

Diabetes in children and adolescents from non-western immigrant families – health education, support and collaboration

*If you're in your native country, you're not alone and you trust the doctor;
you're able to talk to the doctor, because you have the language,
the understanding and the background in common*

Lene Povlsen

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The photo on the cover was taken by the author in New Qurna, Egypt. The quotation on the title page is by an Arabic mother, who has lived in Denmark since 1989.

Abstract

Aims: The general aims of this thesis were 1) To explore how non-western immigrant families' different background and factors related to immigration and acculturation may affect the outcome of education and support in paediatric diabetes management; 2) To provide knowledge on how diabetes education and support for immigrant children and their families should be given to ensure them adequate competence in disease management and the children optimum metabolic control.

Methods: The thesis comprises five studies carried out 2001-2006. Study I was based on national register data on metabolic control (N=977), questionnaires to all 20 Danish paediatric diabetes centres and structured interviews with 38 immigrant families. Study II was an intervention study including the development of guidelines and adapted educational material, followed by a re-education programme for 37 families. Study III was a case study of 11 Turkish and Kurdish children/families comprising data from medical records, a participant observation and qualitative interviews with the parents, one interpreter and three diabetes team members. Study IV included qualitative interviews with Arabic parents of 12 children, living as immigrants in Denmark and in Cairo/Egypt respectively. Study V comprised data on metabolic control and qualitative interviews with 11 young adult immigrants with type 1 diabetes since childhood or adolescence.

Findings: The young immigrants were very unevenly distributed between the Danish paediatric centres. Most teams had little knowledge of and no special educational offers for immigrant families, just as the use of professional interpreters was limited. The immigrant parents had clearly different pre-conditions for diabetes education as compared with ethnic Danish parents, just as most had a low level of acculturation as evaluated by their need for an interpreter. Major differences were identified between the different ethnic groups and between the individual immigrants. The immigrant children and adolescents had different pre-conditions as compared to their parents; most, however, had non-optimum metabolic control. The design of an adapted educational programme could optimise the outcome of diabetes education, but was not sufficient to provide the families with competence in diabetes management and the children/adolescents with good metabolic control of long duration. Many parents in particular experienced difficulty combining diabetes management with their principles relating to good parenthood. In addition, they appeared to be insecure and doubtful about the competence of the Danish health care professionals.

Conclusions: A different ethno-cultural background is likely to create barriers to health education, learning and collaboration. The non-homogeneity of non-western immigrant families requires educational initiatives tailored to the pre-conditions and needs of the individual family members; adapted initiatives such as peer education are suggested. Special support for immigrant children and adolescents should be considered. A close, supportive and trust-filled relationship between the families and health care professionals is needed to facilitate learning, collaboration and good metabolic control.

Key words: Non-western immigrants; children; adolescents; parents; type 1 diabetes; health education; support; collaboration; adaptation; public health; health promotion.

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Abstrakt

Formål: De overordnede mål for denne afhandling var 1) at undersøge hvordan ikke-vestlige indvandrerfamiliers anderledes baggrund og faktorer relateret til immigration og akkulturation vil kunne påvirke udbyttet af undervisning og støtte i håndtering af diabetes hos børn og unge; 2) At bidrage med viden om, hvordan undervisning og støtte skal gives for at sikre, at familierne opnår kompetence i at håndtere sygdommen, og at børn/unge får god metabolisk kontrol.

Metode: Afhandlingen er baseret på fem studier 2001-2006. Studie I omfattede nationale registerdata om metabolisk kontrol (N=997), spørgeskemaer til alle 20 danske børne-diabetescentre og strukturerede interviews af 38 familier med indvandrerbaggrund. Studie II var et interventionsstudie som inkluderede udvikling af guidelines og tilpasset undervisningsmateriale, efterfulgt af et re-undervisningsprogram for 37 familier. Studie III var et case studie af 11 tyrkiske og kurdiske børn/familier og omfattede journaldata, deltager observation og kvalitative interviews af forældre, en tolk og tre team-medlemmer. Studie IV inkluderede kvalitative interviews af arabiske forældre til 12 børn, som henholdsvis levede som immigranter i Danmark og i Cairo/Egypten. Studie V omfattede data om metabolisk kontrol og kvalitative interviews af 11 unge voksne med indvandrerbaggrund og type 1 diabetes siden barndom/ungdom.

Resultater: Børn og unge med indvandrerbaggrund var meget ulige fordelt på de danske børne-diabetescentre. De fleste teams havde begrænset viden om og ingen specielle undervisningstilbud til disse familier, ligesom brugen af professionelle tolke var begrænset. Forældre med indvandrerbaggrund havde meget anderledes forudsætninger for diabetes undervisning sammenlignet med etnisk danske forældre, ligesom de fleste var dårligt akkultureret, vurderet ud fra deres behov for tolk. Der blev fundet store forskelle mellem de forskellige etniske grupper og mellem de enkelte indvandrere. Børn og unge havde anderledes forudsætninger end deres forældre, men de fleste havde dårlig metabolisk kontrol. Udviklingen af et tilpasset undervisningsprogram kunne optimere udbyttet af undervisningen, men var ikke tilstrækkeligt til at give familierne kompetence i at håndtere sygdommen og sikre børn og unge en længerevarende god kontrol. Mange forældre oplevede frem for alt problemer med at skulle tilpasse sygdommen til deres principper for godt forældreskab, ligesom de virkede usikre og tvivlende overfor det danske sundhedspersonales kompetence.

Konklusion: En anderledes etno-kulturel baggrund vil kunne skabe barrierer i forhold til sundhedspædagogik, indlæring og samarbejde. Ikke-vestlige indvandrerfamiliers store forskellighed kræver undervisningsmæssige initiativer, som er skræddersyede til de enkelte familiemedlemmers forudsætninger og behov; der foreslås tilpassede initiativer som f.eks. 'peer education'. Der bør gives specielle tilbud til børn og unge med indvandrerbaggrund. Desuden er der behov for en tæt, støttende og tillidsfuld relation mellem familierne og sundhedspersonalet for at fremme indlæring, samarbejde og god metabolisk kontrol.

Nøgleord: Ikke-vestlige indvandrere; børn; unge; forældre; type 1 diabetes; sundhedspædagogik; støtte; samarbejde; adaptation; folkesundhed; health promotion.

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ORIGINAL ARTICLES

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

- I: Povlsen L, Olsen B, Ladelund S. Diabetes in children and adolescents from ethnic minorities in Denmark – barriers to education, treatment and good metabolic control. *Journal of Advanced Nursing* 2005;6:576-82.
- II: Povlsen L, Olsen B, Ladelund S. Educating families from ethnic minorities in type 1 diabetes – experiences from a Danish intervention study. *Patient Education and Counseling* 2005;59:164-70.
- III: Povlsen L, Karlberg I, Ringsberg K. Support and education of immigrants with chronically ill children – identified needs from a case study of Turkish and Kurdish families. *Health Education Journal* – *In press*
- IV: Povlsen L, Ringsberg KC. Learning to live with a child with diabetes – problems related to immigration and cross-cultural diabetes care. *Submitted*
- V: Povlsen L, Ringsberg KC. Learning to live with type 1 diabetes – from the perspective of young non-western immigrants in Denmark. *Submitted*

Articles I-III have been re-printed with the kind permission of the publishers.

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INTRODUCTION

During the last few decades, most Western European countries have transformed into multi-cultural societies. In Denmark, the number of people with a foreign background has doubled since 1980. At the same time, an increasing percentage of the immigrants originate from distant countries (1). On 1 January 2007, the group of non-western immigrants including their descendants comprised 6.1% of the Danish population (2). Immigration is widely accepted as a possible cause of inequality in health and is described as one of the most important current determinants of global health and social development (3).

