskapsrådet, 2002). The requirement for information implies that the researcher is to inform the participants about their role in the project and the conditions of their participation. The participants should be informed that their participation is voluntary, and that they can discontinue participation at any time without giving any reason. The requirement for consent means that the researcher must obtain respondents' and participants' consent to participate. There should be no dependency between the researcher and the participants. In order to fulfill the requirement for confidentiality, all details of a survey including participants should be given the widest possible confidentiality, and personal data should be stored in such a way that unauthorized persons cannot access them. Finally, the requirement for utilization implies that data collected about individuals can be used only for research purposes (Vetenskapsrådet, 2002).

In order to identify the need for ethical approval for three of the four studies, the scientific secretary of the Regional Ethical Review Board in Gothenburg was contacted. According to the scientific secretary there was no need for formal approval of Study II, as the PDTs were to share their professional experiences but not their private ones (28 April 2009). Therefore, ethical approval was

applied for only for Studies III-IV in October 2009. The Board judged that the two studies were not covered by the Ethics Act and hence did not rule on the permit but approved the studies (Appendix III).

To meet the requirements for information and consent, the professionals at the clinics were verbally introduced to the RFGDs and participation was presented as voluntary: the members of the teams could withdraw at any time during the process (II). As the fathers were recruited at the diabetes clinics (III, IV), they were verbally informed by the pediatric nurse and received an information letter describing the study with a counterfoil for written consent and a postage-paid envelope for the reply. The fathers were informed in writing that their participation was voluntary, that they could withdraw at any time without explanation, that their identity would not be disclosed, and that their potential participation or non-participation was unknown to the PDTs (Appendix I).

The requirement of confidentiality was met by storing the data on University West's server, which performs a backup every 24 hours, and making it exclusively accessible to the researcher. To further maintain confidentiality, an agreement was reached in the RFGD to only use the first names of fathers, mothers and children in the PDTs' narratives (II). The PDTs then knew who the person being discussed was, but since the researcher had no connection to the clinic there was no possibility of revealing the person's identity to the researcher. A further step in strengthening the fathers', mothers' and children's confidentiality was to use codes rather than names in the transcriptions (II).

In the OFGD information letter (III) (Appendix IV), the fathers were offered confidentiality through a personal login and user name. They received information on how to change their user name in order to increase the degree of confidentiality or, if they so wished, to use their own name in the discussion. None of the six participating fathers used these opportunities.

Confidentiality was insured in the written and oral information given to the fathers (III, IV). Initially in the interview situations, the fathers were again informed of the confidentiality, conducted by coding all interviews and concealing their identities in the articles (III, IV).

The requirement for utilization has been fulfilled since the collected data are used exclusively in the current four studies.

# **Findings**

The findings are presented in Figure 4, in an ecological setting from micro- to macro-level.

#### The discursive perspective

Parents' voices were diminished in Nordic pediatric guidelines in favor of the expert discourse (I)

# The professionals' perspective

Pediatric diabetes teams perceived fathers' involvement as being in balance with the mothers' engagement (II)

# The fathers' perspective

The fathers experienced a tension between general professional recommendations and their personal experiences (III)

The fathers portrayed their involvement as being based on general parenting. A fine line was identified between a health promotion perspective and a controlling involvement (IV)

Because focus was on fathers' engagement, the teams began to identify and encourage fathers' involvement (II)

Figure 4. The findings positioned on the macro-, meso-and micro-levels

# The fathers' perspective

# The fathers' interpretations of their involvement

The foundation of the fathers' involvement in their child's diabetes care and daily life was their general, basic parental involvement. Additionally, the fathers expanded their commitment to include the child's disease. The fathers based their general parental involvement on their prioritization of the family and their conscious rearing of the child. Their expanded involvement due to the disease

affirmed their desire to promote the child's health and control the disease, as well as their wish to promote and enable the child's autonomy (Figure 5).

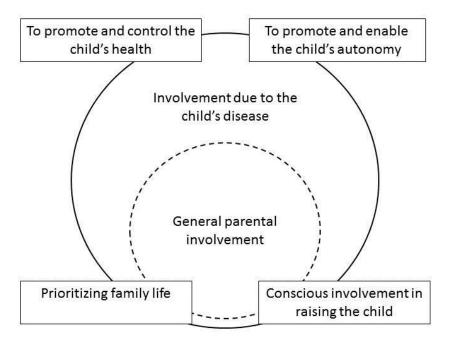


Figure 5.The fathers' understandings of their involvement concerning the child with type 1 diabetes.

## General parental involvement

All but two of the fathers in the sample had been on parental leave, and they felt it was natural to stay at home in order to spend time with their child. The fathers' involvement had been initiated when they were expecting the child and became fathers, rather than when the child was diagnosed with diabetes. They emphasized their desire to be present and accessible to their child, and several made arrangements such as adapting their work hours to the child's school hours, working part-time or, when possible, working from home. Being an involved father was associated with being a good father and a modern man. The importance of a good relationship with the child's mother was also stressed as a base for the fathers' general parental involvement. In contrast, when the relationship with the other parent was strained, the fathers pointed out their engagement as a necessity for their child's health and well-being.

The involvement was also interpreted as a conscious intention to provide the child with necessary and desirable skills, values and norms. The fathers wanted to pass on to their child what they considered important in life. They hoped that by being involved in their child's daily life they would be a good role model. They explained their desire to consciously raise their child by mentioning the good relationship they had with their own father and how they wanted their child to understand the importance of a good parent-child relation.

#### Involvement due to the child's disease

The fathers described the additional involvement due to the child's disease as a supplement to general parenting. Their involvement was categorized in terms of promoting health, controlling the child's disease, and promoting and enabling the child's autonomy. The fathers felt their involvement was necessary to their child's health, and argued that they needed to know more about their child compared to parents whose children did not have diabetes. Some fathers described their involvement as lifelong.

Promoting health and controlling the child's disease included planning and structuring the child's and the family's life, mainly scheduling food and activities. The fathers saw this structuring of daily life as a burden, but also as an integrated part of life. Being involved so as to maintain control also meant that the fathers needed to be prepared for unexpected situations in relation to the diabetes, for instance if the child changed plans and activities. This readiness implied almost always being accessible on short notice, meaning being reachable by phone and quickly physically available. Several fathers expressed worries when their child was out of reach and beyond their control, and described strategies like keeping in contact by cell phone and, in one instance, even checking the child's possible ways to school. Some fathers reported that it was hard to relinquish control. This hesitancy resulted in one father waiting in an adjacent room while his 13-year-old attended leisure activities and another waiting in the pre-school hall until his child had started eating breakfast. When the child was within their control and shared his/her daily life experiences with them, the fathers felt secure.

The fathers also interpreted their involvement due to the child's disease as a responsibility to promote and enable the child to become autonomous in his/her future life. They discussed and argued that their child needed to take control of the disease and not let it take control of him/her. The fathers pointed out that it was their responsibility to provide the child with skills and self-confidence to enable him/her to take control over the disease and his/her own well-being and life.

### The fathers' experiences of the professional support

## The tension between general recommendations and personal experiences

The fathers described a tension between the general professional recommendations and their personal experiences of daily life with their child. The fathers expressed differences between their deeper knowledge of their child and their PDT's medical recommendations for managing the child's diabetes. When the fathers' unique experiences and the PDT's professional knowledge met and enriched each other, the fathers expressed trust in their PDT and the tension was minimized. When the fathers experienced that their PDT did not consider their own personal experiences of daily life with their child, the tension increased and the fathers distrusted their PDT (Figure 6).

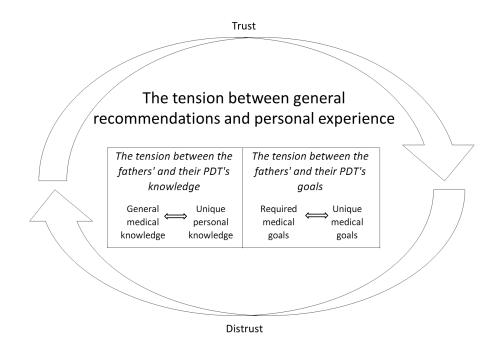


Figure 6. How fathers of children with diabetes experienced the pediatric diabetes teams' support in their everyday life with their child

There were also differences in how well the goals set by the fathers matched those set by their PDT; in some cases the father and the PDT agreed, and in others there was a discrepancy. For the most part, when there was a difference in goals, the fathers accepted higher levels of blood glucose than the recommended ones. The fathers described their wish to fulfill the PDT's requirements and the effect they had, but also highlighted the difficulties in implementing the recommendations in their family life. They insisted that their child did not feel well when they upheld the recommended blood glucose levels, and in some cases this was underpinned by the fathers' fear that the child would become hypoglycemic. In order to decrease the tension caused by differences in goals the fathers played down the blood glucose values, calling them, e.g., 'not so bad', negotiated the goals with

themselves, and tried to compromise between what seemed reasonable to them and the requirements of the PDTs.

Those fathers who expressed differences in knowledge and goals compared to their PDT also pointed out that they experienced implementing recommendations in daily family life as much more complex than was indicated by their PDT. These fathers also perceived that their PDT failed to understand the family's unique situation. When fathers accepted higher blood glucose levels than the recommended ones, this could pose a threat to the child's health and well-being. In situations when the goals of the fathers and the PDTs coincided, the fathers felt trust in their PDT and experienced that they were able to discuss anything.

# The professionals' perspective

## The professionals' perceptions of the fathers' involvement

The PDTs' perceptions of the fathers' involvement were related to the assumption that the mother is the primary caregiver, or as one team member expressed it: "If Dad shows up, we're happy – if Mom doesn't, we become concerned". This perception was built on societal and cultural gender structures, as the PDTs perceived fathers' involvement in their child's daily life as being based on his inherent qualities and gender-specific areas of responsibility. As professionals they experienced the fathers as being more skilled and interested in technology and mathematics than the mothers, and justified this with the fathers' work experiences. They also pointed out a 'natural' gendered division of labor at home, because fathers had more important work than mothers did and mothers had greater opportunities to work part-time. The gendered differences in responsibilities were pointed out as general or 'natural' for all families and therefore also for families with a child with diabetes.

Three categories of fathers' involvement were identified by the PDTs: passive or deputized fathers, fathers who shared commitment with the mother, and fathers who were the primary responsible parent. In all categories, the PDTs reasoned about and balanced the father's involvement in light of the assumption that the mother was the primary caregiver.

#### Passive or deputized involvement

When the father's involvement was perceived as passive or deputized he did not, according to the PDTs, actively assume responsibility for the child's daily life. However, he could have peripheral supporting functions like unburdening the mother by taking care of the garden or the car. According to the PDTs, a passive or deputizing father's lack of involvement could be due to the mother's dominance as caregiver and sometimes her unwillingness to let the father play an active role in the child's care. A father's passivity might also be due to his unwillingness to acquire knowledge about

the disease. When the father's involvement was perceived as deputized, he was thought to have sufficient knowledge to uphold the child's care for a while and temporarily replace the mother; he was the second-best caregiver. As long as the child's health and well-being were under control and the mother monitored the disease in an acceptable way, the PDTs did not request the fathers' attendance at the pediatric diabetes clinic or ask about their disease management skills. The PDTs did not explain or justify the absence of involvement of the passive and deputized fathers on an individual level. Instead, they reasoned about it using general gendered stereotypes, for instance attributing their absence to men having more demanding jobs than women and consequently spending less time at home with the children.

#### Joint involvement

In the second category, the PDTs identified fathers' involvement as a shared or joint commitment with the child's mother. The fathers took practical and moral responsibility for the diabetes regime and the child's daily life. The father and the mother were perceived as equal caregivers with equivalent knowledge of the child and the disease. Here, care-giving was not implicitly or explicitly expressed as gendered. The PDTs thought that the preconditions for the parents' shared commitment were the couples' capacity to work as a team and their ability to communicate well. The parents who had a shared commitment also had overlapping, less gender-stereotyped areas of responsibility and could replace each other in the care of the child.

# The father as the primary involved parent

Thirdly, the fathers the PDTs identified as the primary responsible parent were said to have more knowledge about the disease than the mother, and to assume primary responsibility in their child's daily life. The PDTs considered these fathers to be ambitious and to have full control of the disease management. Yet, only a few fathers were identified as the primary caregiver. According to the PDTs, these fathers' involvement was largely due to the mother's lack of presence or capacity to care for the child. When the fathers were perceived as the primary caregiver, the PDTs explicitly pointed out the mothers' individual reasons for being absent: she could be dead, seriously sick or in prison, or have low cognitive capacity (i.e. based on the gendered stereotype of the mother being the primary caregiver).

#### The development of professionals' attitudes toward fathers' involvement

During the repeated focus group process, the PDTs' attitudes toward and awareness of fathers' involvement changed. Initially, the PDTs perceived and talked about fathers as an undefined part of a parental unit and their perception of the fathers' involvement was vague. Implicitly, they meant the mother when they used the term 'parent'. Later, as the intervention proceeded, the PDTs became more aware of the fathers' involvement and recognized it in more detail. They identified the fathers'

contributions to the child's daily life and talked about him as an individual in the parental unit. At the end of the process, the PDTs highlighted and appreciated the fathers' involvement and explicitly encouraged it. At this stage, the PDTs perceived the fathers as individuals and not only as part of the parental unit.

The awareness process was affected by three factors: the RFGDs, revised fatherhood discourses, and the fathers' own activities. First, each repeated focus group discussion about fathers' involvement narrowed and focused on the PDTs' awareness of the fathers' engagement. Second, the teams pointed out their greater awareness as being a consequence of structural changes in society toward a more nurturing and caring fatherhood discourse. Third, the fathers' own actions increased the PDTs' awareness of their involvement. Sudden or unexpected episodes could increase the father's involvement, and when this happened, the PDTs very much appreciated and encouraged it. On the other hand, the PDTs also described how highly involved fathers disappeared out of their child's life, and how this sudden lack of involvement made the PDTs conscious of the father's former engagement in the child's life. However, the PDTs did not actively initiate the fathers' involvement; if it increased they strongly encouraged it, and if it decreased they regretted it.

## The discursive perspective

Aiming to illuminate the macro-perspective of fathers' involvement, three Nordic guidelines for the pediatric care of children with type 1 diabetes were analyzed for discourses. Because the terms father and mother were very rarely used in the guidelines in favor of parent(s), the latter became the subject in focus in the analysis.

Four discourses were found in the guidelines: the hegemonic Expert discourse monitoring the Medical discourse, the Pedagogic discourse and the Public Health discourse (Figure 7).

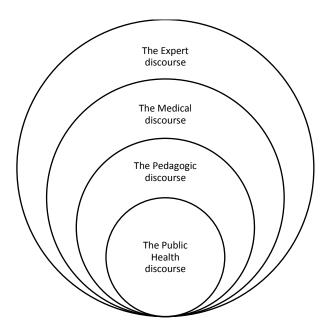


Figure 7. The discourses identified in the guidelines and their hierarchical relationship.

In the guidelines, parents were mainly positioned as being in need of education about the disease. The parents were constructed as exposed and vulnerable, as being in transition from a family with a healthy child to a family with a chronically ill child, and as initially being both incapable of handling the situation and responsible for the disease outcome. They were also constructed as partners with the professionals and resources for the child, and were expected to implement the medical knowledge provided by the medical experts and have a major impact on decisions.

The constructions of parents drew on the Expert discourse, which is based on the Medical discourse. The expert perspective dominated throughout the guidelines, owing to the parents' need for education from the professionals, who possessed medical knowledge about how to treat and relate to the disease. The constructions of parents were also based on a Public Health discourse, as parents were seen as being a vulnerable and exposed group who could benefit from societal intervention – being educated and supported by the experts, i.e. the professionals. Finally, in the constructions of parents as recipients of information and education, the guidelines contained a Pedagogic discourse. An apprenticeship perspective on parents was found in the documents: professionals should overview and assess parents' new knowledge and skills.

Positioning parents as dependent on the experts may cause them to lean on the professionals' knowledge. This could result in parents being less willing to take the initiative, which could turn out to be pacifying: parents may rely heavily on experts and only do exactly what is asked for. This may result in feelings of uncertainty about their own capacity. On the other hand, parents could perceive the situation as a challenge and actively try to find ways to deal with their new life situation. When

parents are positioned as recipients of education, there may be a risk of less initiative-taking and more copying the professionals in order to do the right thing, which could create feelings of insufficiency. However, being educated probably increases parents' knowledge, and with time they are likely to feel more competent and comfortable in dealing with the disease.

The medical perspective in the guidelines is essential to the child's physical health and well-being, but it also diminishes the parents' voice and, thereby, the social context in which the child and the family have lived and will continue to live with the disease.

# **Discussion**

## The health promotion perspective

The findings illuminate the complexity of fathers' involvement by highlighting how the guidelines (I) and the gendered structures mark the fathers' engagement, the PDTs' perceptions of fathers' involvement (II), and the fathers' experiences of the professional support (III). The findings further stress how the fathers' engagement in their child's daily life in addition to the 'stimuli' of the repeated focus group discussions increased and supported the PDTs' health promotion perspective (II). These multiple interactions between the macro-, meso- and micro-levels are logical in relation to the complex social systems involved in health promotion. The findings and the health promotion systems are characterized by being nested in each other, depending on history and culture, and by human agents that act consciously as well as unconsciously in response to stimuli (Tremblay & Richard, 2011). Because the presumption of an ecological model is the interaction between its different levels (Bronfenbrenner, 1979), this nesting suggests a possible domino effect: if a health promotion perspective is adapted in one system, this might affect the other systems at different levels. Accordingly, from a health promotion perspective, consistency, discrepancies and interactions between the levels identified in the findings will be further discussed in order to suggest implications for practice.