For a considerable period of time, one of the objectives of health care in Denmark, as in other Western European countries, has been equality in health for all citizens. However, socially determined inequity in health, a serious issue as regards public health, is still a fact and one of the reasons is a different ethnic background (4). A number of studies (3,5-7) describe non-western immigrants as a vulnerable group with a poorer health status than the general population. Some (8-10) explain this as differences in culture and traditions as well as social marginalisation and structural barriers to the western health care system. Others (3,11-13) explain it as stress related to immigration and acculturation.

As a paediatric nurse and diabetes educator, I have met an increasing number of immigrant children and their families since my authorisation in 1975. It is difficult for all families to learn to manage and adapt to a serious chronic disease such as type 1 diabetes in a child or adolescent. However, as a consequence of their different background, non-western immigrant families are likely to both perceive and present additional and/or different problems and challenges to health care professionals as compared to ethnic Danish families. Despite a large number of studies of health education and support for families with children with type 1 diabetes, very few studies describing families with an immigrant background have been published.

This thesis presents the findings of five studies carried out between 2001 and 2006. The research project was initiated due to perceived problems related to the outcome of diabetes education for immigrant families at the Danish paediatric diabetes centres. The studies have therefore focused on how health education and support for families with a different ethno-cultural background should be provided and how collaboration should be established in order to enable them to adapt and live a good life with the disease. The studies included above all describe how immigrant parents perceive living with a chronically ill child in Denmark and the collaboration between the families and the health care professionals.

Throughout the thesis, the families under study are either referred to as *ethnic minorities*, defined as persons with an immigrant or refugee background who originate from countries outside Western Europe, North America and Australia, or simply as *(non-western) immigrants*. Only children with two non-western immigrant parents were included in the studies.

THEORETICAL FRAMEWORK

Public health - a brief introduction

Public health is the collective action taken by society to protect and promote the health of populations (14). According to Beaglehole & Bonita (14), many countries have now reached 'the era of non-communicable diseases' (frequently, as in this thesis, referred to as chronic diseases). This means that diseases related to individual lifestyle and environmental factors, but also diseases such as cancer, mental diseases and various autoimmune and metabolic disorders, have replaced infectious diseases to an increasing extent as the major cause of morbidity and mortality. In many poor countries, however, the increase in chronic diseases has been smaller and infectious diseases are still predominant (14).

The Acheson Report (15) defines public health as the 'science and art of preventing disease, prolonging life and promoting health through organised efforts of society', usually in groups of people or entire populations. The Ottawa Charter (16) likewise states that health concerns the individual, while public health is the health of people or societies. Rose (17) emphasises that the primary determinants of disease are mainly economic and social and that medicine and politics therefore cannot be kept apart. In its Health 21 – health for all policy (18), the World Health Organisation (WHO) similarly stresses the importance of reducing social and economic inequities in improving the health of the entire population. It is further stated that health is a fundamental right of human beings and that disadvantaged groups must be ensured access to welfare through the provision of 'safety nets' and be given the appropriate health care.

This thesis addresses some important topics relating to public health, namely inequity in health related to social class and ethnicity, described by Beaglehole & Bonita (14) as powerful explanatory variables, and health promotion/health education in chronic disease management. These will be described in more detail in their respective paragraphs.

Immigration from a public health perspective

All the Nordic countries have become increasingly multicultural during the past few decades, but to varying degrees. On 1 January 2007, non-western immigrants (without descendants) comprised 2.2% of the Finnish population (19), 4.2% of the Danish (2), 5.2% of the Norwegian (20) and 8.3% of the Swedish population (21). Data from Iceland were not available (Statistics Iceland; personal communication).

Immigration is likely to place the immigrant in a situation in which previous experiences are no longer sufficient to understand and cope with his/her actual situation (22,23). Although it may be well prepared and self-imposed, the immigration is therefore likely to result in losses and traumatic crises of varying degrees, especially

when it comes to the immigrant's previous perception of his/her identity. For adult immigrants the adaptation process will often be lifelong, indicating that they will always feel like immigrants in the new country to varying degrees (23). As normal, immigrant children will develop their identity in close interaction with parents and siblings, but they are likely to become far more influenced by the new country. This implies that adolescents in particular frequently perceive themselves as living between two cultures and as having one role in the family and another in the community outside (22).

According to Carballo & Nerukar (24), most non-western immigrants are poor people moving from poor economic environments and they therefore carry with them the health profiles that result from poverty. It is further argued (3) that the way in which the immigration process can best be made a healthy and social success will depend upon the new country's ability to respond in a way that can lead to enhanced equity between the immigrants and the general population. As regards the health care system, Ekblad (6) calls for the development of transcultural skills and awareness and increased knowledge of the way different groups of immigrants are likely to communicate disease and psychosocial problems, and how health care professionals can improve in meeting their needs.

Post-traumatic Stress Disorder (PTSD) is a serious condition, related to extremely traumatic experiences. In connection with migration it has been related to possible events before, during and/or after migration. It is primarily described among political refugees and asylum seekers as a condition likely to impair the social and psychological functioning of the individual (25,26). However, most of the children and adolescents included in the studies in this thesis were born in Denmark, just as a large percentage of their parents were workforce immigrants. Most of the participants with a refugee background had also lived in Denmark for several years. PTSD was only identified in three parents from different families in Studies I and II and in one of the young adults in Study V. Since PTSD is also a very comprehensive subject, it will not be described in more detail or be part of this thesis.

Acculturation

Acculturation is described as 'the mutual influence of different cultures in contact' (27) and as 'the behavioural and psychological changes that occur as a result of contact between people belonging to different cultures' (12). Acculturation is divided into different 'levels', related to the immigrant's maintenance of his/her original cultural identity and his/her contact with the culture in the new country. Integration is described as the most adaptive form, i.e. the immigrant's involvement in both the original and the new culture (12).

Acculturative stress refers to stress related to the acculturation process and has been identified as a main cause of affected health in both immigrant children and adults. In adults, factors such as linguistic problems, perceived discrimination and conflicts between values and norms after the immigration are predominant (12). Children are described as being vulnerable in connection with immigration, but their flexibility and

ability to change are pointed out as vital qualities in preventing negative consequences (28). It is further emphasised that the health and development of immigrant children is particularly influenced by the current mental, social and economical situation of the family (28,29).

Culture and its influence on health and illness/disease

Culture refers to the socially transmitted patterns of behaviour that are characteristic of a particular social group (30). Culture comprises peoples' values, knowledge, skills and experiences and is dynamic and perceptually changing. The cultural background of an individual will influence not just the way a disease is perceived and its symptoms labelled and evaluated, but also his/her decisions about what to do, how to cope with the disease and comply with the treatment (31). Helman (32) argues that even though health care professionals and patients may come from the same socio-cultural background, they are still likely to view ill health in different ways.

Some cultural elements may be rather resistant to change, not least the way people think about health, illness and health care (31). Health and illness beliefs are described as determinants of an individual's behaviour, both in order to prevent disease and during disease, where the behaviour aims at seeking treatment and/or getting well (33). Helman (32) views these as cultural factors, but states that cultural beliefs and practices are only part of the aetiology of disease; that social and economic factors should always be taken into account, before the exact role of the cultural factors can be evaluated (32,33).

The concept of health Locus of Control (LOC) distinguishes between whether individuals perceive that they are responsible for and capable of controlling their health themselves or place the responsibility on others (33). LOC has also been related to the individual's ability to change life style behaviour and to the way he/she communicates and collaborates with health care professionals. Hjelm (10,34) found that female Arabic immigrants with diabetes practised less selfcare and more frequently sought advice from health professionals as compared to female Yugoslavian immigrants and ethnic Swedes. She explained this by different health/illness beliefs influenced by culture and religion, but also by the Arabic women's origin in patriarchal and group-oriented cultures.