The identified interaction between the hegemonic expert discourse in the guidelines and the fathers' experiences of a tension concerning the PDTs' general recommendations is problematic, as it illuminates how the disease-oriented approach (Zoffmann & Kirkevold, 2005) impacts the microlevel. Because the guidelines are supposed to guide and instruct the members of the PDTs in their practice with the child and the family at the macro-level (Leach & Segal, 2010), the hegemonic expert discourse in the steering documents is probably impregnated and concretized in the teams' practice. Consequently, the tension the fathers experienced between their unique knowledge and the general recommendations (III) might be traced to their diminished and subordinated voice in the macro-level guidelines (I). There is a consistency between the different levels, in that the discourse is identified at macro-level and experienced at micro-level. However, the approach in the guidelines does not take its starting point in the parents as social actors and agents, but as hosts of medical knowledge who are in need of education and therefore less health-promotive (I). This interaction shows the strengths of the hegemonic discourse and its impact on the individual level. Consequently, an explicit health promotion perspective in the guidelines is likely to have the same impact at micro-level. When the PDTs adopted a health promotion perspective by legitimizing the fathers' knowledge (Tremblay,

Richard 2011) and internalized the fathers' personal experiences, the fathers felt trust in them (III). Moreover, the fathers' goals and the PDTs' goals coincided, which is likely to have a positive impact on the child's health and well-being. Then again, when the PDTs had a disease-over-life priority (Zoffmann & Kirkevold, 2005) the fathers' experience of tension increased: they felt distrust in their PDT, and their goals and the PDT's goals diverged, implying a risk to their child's health.

One way to implement a health promotion perspective in the guidelines would be to involve both the parents (mothers and fathers) and all professionals engaged in the support of the family and treatment of the child. In the present guidelines the majority of the authors are physicians, a likely explanation for the hegemonic expert discourse. Since the guidelines are to support all professionals involved in the care and represent as many interested parties as possible (Hewitt-Taylor, 2003), including the child and his/her family, additional authors should be invited.

The findings show that parents are constructed in the pediatric diabetes guidelines as essential to their child's disease outcome and are strongly encouraged to be actively involved in their child's diabetes care (I). Using the term 'parent' in the guidelines runs the risk of hiding gendered structures (Sunderland, 2006); superficially it refers to both mothers and fathers, while in practice the term will be interpreted as the mother (II). If the importance of both parents in promoting children's health and well-being were expressed more explicitly, mothers and fathers would become more prominent in the documents and thereby be more in focus for those utilizing the documents – the PDTs. The interaction between the meso- and macro-levels is also illuminated by the fact that the PDTs explain their usage of the concept in the same way as it occurs in the documents (II). Due to the assumption that reality is socially constructed (Burr 2003) and macro-, meso- and micro-levels interact (Bronfenbrenner, 1979), the fathers' experiences strongly depend on how they are constructed and positioned at the structural level. If fathers and mothers were specifically approached from a health promotion perspective in the pediatric diabetes guidelines, this would likely have an impact on the PDTs' perceptions of the fathers' involvement and the fathers' experience of the professional support.

The findings on the PDTs' gendered perception of the fathers' involvement (II) also need to be considered from a health promotion perspective. The PDTs' perceptions of the fathers' different levels of involvement reflect different degrees of gendered stereotypes. When the fathers' involvement was perceived as one of the two extremes on the continuum, either as passive or as acting as the primary caregiver, this was based on the assumption that the mother is the 'natural' nurturer. The PDTs also constructed and maintained gendered stereotyped parent roles by pointing out that the fathers' high involvement is a result of the mother's lack of ability to fulfill her

caregiving. By accepting and, in the FGDs, initially not reflecting on the fathers' low involvement, the PDTs maintained and supported the taken-for-granted assumption (Connell, 2002) of mandatory motherhood and voluntary fatherhood (Bekkengen, 2006). Consequently, by maintaining traditional gendered stereotypes in parenting, the PDTs only considered one of the child's parents as a health resource and the child's access to both parents in relation to their diabetes care was not promoted.

Further, the findings reveal that the PDTs' constructions of the fathers' involvement were less stereotyped when they perceived fathers' and mothers' involvement as shared. Here, they referred to the fathers' involvement as a consequence and an effect of the parents' relationship and communication instead of gendered parent roles. This is accordance with findings showing that children of involved fathers have less sex-stereotyped beliefs because they have been raised in a less gendered context, given that their parents have less gendered attitudes toward male and female roles (Lamb & Tamis-Lemonda, 2004). When the PDTs identified the fathers' involvement as a shared commitment they described parenting as a joint and equal task, probably influenced by the fathers' less gendered actions, revealing an interaction between the micro- and meso-levels. The fathers' health promotion activities and their involvement in their child's daily life were of relevance to the PDTs' perception of parental roles.

The findings point out a failure to address both parents' significance at macro- as well as meso-level. From a health promotion perspective, it is essential that the PDTs take into account fathers' involvement in their child's diabetes care and daily life at both macro- and meso-level, not as a goal in itself but in order to provide the chronically ill child with the best possible health resources. If the PDTs explicitly support the empowerment process within both fathers and mothers in their joint parental responsibilities, the child's social capital is likely to increase, thereby promoting a determinant of health and well-being (Rootman, 2001).

From a health promotion perspective, the pediatric diabetes care system must recognize fathers as well as integrate fathers and mothers throughout the entire treatment process, not only initially. Having a health promotion perspective means being pro-active (Kickbusch, 2007) and enabling the child to have access to both parents instead of only involving the second parent as a reaction to poor diabetes adjustment. In order to provide the child with all possible resources to ensure the best quality of life, the PDTs need to relate to the parents' relationship. PDTs are not supposed to be family counselors and should not act as such, but they should not ignore that having two highly involved and cooperating parents is significant to the disease outcomes (Wysocki et al., 2009). Instead, by explicitly and strategically maintaining contact with both parents and supporting their

involvement, even after the initial clinical visits, a pro-active approach might be achieved and a health promotion perspective established.

## Incitement for fathers' involvement

The common factors among the fathers in Study IV were their high involvement in their child's daily life and their use of parental leave. Education has been found to be a major predictor of men's use of parental leave (Sundström & Duvander, 2002) and thereby their involvement in their child's daily life. In Sweden, fathers with a postgraduate education use a quarter of the total amount of the economically supplied days per child, compared to fathers who have not completed upper secondary school, who use only a tenth of the days. For women, the opposite applies: the higher the education level, the lower the use of parental leave (The Swedish Social Insurance Agency, 2011). The educational level distribution of the highly involved fathers in Study IV was approximately equal to that of the Swedish population (IV). This indicates that the fathers' educational level was not an important factor in these fathers' involvement in their child's daily life. Instead, common to all but two fathers was their past use of parental leave, which they also pointed out as an important foundation for their relationship with their child.

Bergman and Hobson (2002) point out that economy is another factor that is a predictor of fathers' involvement in the form of taking paternal leave; however, this factor is subordinate to educational level. Furthermore, Swedish fathers with a high income are more likely to use parental leave than are fathers with a low income (Bergman & Hobson, 2002). The highly involved fathers in the present thesis were not characterized by high income, as their professions suggest incomes varying from low to high (III, IV). Still, the common factor of the fathers was their use of parental leave.

According to statistics the father most likely to use paternal leave, in addition to being highly educated and having a high income, works in the public sector (Bergman & Hobson, 2002). The professions of the fathers in the present thesis differ from those found in previous findings, as they are mainly technically oriented and can be regarded as male-dominated, in contrast to the public sector, which is female-dominated. However, even if the fathers in the thesis did not represent the fathers most likely to take parental leave, they had done so, and indicated high involvement in their child's daily life and diabetes care.

The findings show that the fathers' parental leave is an important factor for their involvement in the child's diabetes care and daily life. This could be explained by the attachment theory. Infants become attached to adults who are sensitive and responsive in their social interactions, and to those who remain consistent caregivers for some months during the period from about six months to two years

of age. Parental responses cause the child to develop patterns of attachment, which construct internal working models. These models will guide the child's perceptions, emotions, thoughts and expectations in later relationships (Bowlby, 1988). Developing a father-child relationship during the child's first years not only contributes to the child's development but also to the father's own growth. If one member of a two-person system undergoes a process of development, the other does as well (Bronfenbrenner, 1979). Support for this explanation based on the attachment theory is further provided by the strong interaction between metabolic control in adults with type 1 diabetes and their attachment style. Adult individuals who had developed a 'secure attachment style', based on an optimal adult-child relationship, had on average the lowest HbA1c levels compared to adults with less successful attachment patterns (Ciechanowski, Hirsch, & Katon, 2002). This connection between positive diabetes management outcomes and the quality of the parent-child relationship further supports the need for a health promotion perspective on fathers' involvement.