Intercultural competence

The term intercultural competence is used both when describing communication between individuals with a different ethno-cultural and a different socio-cultural background (35). Intercultural competence is described as the ability to act and react as expected in a given situation or context (36), and as the ability to communicate between cultures and demonstrate skills outside one's culture of origin (37). A different ethno- or socio-cultural background may result in different interpretations of the information provided. Similarly, a lack of ability to predict the behaviour of a 'stranger' (patient or health care professional) and ignorance of his/her attitudes, feelings, beliefs and/or values may cause uncertainty and thus complicate a meeting or dialogue.

Lundberg (38) describes factors such as personality, attitudes, knowledge and previous experience as essential for the development of intercultural competence. Others add sensitivity, understanding and the ability to communicate (31), plus the need to respect the culture, value systems and ways of being of other individuals (39). Dunn (37) argues that cultural competence requires sensitivity to cultural differences, i.e. learning about, being able to assess from and sharing in the culture of others. This indicates a fundamental change in the way people perceive, understand and interact with the world and includes being curious and asking for explanations to promote a better understanding but also being willing to adapt clinical practice to fit the client's framework (37).

Chronic disease from a public health perspective

According to the WHO (40), chronic (non-communicable) diseases already accounted for 59% of the total global mortality and 46% of the total global burden of disease in 2000; the latter figure is expected to increase to 60% by the year 2020. It is emphasised that the means to prevent and treat many of these diseases already exist.

As in other western societies, the Danish National Board of Health (41) estimates that approximately one third of the Danish population suffers from one or more chronic diseases. At present, these individuals consume 70-80% of the resources of the health care services; a figure which is likely to rise still further due to increasing life expectancy (41). This underlines the need for a re-organisation of the health care system and for more optimum strategies for chronic disease management. The WHO stresses the need for multi-faceted and multi-institutional approaches directed at both individuals and groups and at the social, economic and cultural determinants of chronic diseases (42).

Most non-western immigrants originate from countries with a predominance of communicable diseases, whereas they immigrate to countries where chronic diseases are predominant. As a result, immigrants are likely to have limited pre-knowledge of chronic diseases including the concepts of chronic disease management (43). The WHO therefore encourages recipient countries to adapt their health care facilities to the different background of the immigrants in order to optimise treatment outcome (42).

Type 1 diabetes

Denmark is a high-risk area for type 1 diabetes. Despite a low incidence in the native countries of most non-western immigrants, several studies (44-47) have shown that immigrants, after immigration, obtain the same incidence as the general population in the new country. In the spring of 2002, children and adolescents with a non-western immigrant background comprised 6% of the total number of patients aged 0-18 years with type 1 diabetes at the Danish paediatric diabetes centres (48).

Type 1 diabetes is a metabolic disorder and a serious chronic disease that begins in childhood, adolescence or young adulthood (49). Its cause is not known, but the disease results in a deficiency of insulin production in the pancreas. The treatment consists of daily injections of insulin adapted to food intake, physical exercise and the actual blood glucose level. The aim is to obtain optimum metabolic control and thereby a reduction in the risk of severe future micro- and macrovascular complications (50,51). Good metabolic control has furthermore been associated with better quality of life (52).

The Danish recommendations for good metabolic control in children and adolescents with type 1 diabetes are adapted to the guidelines of the International Society for Pediatric and Adolescent Diabetes (ISPAD) (49,53):

- HbA_{1c} (glucosylated haemoglobin: blood test defining the mean blood glucose level during the previous 4–6 weeks) \leq 7-8%
- A low mean blood glucose level should not result in severe hypoglycaemic events (unconsciousness and/or convulsions)
- Ketoacidosis (bicarbonate $<$ 22 mmol/L) should not occur

Education is a keystone of diabetes care and management (49), since knowledge of the disease is regarded as essential for competence in diabetes management and good metabolic control (51). A multidisciplinary diabetes team consisting of paediatric endocrinologists, paediatric nurses, clinical dieticians, social workers, psychologists and chiropodists should be responsible for providing both treatment and education (49). The 20 Danish paediatric diabetes centres work together closely and the structure of the education is therefore fairly similar: The child and his/her family are provided with individual education during the first 9-12 months after the diagnosis; once a week to begin with and then every 1-2 months. After the completion of the initial education, continuous complementary education is provided either individually or in groups on regular visits to the centre. Education is also given to the staff at the children's day-care centres, school teachers and others.

Selfcare in diabetes management

Selfcare refers to the child's and family's active participation in the management of the disease and is described as 'patients' ability to make informed choices and decisions that will help achieve their personal diabetes care goal' (54). Selfcare means being able to balance the child's blood glucose within defined limits, under both normal and more unusual circumstances. In particular, this requires knowledge of the way physical activity and the composition of a meal are likely to affect the blood glucose but also how to stabilise the blood glucose when/if it becomes either too high or too low. The most essential knowledge to be acquired by the child/family, however, is the ability to evaluate when the condition is not satisfactory and therefore needs correction – either by them or by contact with the diabetes team.

Selfcare practices are learned over time and may be seen as a result of a gradual development of knowledge, skills and confidence in the ability to assume responsibility.

It has been argued that the increasing focus on selfcare in chronic disease management may have negative consequences; that vulnerable groups of patients may not fit into a concept that demands such active participation (55). Leininger (56) similarly emphasises that the concept of selfcare may be counter to cultural beliefs, values and norms, not least in non-western cultures.

Learning to live with type 1 diabetes

Learning to live with type 1 diabetes in a child or adolescent is likely to affect and include the entire family and is described (57) as a complex and multi-faceted process. It involves the acquisition of knowledge and skills in handling disease management in practice, as well as the psychological and social support required to enable the child and his/her family to adapt and come to terms with the disease. Concepts such as health promotion/health education and empowerment strategies, all central within public health, are applied in this process.

Adaptation to a chronic disease

The diagnosis of a chronic disease in a child is a stressful event for every member of a family. The disease is likely to change family life and the relationships between family members, just as it requires the family to adapt (58-60). Lazarus (61) defines coping as 'ongoing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person'. Adaptation refers to the adjustment to new and/or changed circumstances and is defined as the degree to which the family learns to cope psychologically, physiologically and socially with the disease (58).

Adaptation is thus the outcome of a coping process, in which emotion- and problem-focused strategies are often used simultaneously. When a child is diagnosed with diabetes, the most common is to seek information and social support (58). The importance and meaning which the family attaches to the child's chronic disease will have an impact on their ability to cope with it. In the same way their previous experiences, health beliefs and socio/ethno-cultural background will influence the way they explain the disease and develop relevant strategies (32,62,63).

The parents' adaptation has a major impact on the coping and well-being of the ill child and other family members (59). Mothers appear to have more difficulty than fathers, suggesting that they run a higher risk of poor adaptation (59,60). There is also a clear risk that relationships between family members could be impaired. Parents may, for example, be so occupied with the care of the ill child that they neglect the other children, just as the ill child may be overprotected (59,60). A successful adaptation is associated with strategies such as acceptance of the condition, being able to manage the child's treatment and meeting his/her normal developmental needs (58-60). The establishment of a social support system, meeting the needs of other family members

and learning to cope with stress and crises are also described as essential adaptive tasks that require specific knowledge, skills and resources (59).

Most parents will adapt to the child's diabetes in the longer term; some (64) say within the first year. However, studies have reported the presence of parental emotional responses continuing for many years. Even though they appear to have adapted to the situation, these parents may still never fully recover from the impact of the diagnosis of the disease and may suffer from a recurring sadness, described as chronic sorrow (64).