Having a child with a chronic disease probably has an impact on fathers' involvement, as the child's health and well-being depend on parental engagement. In fact, this probably increased paternal involvement since it was based on an already existing father-child relationship from the time the child and the father had spent together during the parental leave. This is also illustrated by the fathers' interpretation of their involvement in their child's diabetes care as being based on their general parenting (IV). Furthermore, fathers who have been on parental leave are more likely to adjust their working conditions, such as working part-time or giving up a job, to accommodate the family situation (Lammi-Taskula, 2007). Having a child with type 1 diabetes might require that the parents make structural adjustments to the family situation. Consequently, the involved fathers in the study who had been on parental leave did adjust their work situation in order to be available to their child with diabetes (IV).

The findings also suggest that the fathers' positive relationship with their own father was a central factor in their involvement in their child's daily life, which is also supported by the attachment theory (Bowlby, 1988). In their childhood, the fathers might have built positive internal working models in their interaction with their own father, thus passing on the 'secure attachment model' to their child. According to Swallow and colleagues (2011), the positive impact of intergenerational connections is evident.

At the child's disease onset, the professionals explicitly and with great engagement invited both parents several times to offer them the same education in diabetes treatment. Later, the attendance of one parent was accepted as sufficient at the pediatric clinical visits, owing to the parents' decisions and opportunities to participate. The professionals estimated that the mother was the

parent who visited most frequently, and as long as the child's diabetes treatment was under control, no further effort was made to contact the other parent, most often the father (II). This failure on the part of child health care to include fathers and support their involvement is well documented (Carlsson, Johansson, Hermansson, & Andersson-Gäre, 2010; Fägerskiöld, 2006; Premberg, Hellström, & Berg, 2008; Wells & Sarkadi, 2012), and was also confirmed by the PDTs (II). Instead of actively promoting fathers' involvement, it was the father's own actions and activities that increased the PDT's perception of him as a health resource for the child's health and well-being. Those fathers who were highly involved were recognized and identified by the PDTs, and because the focus was on involved fathers and their influence on their child, the PDTs' awareness of them as caregivers increased and they started to encourage fathers' involvement. A positive spiral of fathers' involvement was induced, not consciously by the professionals but by the already involved fathers (II). The incitement for fathers' involvement on the professional level was weak, as there was no explicit strategy. Moreover, none of the fathers stated that the PDTs' support was motivation for their involvement in their child's daily life. One way to support fathers' involvement and thereby promote the child's health would be to consciously encourage their activities and maintain good contact. Fathers need to know that they have to be involved (Sullivan-Bolyai, Rosenberg, & Bayard, 2006), and professionals engaged in child and adolescent health care should actively encourage fathers' involvement (Sarkadi et al., 2008; WHO, 2007).

The findings also show that the fathers' degree of involvement depended on their desire to be a good and modern father (IV). Contemporary masculinity is the reflection of a public and governmental understanding of what family and private life should be (Aboim, 2010). In Study IV the fathers practiced the discourse of modern paternity, the nurturing and caring father (Lamb & Tamis-Lemonda, 2004). As the fathers stressed the values of their relationship with their child and their family, and were simultaneously highly involved in their child's life, they represent a child-oriented masculinity, not only on a discursive level but also in practice (Bekkengen, 2006). By doing so, the fathers both supported the discourse and contributed to its maintenance.

The fathers pointed out how governmental visions and economic support for parental leave provide an opportunity for all fathers to develop a good relationship with their child, which has been found to be an incitement for paternal involvement (Chesler & Parry, 2001; McNeill, 2004; Neil-Urban & Jones, 2002). However, the fathers in this thesis also recognized that only a few fathers actually put paternal leave into practice. This is in accordance with the hegemonic position of child-oriented masculinity, which is positively embraced by a majority but is only practiced by few (Connell & Messerschmidt, 2005).

## The fathers' involvement and the shared parental commitment

The fathers in Study IV all scored below 4.29 on the PRQ, which indicates high involvement in their child's daily life. Common to the fathers who scored highest on involvement was that they were single parents: either they had sole responsibility for the child's upbringing, or in a practical sense functioned as a single parent because the mother was in some way temporarily absent, e.g. she might commute to work on a weekly basis (III, IV). Consequently, the fathers with the highest involvement scores were also those with less spousal practical support, which has been found to impede personal growth in fathers of children with long-term medical conditions (Swallow, Macfadyen, Santacroce, & Lambert, 2011). The findings show that the most involved fathers were also those who to a greater extent tried to minimize the experienced tension by adjusting diabeteshealth-related goals to suit their life situation, thereby possibly risking their child's health (III). This is in accordance with findings showing that children with type 1 diabetes living in single-parent families tend to have higher HbA1c levels (Daneman, 2009). The single fathers were also those who found it hard to relinquish their control over the child (IV) and hence had a tendency to take a parenting approach that promoted over-dependency in the child, a factor associated with poorer metabolic levels (Hoey, 2009).

The findings also show that the fathers who scored close to 4 on the PRQ pointed out that their collaboration with the child's mother was an essential factor in their involvement, even if the father did not cohabit with the mother. Their scores indicated parental cooperation marked by equal and interchangeable areas of responsibility and hence fewer sex-stereotyped parental roles (III, IV); in support of this notion, the PDTs also viewed the fathers' involvement as a shared commitment (II). In line with this, effective family function has been found to occur when both fathers and mothers are able to undertake management tasks, and child well-being has been shown to be significantly affected by maternal and paternal adjustment to chronic illness (Swallow, Macfadyen, Santacroce, & Lambert, 2011). Chronically ill children also adjust better if there is more family cohesion and less family conflict (Soliday, Kool, & Lande, 2001). The present findings are consistent with previous results showing that children with highly involved fathers are characterized by increased cognitive competences, increased empathy and more internal locus of control. Two factors have been found to be important in these differences: these children may benefit from having two highly involved parents rather than one, and high paternal involvement may allow both parents to do what is rewarding and fulfilling for them (Lamb & Tamis-Lemonda, 2004). The family context in which the child is brought up therefore seems to be crucial; children do benefit from having parents who communicate and cooperate, which is also illuminated by the child's right to both parents (UN General Assembly, 1989). Both parents monitoring an adolescent's diabetes management predicts better adherence (Berg et al., 2008). Furthermore, having two highly involved adult caregivers is predictive of positive effects on HbA1c, fewer depression symptoms and a lower fear of hypoglycemia (Wysocki et al., 2009). Consequently encouraging both parents, not just one, to take an active role in the child's daily life and diabetes care promotes the chronically ill child's health and well-being.

## **Methodological considerations**

The benchmark of the present thesis is the child's right to both parents and the assumption that this will support the child's health and well-being. The research approach does not attempt to achieve equality between women and men, and should therefore not be seen as a contribution to the debate on equality. This would require a different approach, as paternal leave has not been found to be a way to equality between men and women (Klinth, 2003).

The present thesis claims to have an inductive design, based on its exploratory approach to the relatively less researched area of fathers of children with diabetes and their involvement in their child's daily life. The basic assumption of an inductive naturalistic approach is openness to whatever emerges and a lack of predetermined constraints on findings (Patton, 2002). Having a total openness is the 'perfect' approach to the data in an inductive design but since all researchers inhabit academic, cultural and historical discourses no researcher is a 'tabula rasa'; everyone is impregnated with preunderstandings. Consequently, the inductiveness can be placed on a continuum depending on how well the researcher succeeds in being open-minded and reveals taken-for-granted assumptions. The present thesis claims its predispositions in health promotion, social constructionism and gender, and this has an impact on the inductive design. However, the highest possible degree of openness has been striven for during the data collection and analysis processes in the four studies, and transparency of the researcher's presumptions has been sought. Further, the co-researchers are domiciled in different academics and professional discourses. Accordingly, several approaches have been used and have consequently increased the inductive approach, since different perspectives have been applied to data. Repetitiveness is not a quality criterion in inductive research, but the inductive design is strengthened if other researchers draw similar conclusions from the data (Patton, 2002). In the present thesis there has been an ongoing discussion of the findings in order to validate the conclusions.

The present thesis is strengthened by the different degrees of epistemological rootedness in the chosen analysis methods. Content analysis is considered suitable for inductive research because it has no specific ideological affiliation (Elo & Kyngäs, 2008). GT is defined as a 'neutral' approach because it is explicitly not committed to either qualitative or quantitative research. It provides rigor

in data collection as well as in the analysis process (Glaser & Strauss, 2006). Finally, the analysis of discourses is considered an interlaced 'package' of ontology and epistemology, and based on social constructionism (Winther Jorgensen & Phillips, 2000). By combining these three methods the theoretical base of the present thesis in social constructionism is internalized. Consequently, the choice of methods is in accordance not only with the specific aims but also with the theoretical frame of the thesis.

The consequent use of the ecological model throughout the entire research process further strengthens the thesis. The model allows for transparency and clearness of the research strategy and the presented findings, which allow the reader to judge the claims (Malterud, 2001).

The consensus between the inductive design and the use of a quasi-intervention approach in Study II is an additional strength. By applying an inductive approach to explore how the PDTs' attitudes toward fathers' involvement developed without having pre-conceived ideas about the results, the qualitative approach was confirmed and clearly distinguished from a quantitative intervention approach, as no hypothesis was presented to be accepted or rejected, and no predicted results were assumed (Bowling & Bowling, 2002).

The variation and rigor in the data collection methods as well as in the analysis methods further strengthen the present thesis. The simultaneous data collection and analysis process in the RFGD with the PDTs, guided by purposive and theoretical sampling, was an attempt to grasp the whole and not to compare the different teams' perceptions. Even if the order in which the teams were invited to the RFGDs was based their time constraints, this 'random' order of the data collection was in line with the method, as the data emerging from one occasion directed the next session (Charmaz, 2006). This approach was further strengthened in that all teams adapted their work to the pediatric diabetes guidelines and were therefore likely to share a common view of the families and the parents, as recommended in the pediatric diabetes guidelines (Örtqvist, Forsander, & Sjöblad, 2008). The variation in the composition of the individual professionals on the teams, from meeting to meeting, is both a strength and a limitation. It might have been optimal to have identical teams at each session, but because the team members cooperated in their work on a daily basis and were assumed to have internalized their perceptions of and attitudes toward fathers' involvement, and because some professionals participated in all sessions on all three teams, the data collection approach was judged to be credible.

The variation in the fathers' socio-economic background also strengthens the thesis, as variation in the data is a quality criterion in qualitative research (Larsson, 1993). The fathers' wide socio-economic distribution, in combination with their high scores on involvement, increases the credibility

and transferability of the present thesis (Charmaz, 2006), thus indicating the extent to which the findings can be interpreted in a wider context. One limitation in relation to the variation is the lack of fathers originating from countries other than Sweden. Because the findings indicate that parental leave is an incitement for fathers' involvement and that equal paternal leave is a significant goal in Swedish society (Brandth & Gislason, 2010), including fathers with an immigrant background might have enriched the findings with a widened perspective.

Different settings were used in the interviews, and it was a strength that all fathers chose their interview setting and were offered several options. Telephone interviews were not offered, but were carried out at some fathers' requests. These differences in settings might have affected the data and hence the findings; for instance, the telephone interviews were shorter than those conducted face-to-face. The time differences turned out to be differences in the duration of the initial small talk and not the data collection part, which is in accordance with results showing a higher degree of small talk in face-to-face interviews (Underhill & Olmsted, 2003).

It is also important to emphasize that the results revealing the importance of both parents' involvement do not indicate that the nuclear family is the solution. By including both cohabiting and not-cohabiting fathers, the importance of parental cooperation was highlighted regardless of their civil relationship with the child's mother.

A limitation of the thesis was the unexpected low engagement of the fathers in the OFGDs. Given that individual interviews and focus groups discussions vary in intention and outcome (Patton, 2002) this change in data collection method may have affected the findings. If the OFGDs had been more successful, they might have provided more information based on discussions and interaction between the fathers. This can be contrasted with the semi-structured interviews, which probably contributed more in-depth data.

## **Conclusions**

The present thesis concludes that fathers' involvement in their child's daily life with type 1 diabetes is constructed in a complex way in the context of interactions between the pediatric diabetes guidelines, the PDTs' perception of fathers' involvement and the fathers' own perceptions of their involvement. It is further concluded that the incitements for fathers' involvement are closely related to their use of parental leave and their practice of child-oriented masculinity, but that their involvement is not explicitly or pro-actively encouraged by the PDTs. Furthermore, the present findings suggest that the basis for balanced and health-promoting care of a child with a chronic disease takes its starting point in shared rather than gender-stereotyped parenting.

The studies included in this thesis also show that fathers' involvement in their child's daily life and diabetes care represents a delicate balance between health promotion and disease control, due to the complex interaction between macro-, meso-, and micro-level. On the macro-level the hegemonic expert discourse, prioritizing the medical perspective, emphasizes the disease control perspective. The PDTs' increased awareness of fathers' involvement as a health resource, at the meso-level, was a step towards a health promotion perspective. Finally, the balance between health promotion and disease control appears to be affected by the fathers' spousal support and their experiences of not being heard by the PDTs.

The thesis further highlights the PDTs' stereotyped and gendered view of parenting roles, and thereby scrutinizes and challenges the discourse on fathers' and mothers' parenting.

# **Recommendations for practice and research**

Based on the present findings, the following implications for practice are proposed:

#### At the meso-level

PDTs should explicitly and strategically focus on both parents in order to enhance the child's health-promotive resources in a pro-active way.

Health care professionals need to scrutinize taken-for-granted discourses and explicitly pay attention to perceptions of gender-stereotyped parenting roles within the teams. This could for example be done in team-discussions similarly to the RFGDs presented here.

#### At the macro-level

Guidelines for type 1 diabetes should be elaborated by all interested parties and include perspectives from all professions involved in the support and health care as well as from children, adolescents and parents familiar with diabetes self-management.

The importance of two involved parents and their unique knowledge of their child should be elucidated in pediatric diabetes guidelines, in order to support a health promotion perspective and clarify the interaction between the macro-, meso- and micro-levels of diabetes care.

Furthermore, awareness of gender structures and other knowledge that contributes to a critical perspective on norms should be included in health professional educational programs.

It is important that society support fathers' involvement in their child's diabetes care and daily life on the macro-level. Moreover, it would seem important to deconstruct the discourse of mandatory motherhood and voluntary fatherhood in order to facilitate the child's optimal health and well-being. Several areas need future exploration in order to obtain further knowledge regarding fathers' involvement in their child's daily life. Gender structures, like these presented here, are often persistent and long-lived. Instead of traditional information it would be interesting to proceed with an extended intervention study on how a reflecting perspective on gendered issues in pediatric health care, like the RFGDs, might in a sustainable way affect the professionals' attitudes. Through an observational study, the interaction between fathers and professionals could be further explored. In order to broaden our knowledge concerning fathers' involvement in their child's diabetes care, it is of importance to study the involvement of fathers with immigrant backgrounds. The highest-scoring single fathers' involvement and their impact on their child's health are also of interest for future research. Furthermore, the present study may be extended with a deductive study exploring the correlation between fathers' use of paternal leave and their child's HbA1c levels.

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Hej!

För en tid sedan tackade du ja till att delta i en studie; Pappors möten med diabetesvården. Som ett första led i undersökningen vill jag be dig fylla i denna enkät och skicka den till mig i medföljande kuvert. Informationen kommer att ligga till grund för vilken diskussionsgrupp på internet som du kommer att bli inbjuden till. Allt material kodas och behandlas konfidentiellt.

De första fyra sidorna handlar om dig och ditt barn med diabetes. När du fyllt i dessa väljer du ett av de tre sista frågeformulären (1, 2 eller 3), det som stämmer in åldersmässigt på ditt barn med diabetes och ringar in eller kryssar för de alternativ som stämmer bäst in på din och ditt barns situation.

Du är välkommen att vid behov kontakta mig. Du kan nå mig på <u>ase.boman@hv.se</u> eller på 070-227 80 76

Hälsningar

## Åse Boman

	Frågor om dig
1	Vilket år är du född?
2	I vilket land är du född?
3	Var bor du?
	□ I storstad, mer än 200 000 invånare
	□ I större stad, 50 001 - 200 000 invånare
	□ I medelstor stad, 20 001 – 50 000 invånare
	□ I glesbygd eller kommun med mindre än 20 000 invånare
4	Vilket är ditt civilstånd?
	□ Ensamboende
	☐ Gift/partnerskap/sambo
	□ Annat

5	Om du är frånskild/separerad, hur stor del av vårdnaden av barnet med diabetes har du?					
	□ Ingen					
	☐ Mindre än hälften					
	☐ Hälften eller mer					
6	Vilken är din högsta examensnivå?					
	□ Grundskola					
	□ Gymnasium					
	☐ Högskola/universitet					
	□ Annan					
7	Vilken är din sysselsättning? Du kan ange fler alternativ					
	□ Anställd	Omfattning i %?				
	☐ Egen företagare	Omfattning i %?				
	Antal anställda i företaget, exklusive dig själv:					
	☐ Arbetssökande	Omfattning i %?				
	☐ Studerande	Omfattning i %?				
	☐ Hemarbetande	Omfattning i %?				
	Har du vårdbidrag kopplat till barnet med diabetes? Ja □ Nej □					
	Om Ja, hur stort vårdbidrag i kronor/månad?					
	□ Annat	Omfattning i %?				