Parents with adequate personal and social resources, a higher level of education and higher income are likely to adapt better than those with poorer resources and a lower level of education and income (60). Lazarus (61) found that the actual life situation of the individual might affect the coping process. Lowes & Lyne (64) further mention that studies of parents from another cultural background suggest that they may react differently, by keeping their child's disease a secret due to fear of social stigmatisation, for example, and that this may disrupt the adaptation process.

Health promotion

In the Ottawa Charter (16), health is defined as 'a resource for everyday life and not just the objective of living'. Health promotion is described as 'the process of enabling people to increase control over and improve their health'. It is furthermore pointed out that in this process, the health care sector should move beyond its responsibility for providing care and curative services and focus on the total needs of the individual. The WHO (16) emphasises the use of empowering strategies in health promotion by stating that 'people cannot achieve their fullest health potential unless they are able to take control of those things which determine their health'.

Health promotion was inspired by ideologies from the 1960s and 1970s focusing on the liberation and development of people. Paolo Freire is described as one of the main sources of inspiration, first and foremost of the empowerment concept (65). It is argued (66) that empowerment is consistent with the ideological commitment to equity and the values of health promotion. Tones & Tilford (66) describe health promotion as 'any planned measure that promotes health' and summarise the ethical and moral views of health promotion in the Ottawa Charter in the following way:

- The pursuit of holistic goals: health should be viewed holistically. Health promotion should therefore focus on achieving mental, physical and social well-being, instead of only being concerned with different aspects of disease and prevention.
- The pursuit of equity: existing differences in health between and within nations and/or social groups should be eradicated in order to achieve health and prevent and control illness. 'Equity' thus has a moral and ethical dimension and refers to differences that are unnecessary and avoidable and are also judged as being unfair as compared to society in general.

- Voluntarism and empowerment: people should be encouraged to make free choices and be trusted to act independently and in a responsible manner. Health services should be organised to facilitate collaboration and empowerment, since health is influenced by many different services and institutions. This further indicates the need for multidisciplinary initiatives and inter-sectoral collaboration.

Holistic views and goals of health

At the institution of the WHO in 1946, it was stated that ‘health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (67), indicating that health should be viewed holistically. Within humanism, the individual is viewed as active and creative and as part of the context in which he/she acts. A holistic view of health therefore includes the individual’s ability to achieve his/her goals on the basis of the existing social, economic and cultural conditions (68).

Tones & Tilford (66) argue that the difference between a medically oriented view of disease and a broad, salutogenic approach to health and health promotion should not be over-emphasised. In spite of this, they underline that a bio-medical focus is likely to ignore the psychosocial dimension of health and could therefore be misleading, both when defining holistic goals of health and in the prevention and care of chronic and lifestyle-related diseases. A shift from the traditional ‘top-down’ to ‘bottom-up’ approaches should therefore be considered, i.e. integrating the individuals as much as possible to promote empowerment (66).

Contrary to pathogenesis, salutogenesis is defined as the factors that help to promote, increase and maintain health (69) and it can thus be viewed as a holistic approach. Health is not viewed as a biological problem but as a psychosocial concept and a resource. This indicates that health is not just affected by body, mind and the close environment but also by the way society is built up and how the individual manages to act and live in it (70). Antonovsky (69) identified ‘Sense of Coherence’ (SOC) – the state in which the individual perceives his/her life situation as meaningful, comprehensible and manageable, as an essential salutogenic factor.

SOC has been related to the health of immigrants. Ekblad (71) views SOC as being important for the immigrant’s ability to master and resist ill health as a result of migration. She argues that problems should be made comprehensible and manageable challenges to be solved in the immigrants’ own context, just as it is suggested that empowerment may be introduced as a new approach in the integration process (71).

Mæland (65) describes health promotion as a salutogenic approach because of its focus on strengthening people’s health and the underlining of positive resources for health. Concepts such as trust, social network and perceived control and mastery are also emphasised, indicating that health promotion should aim at promoting and strengthening the individual’s perception of coherence. Hanson (70) further argues that, by using meaningfulness as a motivational factor, health education may have a new and more positive basis for communicating lifestyle disease prevention.

Health education and empowerment strategies

Rose (17) argues that education is the foremost enabler of health; that it is through education that people learn to acquire information to guide their choices. In the same way it is emphasised (66) that health education is aimed primarily at the voluntary actions people can take on their own, individually or collectively, as citizens looking after their health.

Empowerment is described as an action process by which individuals gain control over their lives and actively participate in their community (72,73), based on the idea that participation in group dialogues will increase the participants' control, mastery and ability to change their situation (66). This indicates that empowerment is built up gradually and cannot be given – people can only empower themselves (73). Individual empowerment includes competences and capabilities that are likely to give the individual person a high degree of control over his/her life and health (66).

Health education is defined (66) as activities designed to achieve health- or illness-related learning aiming at:

- Producing changes in knowledge, understanding or ways of thinking
- Influencing or clarifying values
- Bringing about some shifts in belief or attitude
- Effecting changes in behaviour or lifestyle

Gabrielsen & Mach-Zagal (74) argue that health education differs from education in general in terms of the concept of health and its aim to translate the knowledge provided into practice, action and/or change. Health education should result in learning to promote health and is described as a stepwise process, in which the content should be adapted to the interest and motivation of the recipient/patient (75). According to Mæland (65), the outcome of health education is poorer in groups with a limited educational background and low socioeconomic status.

Patient-centred communication is regarded (33) as the optimum way to provide interpersonal health education. This means that the communication includes the patient's knowledge and experience and is not merely the transfer of knowledge from an expert health care professional (33,76). Fossum (77) describes patient-centred communication as being based upon mutual trust and a holistic view of the patient; an encounter in which the patient's life world, expectations and anxieties are central and the basis for collaboration. According to Ogden (33) it includes three central components:

- The health care provider's receptiveness to the patient's opinions/expectations
- The patient's involvement in decision-making and planning
- Attention to the affective content of the consultation

Ogden (33) defines compliance as 'the extent to which a patient's behaviour coincides with the medical advice given'. She argues that leaving the traditional view of 'doctor

as expert' and emphasising the interaction between the patient and the health care provider or the 'meeting between experts' indicates a shift in terminology from compliance to adherence; that adherence is a result of the patient being involved in the decision-making. The patient-centred approach may likewise address the imbalance of power between health care professionals and patients (76), but it also stresses the need to communicate mutual health/illness beliefs and expectations (33) in order to facilitate collaboration.

Education and learning

Learning refers to what takes place inside the individual who is being educated and should result in new knowledge, skills and/or changes in terms of behaviour, attitudes and feelings (78). In order to achieve this, however, the educator needs to establish a relationship with the person and be able to adapt the education to his/her individual background, motivation and needs (78). In the same way, culture, socialisation and communication will influence what and how an individual learns (79). The provision of new knowledge must therefore be coherent with the individual's personal, psychological, socio-economic and cultural context (80,81).

Learning is described (81) as a socio-cultural process in which knowledge is developed in the interaction between people. The acquisition of new knowledge is closely related to the way a phenomenon is experienced, perceived and understood by the learner (82,83). Marton (82) argues that the content of the education needs to become part of what the person already knows; that genuine learning is likely to fail if the content is not related to the reality of the learner. Accordingly, education should be guided by the individual person and be based upon his/her problems and experiences (79).

Education and empowerment in chronic disease management

Health education is viewed as a means to enable the active participation of the patient in treatment and decision-making, essential to prevent progression and complications of chronic diseases (84). Action competence is described as the ability to make healthy choices and take responsibility for your health; including the knowledge of a problem, an attitude towards it and the ability to act or deal with it (74,85). Health education thus aims to help people with chronic conditions cope with their circumstances and improve quality of life by ensuring that the pre-conditions for self-management are met (73).

Empowerment includes the identification of problems and their causes and the subsequent development of strategies for change (65,72). Within health education, empowerment implies that the patient and the educator work together to identify and implement the strategies relevant for achieving the patient's (self-identified) goals. The role of the educator is to provide expert information and guidance in order to facilitate learning and a critical reflection process and thereby enhance the patient's ability to make his/her own decisions (86,87). The goal of empowerment education is therefore

not primarily to achieve more healthy behaviour but to create the basis for informed choices.

Funnell & Anderson (9,54,88) describe the belief in patient autonomy and the right and responsibility of patients to make their own decisions as essential (54). It is further argued that the educator's main contribution should be to establish a trusting relationship in which the patient feels valued, trusted and safe; that empowerment is more than simply offering the patient a role in decision-making (54). Empowerment therefore represents an essential challenge and change to the traditional professional role and presupposes that educators are willing to yield power and control. This should be based on a belief in patients' right and ability to take responsibility and make decisions, provided that they have the knowledge necessary to do so (9,65,73). It is further emphasised that empowering capabilities arise from egalitarian relationships, negotiation and the sharing of power (73,86,87).

'Diabetes education'

Education in diabetes management has been provided for several decades and has gradually developed from authoritarian instruction to a dynamic and continuous process based on dialogue and experience, with the educator placed in an interactive role (80). Knowledge about diabetes does not necessarily correlate with good metabolic control, but it is still a pre-condition for successful problem-solving and self-management (49). Diabetes education is a dynamic and continuous process during which the patient and his/her family learn to handle the disease and eventually to 'recognise, judge and take decisions' (89). A recent study (90) found that the patient/family perceived education in diabetes management as an on-going learning process starting whenever they were exposed to new life situations.

Therapeutic patient education (89) was introduced in the 1990s and has been frequently used within diabetes education. It involves the entire diabetes team in a continuous educational process, taking place in close collaboration with the individual patient and his/her family. 'Learning by doing' is a central concept, indicating that education is provided according to the needs identified by the patient/family, based on their perceived problems (89). The model presented in Figure 1 illustrates the aims and concepts included in the term 'diabetes education' the way I understand it and have used it as the basis of the data analysis in this thesis. It shows that:

- Health education and psycho-social support should be provided simultaneously and be seen as the foundation for providing knowledge/skills and for establishing collaboration between the patient/family and the health care professionals
- Collaboration promotes a mutual dialogue and thereby the opportunity to provide more individually adapted and relevant education and support, based on the patient/family's problems, needs and experiences from everyday life
- The aim is to facilitate more optimum selfcare/competence in disease management, adaptation to the disease and subsequent good metabolic control

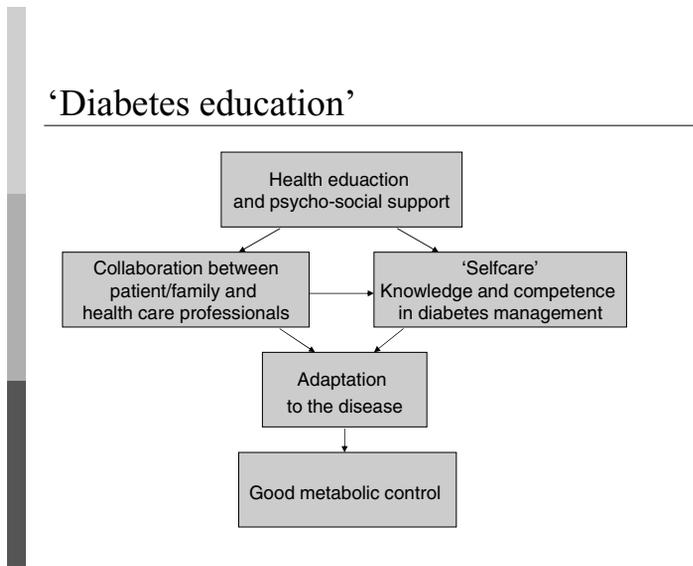


Figure 1. Model illustrating the aims and concepts included in ‘diabetes education’.

Children and adolescents should gradually take charge of their diabetes. In Denmark, more proper training and the transfer of responsibilities are normally first initiated around the time the children start going to school, i.e. at the age of six years. This means that children’s cognitive development as described by Piaget (91) is recognised and their training adapted accordingly. Children may vary in their ability to learn and accept new responsibilities and no child should be hurried. On the other hand, children should have a good understanding of diabetes and should have learned the necessary skills before the onset of puberty in order to facilitate ‘independent’ self-management (49).

Peer education and bilingual health educators

Peer education is a term frequently used in education in chronic disease management. It means that a person with a longer duration of a certain disease shares his/her experience with more recently diagnosed individuals. Peer education is described as a suitable means of promoting learning and emotional support and thereby enabling the participants to gain control of and come to terms with the diagnosis of a chronic disease (37,92,93). In the same way, the use of bilingual health educators or trained link workers from other cultures is recommended to facilitate more culturally competent approaches to health education of immigrants (94,95). Education in their native language and allowing for cultural habits are described as effective because of the perceived trustworthiness of the information source and role modelling (96).

PROBLEMS AND AIMS

The immigrant families included in this thesis represent a different and vulnerable group in the Danish population. Despite the fact that most of them have lived in Denmark for several years, many – not least the parents – are still likely to face problems related to immigration and acculturation, just as they may experience social marginalisation and structural barriers to the Danish society to varying degrees. The diagnosis of a serious chronic disease in a child or adolescent with an immigrant background may thus represent a challenge to the families and to health care professionals. This research project was initiated due to perceived problems related to the outcome of diabetes education for immigrant families at the Danish paediatric diabetes centres. At the same time, few studies describing health education and support for families with a non-western immigrant background and children with type 1 diabetes have been published.

Studies I and II were based on the hypothesis, that knowledge of the background of the immigrant families and the subsequent adaptation of the educational strategies could optimise the effect of health education. However, even though the intervention (II) was evaluated positively by the families and the assigned ‘experts’, the effect was not convincing. The additional questions that were raised were primarily related to the parents’ level of acculturation and the extent to which they were still influenced by norms and values from their country of origin. As a result, Studies III, IV and V have focused on describing problems and experiences related to diabetes education and support as perceived by immigrant parents, young adults with diabetes since childhood or adolescence and Danish health care professionals. All the studies were carried out from my perspective as an experienced paediatric nurse and diabetes educator.

General aims

To explore how non-western immigrant families’ different ethno-cultural background and factors related to immigration and acculturation may affect the outcome of education and support in paediatric diabetes management.

To supply knowledge of how diabetes education and support for immigrant children and their families should be provided to ensure them adequate competence in disease management and the children optimum metabolic control.

General research questions

How may non-western immigrant families’ different background and factors related to immigration and acculturation affect their opportunity to benefit from diabetes education and learn to live with diabetes in a child or adolescent?

How may immigration/acclulturation and a different background affect collaboration between immigrant families and health care professionals?

How should health education and support be provided to ensure immigrant children, adolescents and their families adequate competence in diabetes management and thereby promote good metabolic control?

Specific aims of Studies I-V

- To investigate whether the metabolic control in children and adolescents of other ethnic backgrounds with diabetes differed from that of young Danish patients and to learn about factors affecting the opportunities of ethnic minorities to achieve good metabolic control. (Article I)
- To evaluate if an adapted educational programme was able to optimise the metabolic control of immigrant children and adolescents as well as the knowledge of diabetes in the families. (Article II)
- To analyse how Turkish and Kurdish parents and their health care professionals perceived the education and support provided and to assess what was required to improve collaboration between the families and the team in order to optimise selfcare and metabolic control. (Article III)
- To explore variations in the way Arabic parents living as immigrants in Denmark and in their native country respectively had perceived learning to live with a child with diabetes. This was done in order to identify potential problems related to immigration and cross-cultural care which should be considered in the provision of diabetes care to immigrant families. (Article IV)
- To explore how young adults with a non-western immigrant background and type 1 diabetes since childhood/adolescence have perceived learning to live with the disease, with special focus on health education and support. This was done to identify factors that need to be considered in the provision of diabetes care to Danish immigrant families in order to optimise adaptation and metabolic control. (Article V)

METHODS

Overview of the studies and the methods applied

The thesis includes five studies carried out between 2001 and 2006 (Table 1). Studies I and II describe an intervention project in 2001-2003 at the paediatric diabetes clinic at Glostrup University Hospital in Copenhagen (henceforth referred to as Glostrup). This project was planned from the very beginning, whereas the subsequent studies were developed over time, based on the findings and questions that emerged from the previous studies.