8	Vilket är ditt yrke?				
9	Har du ändrat något i dina arbetsförhållanden pga. att ditt barn har diabetes? □Ja □Nej				
	Om du svarat Ja, hur har du ändrat dina anställningsförhållanden?				
10	Vad är hushållets sammanlagda inkomst före skatt?				
	□ < 14 000kr/mån				
	□ 14 000-23 000kr/mån				
	□ 23 000 – 39 000kr/mån				
	□ > 39 000kr/mån				
11	Hur många personer (vuxna och barn) finns det totalt i hushållet?				
	Hur många av dessa är under 18 år?				
	I vilken omfattning bor barnen i ditt hushåll? Avser alla barn som bor i hushållet.				
	Barn 1	□ heltid	□ deltid		
	Barn 2	□ heltid	□ deltid		
	Barn 3	□ heltid	□ deltid		
	Barn 4	□ heltid	□ deltid		
	Barn 5	□ heltid	□ deltid		
12	Har du varit för	Har du varit föräldraledig med ett eller flera barn?			
	☐ Ja (om ja, gå till fråga 13)				
	□ Nej (om nej g	å till fråga 16)			

13	Om du svarat Ja på fråga 12 Hur många barn har du varit föräldraledig med?					
14	Hur länge var du föräldraledig?					
	Antal månader barn 1					
	Antal månader barn 2					
	Antal månader barn 3					
	Fler barn:					
14	Omfattningen av din föräldraledighet					
	Barn 1	Barn 2	Barn 3			
	□ Deltid	□ Deltid	□ Deltid			
	□ Heltid	☐ Heltid	☐ Heltid			
	Fler barn:					
16	Har du själv diabetes?					
	□ Nej					
	☐ Ja, jag behandlar med insulin injektioner					
	☐ Ja, men jag behandlar <b>inte</b> med insulininjektioner					
17	Ditt siviletend till ditt have som hav dich store					
17	Ditt civilstånd till ditt barn som har diabetes					
	☐ Biologisk pappa ☐ Adoptionspappa					
	☐ Annat					

	Frågor om ditt barn som har diabetes
18	När är ditt barn fött? År: Månad: Dag:
19	När fick ditt barn diabetes? År: Månad:
20	Var tillbringar ditt barn sin vakna tid på vardagar? Fler alternativ är möjliga
	□ I hemmet
	☐ Hos dagbarnvårdare (dagmamma)
	□ På förskola (dagis)
	□ I grundskola
	□ I fritidshem (fritids)
	□ I gymnasieskola
	□ Annat:
21	Gradera, på skalan 1,2,3 ansvaret för olika delar av skötseln av barnets diabetes. 1 är högsta ansvar, 2 är lika delat ansvar 3 är minst ansvar. Om du har delad vårdnad av barnet gör en bedömning utifrån <b>barnets hela situation,</b> inte bara den tid barnet är hos dig
	Insulin:pappamammabarnet
	Mat:pappamammabarnet
	Blodsockerkontroller:pappamammabarnet
	Kontakt med diabetesteamet:pappamammabarnet

22	Övrigt

Fortsättningsvis finns tre olika frågeformulär. Välj det formulär som stämmer med åldern på ditt barn med diabetes. Om du har delad vårdnad av barnet gör en bedömning utifrån **barnets hela situation**, inte bara den tid barnet är hos dig

### Frågeformulär 1: för barn i åldrarna 1 -5 år, före skolstart

Fråga 1-4 besvaras endast av dig som har barn på förskola("dagis") eller på familjedaghem ("dagmamma")

1 = Enbart pappa 5 = Oftare mamma

2 = Nästan enbart pappa 6 = Nästan enbart mamma

3= Oftare pappa 7 = Enbart mamma

4 = Lika ofta pappa som mamma

Ringa in eller kryssa det alternativ som stämmer bäst. Om du har delad vårdnad av barnet gör en bedömning utifrån **barnets hela situation**, inte bara den tid barnet är hos dig

Vem följer barnet till förskola/familjedaghemmet?	1	2	3	4	5	6	7
2. Vem hämtar barnet från förskolan/familjedaghemmet?	1	2	3	4	5	6	7
3. Om det uppstår ett problem på							
förskolan/familjedaghemmet, vem ringer då personalen till i första hand?	1	2	3	4	5	6	7
4. Vem stannat hemma när barnet är sjukt?	1	2	3	4	5	6	7
5. Vem går med barnet till läkaren/tandläkaren?	1	2	3	4	5	6	7
6. Vem köper kläder till barnet?	1	2	3	4	5	6	7
7. Vem köper leksaker till barnet?	1	2	3	4	5	6	7
8. Vem avgör om barnet behöver nya kläder?	1	2	3	4	5	6	7
9. Vem tar med barnet på bio, teater, simhall etc.?	1	2	3	4	5	6	7
10. Vem tar fram de kläder barnet behöver och avgör när det							
är dags att byta?	1	2	3	4	5	6	7
11. Om ni behöver barnvakt, vem ordnar det?	1	2	3	4	5	6	7
12. Vem leker med barnet?	1	2	3	4	5	6	7
13. Vem läser för barnet?	1	2	3	4	5	6	7
14. Vem lägger barnet på kvällen?	1	2	3	4	5	6	7

### Frågeformulär 2: skolår 0 - t.o.m. år 6 (barnets ålder ca 6 - 12 år)

1 = Enbart pappa 5 = Oftare mamma

2 = Nästan enbart pappa 6 = Nästan enbart mamma

3= Oftare pappa 7 = Enbart mamma

#### 4 = Lika ofta pappa som mamma

Ringa in eller kryssa det alternativ som stämmer bäst. Om du har delad vårdnad av barnet, gör en bedömning utifrån barnets hela situation, alltså i förhållande till den andra förälderns insats

TOTALACTIO INSACS							
1. Vem följer barnet till skolan/fritidshemmet på morgonen?	1	2	3	4	5	6	7
2. Om det uppstår ett problem på skolan/fritidshemmet, vem							
ringer då personalen till i första hand?	1	2	3	4	5	6	7
3. Vem stannat hemma när barnet är sjukt?	1	2	3	4	5	6	7
4. Vem går med barnet till läkaren/tandläkaren?	1	2	3	4	5	6	7
5. Vem köper kläder till barnet?	1	2	3	4	5	6	7
6. Vem köper leksaker till barnet?	1	2	3	4	5	6	7
7. Vem avgör om barnet behöver nya kläder?	1	2	3	4	5	6	7
8. Vem tar med barnet på bio, teater, simhall etc.?	1	2	3	4	5	6	7
9. Vem tar fram de kläder barnet behöver och avgör när det							
är dags att byta?	1	2	3	4	5	6	7
10. Om ni behöver barnvakt, vem ordnar det?	1	2	3	4	5	6	7
11. Vem leker/spelar spel med barnet?	1	2	3	4	5	6	7
12. Vem läser för barnet?	1	2	3	4	5	6	7
13. Vem "nattar" barnet på kvällen?	1	2	3	4	5	6	7
14. Vem säger till barnet om han/hon gör något han/hon inte får?	1	2	3	4	5	6	7

### Frågeformulär 3: skolår 7 – t.o.m. gymnasiet (barnets ålder ca 13 - 18 år)

1 = Enbart pappa 5 = Oftare mamma

2 = Nästan enbart pappa 6 = Nästan enbart mamma

3= Oftare pappa 7 = Enbart mamma

#### 4 = Lika ofta pappa som mamma

Ringa in eller kryssa det alternativ som stämmer bäst. Om du har delad vårdnad av barnet, gör en bedömning utifrån barnets hela situation, alltså i förhållande till den andra förälderns insats

Torura	21110 1110400							
1.	Vem går på föräldramöten/utvecklingssamtal i skolan?	1	2	3	4	5	6	7
2.	Vem sätter gränser, t.ex. bestämmer tid när barnet ska vara hemma??	1	2	3	4	5	6	7
3.	Vem kör barnet till fritidsaktiviteter??	1	2	3	4	5	6	7
4.	Vem hjälper barnet med läxor?	1	2	3	4	5	6	7
5.	Vem pratar förtroligt med barnet, t.ex. pratar om känsliga ämnen?	1	2	3	4	5	6	7
6.	Vem ger barnet pengar vid behov?	1	2	3	4	5	6	7
7.	Vem lagar mat till barnet?	1	2	3	4	5	6	7
8.	Vem går till läkare/tandläkare med barnet?	1	2	3	4	5	6	7
9.	Vem går på bio, teater eller liknande med barnet?	1	2	3	4	5	6	7
10.	Vem tillrättavisar barnet??	1	2	3	4	5	6	7
11.	Vem väcker barnet på morgnarna?	1	2	3	4	5	6	7
12.	Vem påminner barnet om läxor?	1	2	3	4	5	6	7
13.	Vem spelar spel/sportar med barnet?	1	2	3	4	5	6	7
14.	Vem handlar kläder till barnet?	1	2	3	4	5	6	7
15.	Vem tvättar barnets kläder?	1	2	3	4	5	6	7



### <u>Regionala etikprövningsnämnden i Göteborg</u>

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**Dnr:** 518-09

Exp. 2009-10-22

Åse Boman OHK, Högskolan Väst 461 86 Trollhättan

Sökande: Nordiska högskolan för folkhälsovetenskap

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Kerstin Grundén

Anna-Karin Kollind

Skans Kersti Nilsson

#### Ledamöter som företräder allmänna intressen

Lisbeth Ekman

Bengt Fernström

Marianne Henningsson

**Projekttitel**: Pappor till barn med diabetes typ 1. Vad stödjer dem att vara involverade i barnets vardagsliv?

# Beslutsprotokoll från sammanträde med Regionala etikprövningsnämnden i Göteborg, Avdelningen för övrig forskning, den 19 oktober 2009.

Föredragande: Skans Kersti Nilsson

Rådgivande yttrande

Etikprövningsnämnden finner att studien inte omfattas av etikprövningslagen och avger följande rådgivande yttrande.

Nämnden tillstyrker studien, dock:

att informationsbreven bör kompletteras med information angående hantering av data och sekretess, personuppgiftsansvarig samt hur forskningspersonen kan ta del av resultatet allt enligt mallen för forskningspersoninformation (www.epn.se). I samband med detta påpekas även att vädjande formuleringar ska undvikas.

att det utformas ett samtyckesformulär enligt samma mall.

att datamaterialet (inklusive banden) sparas under 10 år för att möjliggöra granskning och att

Box 100, 405 30 Göteborg

Besöks- och leveransadress: Medicinaregatan 3, 413 90 Göteborg Tel: 031-786 68 21, 786 68 22, 786 68 23, Fax: 031-786 68 18 detta framgår av informationsbrevet.

Att denna avskrift i transumt överensstämmer med originalet intygar:

Tuny Hill Mou Inger Hellström, byråsekr

#### Välkommen till diskussionen Pappors möte med diabetesvården!

Jag är mycket glad att du tackat ja till att delta i studien Pappors möte med diabetesvården, vars syfte är att ytterligare förbättra vården för barn och ungdomar med diabetes, och bjuder nu in dig till att delta i ett diskussionsforum.

Till forumet är 4-5 pappor till barn med diabetes inbjudna, alla har fått ett låtsasnamn tilldelat och inläggen blir därför anonyma.

Forumet kommer att vara öppet dygnet runt fr. o m. 2011-01-28 t.o.m. 2011-02-08. Min önskan är att du under denna tid ska berätta, diskutera och göra inlägg om hur du upplever dina möten med diabetesteamet, berätta om bra respektive dåliga möten, vad du vill ha av teamet och vad du tycker är viktigt i ditt möte med personalen på barndiabetesmottagningen.

När du loggar in, instruktioner finns på nästa sida, så ser du att jag har förberett med frågor i forumet. Jag kommer att vara aktiv i forumet och du kommer se mig som Åse (med bild). Endast de pappor som är inbjuda och jag själv har tillgång till diskussionen, inga utomstående eller personal från diabetesteamen har eller kommer att få tillgång till vad som skrivs där.

Du är hjärtligt välkommen att kontakta mig om du har frågor, fundering eller något du vill diskutera. Mina kontaktuppgifter hittar du längst upp till höger.

Ditt fiktiva namn är Tore Toresson och du kommer att synas som Tore Toresson i diskussionen

Ditt användarnamn vid inloggning är: pappa19

Ditt lösenord vid inloggningen är: pappa19

Med hopp om en givande diskussion!

#### Instruktioner:

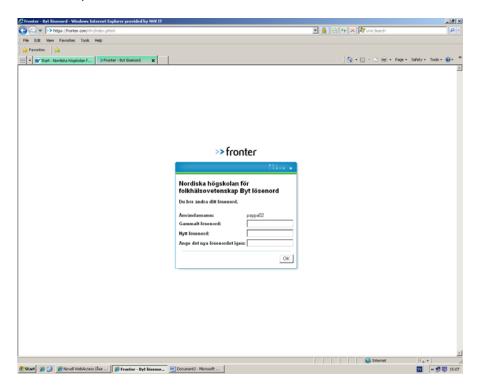
Gå till <a href="https://fronter.com/nhv/">https://fronter.com/nhv/</a>

Användarnamn: pappa19 lösenord: pappa19

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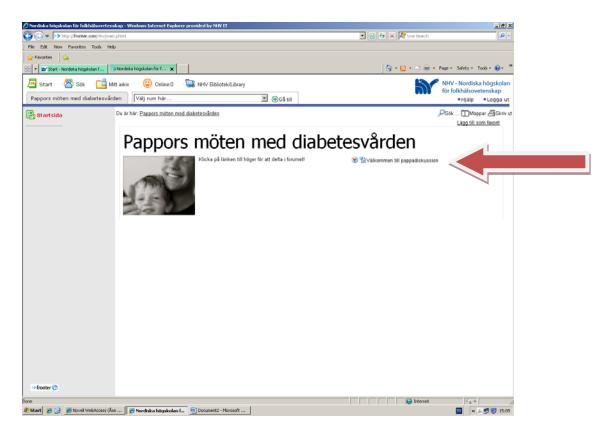
Du blir nu ombedd att byta lösenord

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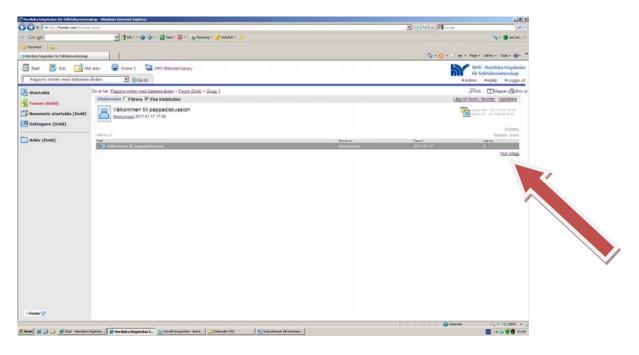


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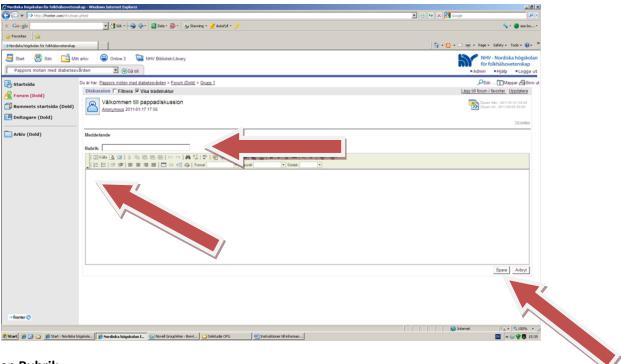
Fyll i och klicka på **OK** 



Klicka på Välkommen till pappadiskussionen



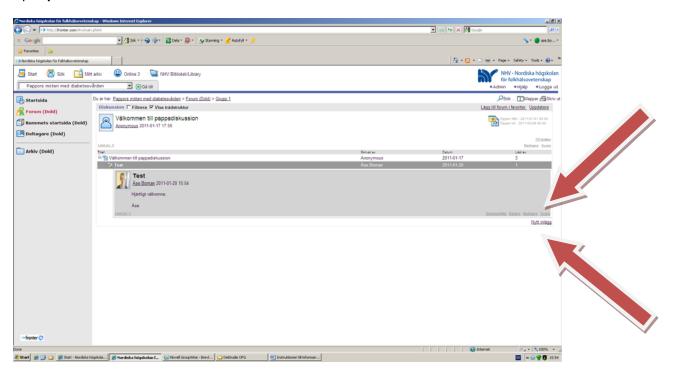
Kilcka på Nytt inlägg



#### Skriv en Rubrik

#### Skriv ditt inlägg

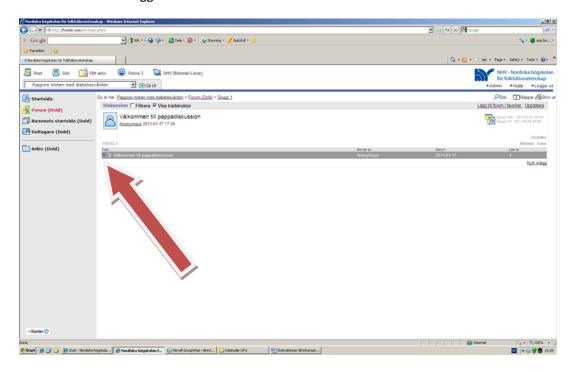
#### Klicka på Spara



Du kan svara på ett inlägg genom att klicka på **Svara**, eller göra ett **Nytt inlägg** 

Glöm inte att Spara efter varje inlägg

Om du inte kan se de olika inläggen, klicka på **+tecknet** framför Välkommen till pappa diskussionen så ser du ditt och andras inlägg



Din åsikt är väldigt viktig och teknik ska inte hindra den från att komma fram, så vid minsta problem, hör av dig!

God diskussion!