Table 1. Overview of the studies included in the thesis.

Study	Design	Data collection	Participants
I	Quantitative	National register data Structured interviews Questionnaires	977 children 38 immigrant families 20 centres
II	Intervention	Data on metabolic control Structured interviews Expert evaluation/comments	37 immigrant families 13 experts
III	Case study	Qualitative interviews Participant observation Data from medical records	11 Turkish/Kurdish families 3 team members 1 Turkish interpreter
IV	Qualitative	Qualitative interviews	The parents of 12 children in Denmark and Egypt
V	Qualitative Quantitative	Qualitative interviews Data on metabolic control	11 young adults with an immigrant background

Overall study design

All the studies in the thesis have focused on non-western immigrant families with children and adolescents diagnosed with type 1 diabetes.

- Study I was a prelude to Study II. It included an investigation of potential differences in metabolic control between Danish and immigrant children and adolescents using data from a national diabetes register. Furthermore, factors affecting the immigrant families' and the paediatric diabetes teams' opportunities

to achieve successful collaboration and thereby good metabolic control in the children were investigated by means of structured interviews and questionnaires.

- Study II was an intervention project and included the development of adapted educational material and guidelines for health care professionals, partly based on data from Study I, and a subsequent re-education programme for immigrant children, adolescents and parents.

Study II demonstrated that the adapted educational programme was able to improve the families' knowledge of diabetes and the metabolic control of the children, but with a doubtful long-term effect and limited effect among some of the children/families. Since the parents appeared to be the ones who experienced most difficulty, the subsequent two studies focused on how they perceived the disease and the education and support provided, including their collaboration with the diabetes team. Qualitative research approaches were chosen as an appropriate method for these studies.

- Study III was a case study comprising Turkish and Kurdish families. It included qualitative interviews with the parents, the team and the Turkish interpreter, a participant observation of an educational session and information from medical records. The study aimed to analyse a new educational programme.
- Study IV included qualitative interviews with Arabic parents living as immigrants in Denmark and in their native country (Egypt) respectively. The study aimed to describe potential variations in the parents' perceptions of the process of learning to live with a child with diabetes.
- Study V was designed in order to include the 'voices' of immigrant children and adolescents. It comprised data on metabolic control and qualitative interviews with young adult immigrants of different nationalities, who had been diagnosed in childhood or adolescence, and focused on their perceptions of learning to live with the disease.

Quantitative and qualitative research approaches

Most research questions can be addressed using more than one method; using more than one can have substantial advantages, not least when it comes to permitting triangulation (97). Furthermore, there has been an increasing recognition that both quantitative and qualitative approaches are needed and considered equally important in developing new knowledge within public health science (98). The selection of research method(s) should thus be based on the kind of information that is being sought; from whom and under what circumstances (97,99).

Quantitative approaches are typically used in research focusing on frequencies and the strength of the association between health behaviour and disease (99) and of the impact of social and environmental factors on health (98). Quantitative methods are also used to test hypotheses and evaluate the outcome of interventions (99). Qualitative research

is described as explorative, descriptive and inductive (100,101) because of its focus on the way human beings organise themselves and make sense of their surroundings (100,102). The strength of qualitative studies lies in their ability to describe the meaning and significance which people ascribe to incidents in their daily lives and thereby enable an understanding of society and the social world (98,99,101). In this way, qualitative methods may generate hypotheses (99).

In order to supplement and validate the findings, both quantitative and qualitative research methods were used in the studies presented in this thesis. In Study III for instance, quantitative differences in metabolic control were elucidated by means of qualitative interviews, observations and medical records. In Study V, quantitative data on metabolic control were included in the qualitative analysis.

Interventions

Therapeutic intervention studies, as applied in Study II, aim to change a condition; within quality development to test new strategies in order to improve the outcome of a treatment/procedure (99). Kjærgaard et al (99) point out that since intervention programmes are often made up of more minor interventions, it may be difficult to identify the effect of the individual parts. In order to identify problems, develop new strategies and facilitate the subsequent implementation of the results, it is recommended (97) that practitioners and educators should take an active part in the intervention process.

The intervention programme in Study II included the development of guidelines for diabetes educators and adapted educational material translated into Arabic, Turkish, Urdu and Somali (103). The programme was evaluated, adjusted and further developed during the subsequent re-education of immigrant children, adolescents and adults. The re-education was carried out in small groups. The parents were divided up according to their ethnic background and the education was given with the assistance of experienced professional interpreters. The intervention is described in more detail in Article II.

Case studies

Case study design, as applied in Study III, is recommended by Yin (104) to obtain knowledge of an unusual and complex social area. Case studies aim to obtain knowledge and understanding of the phenomenon under study from a wide and multi-faceted perspective, by collecting data from different sources and methods to enable a broad holistic analysis (102,104). Accordingly, it is a methodological approach that incorporates a number of data-gathering measures such as interviews, observations and various documentary sources (104). Case studies are described as the systematic gathering of information about a person, setting, event or group to enable the researcher effectively to understand how the subject under study operates or functions (102). Case study design is used within traditional social research areas, in social work and education (104) and for evaluating innovative programmes (104,105).

The weakness of case studies lies primarily in the difficulty associated with analysing the frequently extensive and differently collected data and thereby problems as regards the validity of the findings. Yin (104) therefore recommends that the various results are continuously and thoroughly compared. Likewise, a detailed description of every part of the research process is recommended to create confidence in its validity (102,104). The scientific benefit of case studies lies in the data collection from various sources which can be used for triangulation. Berg (102) also emphasises the ability of the method to capture nuances, patterns and more latent elements which other approaches might overlook and thereby the ability to provide a basis for insights and even hypotheses.

Phenomenography

Phenomenography, as applied in Study IV, is a research approach developed during the 1970s within educational research. It is based on the idea that the educator needs to take account of how the learning content is perceived, understood and handled by the learners (82,83). Phenomenography is the study of the qualitatively different ways in which phenomena in the world are experienced, understood and perceived by the individual from a lived experience or 'second order perspective' (83,106).

Phenomenography shares similarities with phenomenology in the study of human experiences but differs in its focus on differences and variations in the phenomenon as experienced, indicating that the world is dynamic and changes over time (82,107,108). Phenomenography thus aims to describe how the same phenomenon in the same situation is perceived and understood in different ways by different individuals (109), based on their individual and subjectively interpreted experiences.

In recent years there has been a shift of focus to more theoretical concerns, the so-called 'new phenomenography', where the emphasis is placed on characterising particular ways of experiencing and on the ways the critical terms of a phenomenon are discerned by different learners (109). Within this 'theory of variation', the variations are described as experienced by the learners but described by the researcher.

The pedagogic potential of phenomenography is emphasised (107). The research approach is often used within public health, education and nursing research (106,107). It may for example be used for studies of the way patients perceive a disease, its symptoms, treatment etc. and the findings subsequently applied in training/education prior to clinical practice (106).

Participants

Non-western immigrant families of various ethnic origin and members of the Danish paediatric diabetes team were the main participants in the studies. In order to validate the findings, they were supplemented by other professionals who acted as 'experts' and contributed knowledge, experience and supervision.