Åse

1983:1	Hälsa för alla i Norden år 2000. Föredrag presenterade på en konferens vid Nordiska hälsovårdshögskolan 7–10 september 1982.
1983:2	Methods and Experience in Planning for Family Health – Report from a seminar. Harald Heijbel & Lennart Köhler (eds).
1983:3	Accident Prevention – Report from a seminar. Ragnar Berfenstam & Lennart Köhler (eds).
1983:4	Självmord i Stockholm – en epidemiologisk studie av 686 konsekutiva fall. Thomas Hjortsjö. Avhandling.
	1984
1984:1	Långvarigt sjuka barn – sjukvårdens effekter på barn och familj. Andersson, Harwe, Hellberg & Syréhn. (FoU-rapport/shstf:14). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
1984:2	Intersectoral Action for Health – Report from an International Workshop. Lennart Köhler & John Martin (eds).
1984:3	Barns hälsotillstånd i Norden. Gunborg Jakobsson & Lennart Köhler. Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
	1985
1985:1	Hälsa för äldre i Norden år 2000. Mårten Lagergren (red).
1985:2	Socialt stöd åt handikappade barn i Norden. Mats Eriksson & Lennart Köhler. Distribueras av Allmänna Barnhuset, Box 26006, SE-100 41 Stockholm.
1985:3	Promotion of Mental Health. Per-Olof Brogren.
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	1996
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	1997
1997:1	Victims of Crime in a Public Health Perspective – some typologies and tentative explanatory models (Brottsoffer i ett folkhälsoperspektiv – några typologier och förklaringsmodeller). Barbro Renck. Avhandling. (Utges både på engelska och svenska.)
1997:2	Kön och ohälsa. Rapport från seminarium på Nordiska hälsovårdshögskolan den 30 januari 1997. Gunilla Krantz (red).
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Report from the workshop at the Nordic School of Public Health, May 24-26, 1998.

#### 1999

1999:1 Tipping the Balance Towards Primary Healthcare Network. Proceedings of the 10th Anniversary Conference, 13-16 November 1997. Editor: Chris Buttanshaw. 1999:2 Health and Human Rights. Report from the European Conference held in Strasbourg 15-16 mars 1999. Editor: Dr. med. Stefan Winter. Learning about health: The pupils' and the school health nurses' assessment of 1999:3 the health dialogue. Ina Borup. DrPH-avhandling. 1999:4 The value of screening as an approach to cervical cancer control. A study based on the Icelandic and Nordic experience through 1995. Kristjan Sigurdsson. DrPHavhandling. 2000 2000:1 Konsekvenser av urininkontinens sett i et folkehelsevitenskapelig perspektiv. En studie om livskvalitet hos kvinner og helsepersonells holdninger. Anne G Vinsnes. DrPH-avhandling. 2000:2 A new public health in an old country. An EU-China conference in Wuhan, China, October 25-29, 1998. Proceedings from the conference. Lennart Köhler (ed) 2000:3 Med gemenskap som grund - psykisk hälsa och ohälsa hos äldre människor och psykiatrisjuksköterskans hälsofrämjande arbete. Birgitta Hedelin. DrPHavhandling. ASPHER Peer Review 1999. Review Team: Jacques Bury, ASPHER, Franco 2000:4 Cavallo, Torino and Charles Normand, London. 2000:5 Det kan bli bättre. Rapport från en konferens om barns hälsa och välfärd i Norden. 11-12 november 1999. Lennart Köhler. (red) 2000:6 Det är bra men kan bli bättre. En studie av barns hälsa och välfärd i de fem nordiska länderna, från 1984 till 1996. Lennart Köhler, (red) 2000:7 Den svenska hälso- och sjukvårdens styrning och ledning – en delikat balansakt. Lilian Axelsson, DrPH-avhandling, 2000:8 Health and well-being of children in the five Nordic countries in 1984 and 1996. Leeni Berntsson. DrPH-avhandling. 2000:9 Health Impact Assessment: from theory to practice. Report on the Leo Kaprio Workshop, Göteborg, 28 - 30 October 1999. 2001

2001:1 The Changing Public-Private Mix in Nordic Healthcare - An Analysis John Øvretveit.

2001:2	Hälsokonsekvensbedömningar – från teori till praktik. Rapport från ett internationellt arbetsmöte på Nordiska hälsovårdshögskolan den 28-31 oktober 1999. Björn Olsson, (red)
2001:3	Children with asthma and their families. Coping, adjustment and quality of life. Kjell Reichenberg. DrPH-avhandling.
2001:4	Studier av bruket av dextropropoxifen ur ett folkhälsoperspektiv. Påverkan av ett regelverk. Ulf Jonasson. DrPH-avhandling.
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2001:6	Ett pionjärarbete för ensamvargar Enkät- och intervjuundersökning av nordiska folkhälsodoktorer examinerade vid Nordiska hälsovårdshögskolan under åren 1987 – 2000. Lillemor Hallberg (red).
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2002:3	Annual Research Report 2001. Lillemor Hallberg (ed).
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	2003
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2003:3	NHV 50 år (Festboken)
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2010:3 R	Utvärdering av verksamheten vid Enheten för Asyl- och flyktingfrågor, Västra Götalandsregionen			
2010:4 R	Utvärdering av försöksverksamhet med samverkansgrupper och coacher i Vänersborg och Mellerud			
2010:5 R	Utvärdering av projekt GEVALIS – Unga vuxna			
2010:6 R	Utvärdering av Program Sexuell hälsa, Västra Götalandsregionen			
2010:7	Perceptions of public health nursing practice - On borders and boundaries, visibility and voice Anne Clancy. DrPH-avhandling			
2010:8	Living with head and neck cancer: a health promotion perspective – A Qualitative Study Margereth Björklund. DrPH-avhandling			
2010:9 R	Barnhälsoindex för stadsdelarna i nordöstra Göteborg  – Ett förslag till uppföljning av barns hälsa och välbefinnande Lennart Köhler. NHV i samarbete med Västra Götalandsregionen, Angereds närsjukhus			
2010:10 R	Utvärdering med lärande ansats av pandemiplanering inklusive vaccinationsprogram i Västra Götalandsregionen Lars Edgren, Stefan Thorpenberg, Bengt Åhgren			
2010:11 R	Psykiatrisk registerforskning i Norden. En beskrivelse af forskningsmuligheder i psykiatrirelevante registre i Danmark, Sverige og Finland Thomas Munk Larsen, Merete Nordentoft, Mika Gissler, Jeanette Westman, Kristian Wahlbeck			

2010:12 R	Fysisk aktivitet på recept i Norden – erfarenheter och rekommendationer. Lena V Kallings, på uppdrag av Nordisk nettverk for fysisk aktivitet, mat og sunnhet
	2011
2011:1 R	Arbeidsledighet og psykisk helse blant unge i Norden En kunnskapsoversikt Anne Reneflot og Miriam Evensen
2011:2	Psychotropic drugs among the elderly – Population-based studies on indicators of inappropriate utilisation in relation to socioeconomic determinants and mental disorders Eva Lesén. DrPH-avhandling
2011:3	Intensivpasientens gåtefulle kunnskap – om erfart kunnskap og kunnskapsformidling i en intensivkontekst Sven-Tore Dreyer Fredriksen. DrPH-avhandling
2011:4 R	Från reformintention till praxis - hur reformer inom psykiatri och socialtjänst översatts till konkret stöd i Norden Rafael Lindqvist, Steen Bengtsson, Lars Fredén, Frode Larsen, David Rosenberg, Torleif Ruud, Kristian Wahlbeck
2011:5 R	Kartläggning av studier om nordiska ungdomars psykiska hälsa Hanna Augustsson och Curt Hagquist
2011:6	Health-Promoting Leadership: A Study of the Concept and Critical Conditions for Implementation and Evaluation Andrea Eriksson. DrPH-avhandling
	2012
2012:1	Nordic and Infertile. – A study of options and decisions. Helga Sól Ólafsdóttir. DrPH- avhandling
2012:2	Lay Health Worker Programmes as a Public Health Approach in South Africa Karen Daniels. DrPH- avhandling
2012:3	Fra avmakt til makt i eget liv. Anmeldelse av seksuelle overgrep og helse. Hildur Vea. DrPH – avhandling
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2012:5	The Importance of Social Capital in Later Life. Mental Health Promotion and Mental Disorder Prevention among Older Adults Anna K Forsman. DrPH-avhandling
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2012:7	Antenatal and delivery care utilization in urban and rural contexts in Vietnam - a study in two health and demographic surveillance sites  Tran Khanh Toan. DrPH-avhandling
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2012:9 R	Funktionshinder ur ett folkhälsoperspektiv Anders Möller (red.)
2012:10	I all fortrolighet – En undersøkelse av meldinger om psykisk helse på internett i Norge og Sverige Anders Johan W. Andersen. DrPH-avhandling
2012:11	Utveckling av samverkan - Ett deltagarorienterat aktionsforskningsprojekt inom hälso- och sjukvård Ingela Furenbäck. DrPH-avhandling
2013:1	Fathers Involved in Children with Type 1 Diabetes: Finding the Balance between Disease Control and Health Promotion Åse Boman, DrPH-ayhandling