Non-western immigrant families

The population of non-western immigrants in Denmark comprises some widely differing groups of individuals. The large group of workforce immigrants arrived around 1970, primarily from Turkey, Pakistan, Morocco and the former Yugoslavia. Most of these immigrants came from rural areas and had a limited educational background. The subsequent groups of refugees from countries such as Kosovo, Bosnia, Iraq, Iran, Afghanistan, Somalia and Eritrea are much less homogeneous and comprise both humanitarian and political refugees, the latter often well educated.

Participants from different ethnic groups were included in the five studies. This was done in recognition of the fact that the ethnic groups are not homogeneous – despite frequent references to immigrants as a group. In Studies I and II, various ethnic groups were included, due to the aim of ‘mapping’ them prior to the design of the adapted educational programme and the subsequent re-education. Since the interviews in Studies III and IV were performed in groups with the assistance of a professional interpreter, only people speaking the same language were included. Study V included participants from a variety of ethnic groups as they were interviewed individually and they all spoke Danish.

The participants for the qualitative studies were strategically selected. The majority of the families in the structured interviews in Study I, all the participants in Studies II, III and the Danish families in Study IV came from Glostrup. The selection was related to both the availability of participants and the theme under study. The Turkish/Kurdish families in Study III were chosen, because they were evaluated by the diabetes team as being less competent in diabetes management as compared to other ethnic groups. All the Turkish-speaking Turkish and Kurdish families at Glostrup at the time of the study were included.

In Study IV, Arabic families were chosen because a larger number of children with an Arabic background had recently been diagnosed. The Arabic parents were mainly political refugees, i.e. they had lived in Denmark for a shorter period of time as compared to workforce immigrants. Furthermore, they were evaluated by the team as being more competent in disease management as compared to other immigrant families. In addition, a previously established contact with the AYD (Assistance to Young Diabetics) education centre in Cairo gave access to interviews with matched Arabic families there.

Health care professionals

Study I included all the Danish paediatric diabetes centres. Members of the paediatric diabetes team at Glostrup also participated in the planning of Studies I and II, just as some were included in Studies I, II and III. Glostrup is responsible for the treatment of all diabetic children aged 0-18 years from the Greater Copenhagen area and is by far the largest paediatric centre in Denmark.

As an experienced paediatric nurse and diabetes educator at Glostrup at that time, I was responsible for the design, development and completion of the intervention programme in Study II. A diabetes nurse and a clinical dietician from the team participated in some of the educational sessions for the parents, just as members of the team were among the 'experts' who evaluated the adapted educational programme. In Study III, three members of the team at Glostrup were interviewed, while two team members conducted the educational session selected for observation.

Study IV was carried out in cooperation with the AYD education centre in Cairo which was chosen due to previous contact. This centre, which is unique in Egypt, was established in 2002 and has been internationally acknowledged for its educational programme (110). The education at the AYD is provided by a multidisciplinary team, consisting of doctors, pharmacists (working as educators due to the limited educational background of most Egyptian nurses), dieticians and psychologists. Many team members at the AYD are themselves parents of children with diabetes.

Other professionals

People from different professions have contributed knowledge, experience and supervision, especially during Study II which included 'experts' with no connection to paediatric diabetes clinics. They were people with either an ethnic minority background and/or professional experience of diabetes education or of teaching Danish and introducing new immigrants to the Danish society.

A number of professional interpreters also contributed knowledge and supervision during the entire research project. They were primarily the ones who were involved in the preparation of the educational material and participated in the subsequent re-education programme in Study II. However, the interpreters who assisted in Studies III and IV also functioned as 'cultural interpreters' and sparring partners.

Data collection

Data were collected using various methods: register data, questionnaires and structured interviews, participant observation, information from medical records and semi-structured qualitative research interviews. The variety of methods was chosen in order to supplement and validate the findings, since the phenomena under study were viewed as complex and multi-factorial.

Data on metabolic control

Clinical registers/databases comprising various prognostic factors are designed to measure the clinical quality of a treatment (99). The benefit of these registers lies in the content of a large volume of data of clinical relevance to a specific disease, while the obvious weakness lies in the lack of quality and accuracy of the data submitted. The

Danish Register of Childhood and Adolescence Diabetes supervises the quality of the treatment offered by all Danish paediatric diabetes centres. Every year around the child's birthday, data relevant to the disease including a blood sample for central analysis of HbA_{1c} should be sent to the register, which is based at Glostrup University Hospital.

Data on metabolic control can be used to estimate the adaptation of the patient/family and their competence in diabetes management. Likewise, metabolic control may be used to evaluate the effect of the education and support provided. The following data on metabolic control were included in the studies:

- HbA_{1c} (glucosylated haemoglobin): blood test defining the mean blood glucose level during the previous 4–6 weeks
- Incidents of severe hypoglycaemic episodes: unconsciousness and/or convulsions
- Incidents of ketoacidosis: bicarbonate <22 mmol/L

Data on metabolic control analysed at Glostrup were included in Studies I, II and III. HbA_{1c} values were analysed at a central laboratory using a high-pressure liquid chromatographic method Hi-Auto A_{1c} (Type 8121, Kyoto Daiichi Kagaku Co., Kyoto Japan), normal range 4.3-5.8% (mean 5.3%). In Study V, data on HbA_{1c} from a large number of diabetes centres all over Denmark were included. These HbA_{1c} values are likely to differ by $\pm 5\%$, corresponding to SD ± 0.3 - 0.6 HbA_{1c}% (Steno Diabetes Centre, DK-2820 Gentofte; personal communication).

Questionnaires and structured interviews

Questionnaires can either be completed by the individual person or be filled in as structured interviews by an independent interviewer. Both methods present possible problems. The self-administered questionnaire demands detailed instructions, as well as clear unambiguously formulated answers. The structured interview in particular presents problems in terms of interaction between the interviewer and the informant and in the precise formulation of the questions and marking of the answers (97,99).

Study I included self-administered questionnaires for all Danish paediatric diabetes centres and structured interviews/questionnaires for immigrant families, filled in by professional interpreters. The study aimed to collect various demographic and factual data on the centres and the families and to learn about factors affecting the opportunities of immigrant families to benefit from the education and treatment provided. The content of the questionnaires is described in more detail in Article I. The final version of the questionnaire to the families was preceded by a pilot test. All the interpreters were instructed at a joint meeting to secure the valid and uniform collection of data. Likewise, the questionnaires were translated into the various languages of the participants included in the study to secure the uniform wording of the questions. Prior to the interviews, the quality of these translations was validated by other professional interpreters who verbally translated them 'backwards' into Danish.

Study II also included structured interviews/questionnaires for immigrant families, filled in by professional interpreters and using the same measures as described above. The interviews were used to evaluate the effect of the intervention and focused on the experience and significance of the programme. Furthermore, they included an evaluation of the family's basic knowledge of diabetes, assessed both prior to and after the intervention. The contents of the questionnaire are described in more detail in article II.

Participant observation

It is argued (97) that the benefit of observations lies in their directness; that the researcher watches what the people under study do and listens to what they say. According to Berg (102), observations enable the researcher to examine various phenomena as perceived and described by the participants. Observational data may serve as a supplement to self-reported data and lead to a more complete understanding of a complex situation (111). Furthermore, observations may complement information gathered using other methods and thus serve as a supportive and supplementary technique to be used for triangulation and validation (97).

The disadvantages of observations mainly relate to the extent to which the observer is likely to interact with the individuals in the setting and affect the situation under study (102,111). Study III included participant observation of an (single) educational group session with Turkish/Kurdish families at Glostrup. It was a 'participant-as-observer' observation, indicating that the group was informed from the start about the role of the observer (97). The observation focused on group dynamics and communication and on how education and support were provided.

Information from medical records

The study of written documents may be used to validate other research measures and is described as unobtrusive and non-reactive (97,102). It is argued that documents are most often written for other purposes; when analysing them it is therefore important to consider the purpose as well as the context in which they were produced (97). According to Taylor & Bogdan (101), the study of documents can provide an insight into the assumptions, concerns and activities of the people who wrote them. Study III included information from the medical records of the Turkish and Kurdish children and focused on the descriptions of the families' knowledge of diabetes, level of selfcare and collaboration with the team and the way education and support were provided.

Qualitative research interviews

Qualitative research interviews are described as a conversation between (two) people conversing about (one) person's perceptions of events of daily life (102,112). It is emphasised that the interviewer needs to be conscious and reflective throughout the

session; carefully watching and interpreting the statements, based on the cues, clues and encoded messages offered (102,112). Using the phenomenographic approach, the interviewer should be reflective and exploratory and maintain focus on the phenomenon as experienced and reflected by the individual (107,108), i.e. aim at obtaining a clear understanding of the way the individual understands the phenomenon under study (106).

It is recommended that the interviewer should know his/her 'audience', i.e. understand the background and culture of the group(s) from which the individuals for interview are drawn (102). Berg (102) further describes it as beneficial that the interviewer is able to use his/her insight during the interview and thus follow up on subjects initiated by the informants. Kvale (112) argues that just as interviews vary according to the phenomena under study, different interview subjects require different approaches. Individual interviews may provide a basis for obtaining a deeper meaning and richer data, just as the informants, contrary to participants in group interviews, can be assured confidentiality (113).

On the other hand, interviews in groups may lead to more lively, spontaneous and emotional statements based on the social interaction in the group. They may furthermore be chosen to make the participants feel more comfortable with the situation and thus promote a good dialogue (102,112). Some (101,102) argue that interviews in groups are most appropriate, when the researcher has specific topics to explore; just as they are especially recommended for exploring cultural values and health beliefs (102,113). Difficulty following up the views of individuals, the risk that some members of the group may dominate the debate and the interviewer's reduced control of the situation are described as the main disadvantages of the method (97,102,112,113).

Study V included individual interviews, whereas the interviews in Studies III and IV were conducted in small groups. The assistance of professional interpreters was unavoidable in Studies III and IV, since all dialogue had to be translated. The use of interpreters involved the risk of incorrect and/or incomplete translations, just as it turned the group interviews into rather traditional interviews. Several measures were taken in order to validate the findings. The interpreters were carefully selected and instructed prior to the interviews. The quality of the translations was evaluated by another interpreter who listened to randomly selected parts of the recordings prior to the transcription.

Data analysis

Statistical analysis

Study I aimed to investigate whether the metabolic control in children and adolescents with an immigrant background differed from that of young Danish patients, and whether differences could be identified between the different ethnic groups. As it emerged that data on 30% of the immigrant patients were not included in the Danish Register of Childhood and Adolescence Diabetes in 2001, an analysis of these drop-outs was

performed in order to validate the findings. Study II included data on metabolic control before and 0-3-6 months after the intervention to evaluate the effect.

Data on metabolic control were analysed using linear regression and non-parametric tests. All the tests were two-tailed, with a 5% significance level used to indicate statistical significance. The comparisons between the different ethnic groups were performed using the Kruskal-Wallis test; comparisons between the Danish and the total group of immigrant patients were performed using the Mann-Whitney test (114). To estimate the influence of the 'ethnicity' of the immigrant patients, a linear regression analysis was carried out, describing HbA_{1c} by ethnicity, age and diabetes duration. The linear regression analysis was performed using the statistical package R (R Development Core Team (2003). Vienna, Austria. ISBN 3-900051-00-3).

Study III included the average HbA_{1c} values of the Turkish and Kurdish children during a one-year period prior to the study. Study V included data on the annual average HbA_{1c} values for the past five years. In both studies metabolic control formed part of the general analysis.

Qualitative analysis

Studies III, IV and V were mainly based on qualitative interviews and analysed by content analysis and phenomenography respectively.

Content analysis

Content analysis, mainly manifest, was used in the analysis of the interviews in Studies III and V and the data from medical records in Study III. Content analysis focuses on subject and context and aims to identify, code and categorise data relating to a social phenomenon (115). It is described as a process of identifying the primary patterns in the data (116) and as a method to make data systematically comparable (102). The analysis can focus on the manifest content in the text, but it may also include interpretations of the latent content. Graneheim & Lundman (115) argue that both manifest and latent content analysis comprise interpretations, but that these vary in terms of depth and degree of abstraction.

The analysis was performed using the method described by Graneheim & Lundman (115):

- Reading the text carefully several times to obtain an overall impression
- Identifying words and sentences expressing a central meaning (meaning units)
- Condensing data systematically without changing the original meaning
- Labelling the meaning units with a code, stating their content
- Creating categories, including a number of sub-categories, consisting of groups of codes according to the main themes of the interview

Within content analysis, validity/trustworthiness is especially related to clear differences between (external homogeneity) and similarities within (internal homogeneity) codes and categories (115).

Phenomenographic analysis

Study IV was analysed by means of phenomenography. The phenomenographic analysis focuses on how individuals perceive a phenomenon and how different perceptions can be related to each other (108). Within phenomenography, validity/trustworthiness is especially related to whether the described differences are supported by the empirical data (106).

The phenomenographic analysis was performed using the method described by Alexandersson (108), who divides it into four phases:

- Becoming familiar with the data and establishing an overall impression
- Identifying differences and similarities
- Developing descriptive categories; these should be qualitatively different and not overlap
- Examining the underlying structure of the descriptive categories (outcome space)

The main result of the phenomenographic analysis is the categorised descriptions (107). To further validate the findings, an independent co-examiner may be assigned to test the inter-subjective agreement of the results and the degree of concordance. This is done by presenting the categories, sub-categories and quotations separately to the co-examiner and asking him/her to match them (106,107).

Validity

All scientific research requires the correct collection of data and a systematic and thorough analysis, just as the results should be rooted in empirical data and a precise description of the research process (112). Some argue that quantitative and qualitative methods should be subject to the same validity criteria, while others have defined supplementary and special criteria for qualitative studies. They focus in particular on the researcher's ability to provide the reader with a clear impression of the rigour and trustworthiness of the process and of the findings and conclusions reached (115,117).

Patton (116) argues that the credibility of qualitative research depends on a general belief in qualitative methods and holistic thinking, the gathering of high-quality data and the credibility of the researcher. Kvale (112) points out that the researcher should constantly be critical of the findings and test their validity and whether they are correctly understood and interpreted. Larsson (118) emphasises that the results should be rich and descriptive, the analysis logical, consistent and closely rooted in data, just as the discussion should carry conviction.

Several measures were taken throughout the data collection and analysis in order to validate the findings and establish trustworthiness (115)

- The questionnaires used in Studies I and II were preceded by pilot tests. The structured interviews were performed by thoroughly instructed professional interpreters who used translated questionnaires to ensure the valid and uniform collection of data
- A drop-out analysis was performed in Study I. All the statistical analyses in Studies I and II were carried out in co-operation with a professional statistician
- The professional interpreters who participated in Studies III and IV were carefully selected and instructed prior to the interviews. The quality of their translations was evaluated by other interpreters
- Various professionals were assigned as ‘experts’ and contributed knowledge, experience and supervision during Study II. The professional interpreters included in Studies II, III and IV functioned as ‘cultural interpreters’ and sparring partners
- During the qualitative research interviews, spontaneous and relevant ‘answers’ to the phenomena under study were aimed at. The interview process was open and flexible, thereby enabling statements to be followed up and clarified to ensure correct comprehension
- Quotations from the interviews are presented in the text to facilitate the reader’s evaluation of the validity of the findings. The inter-subjective agreement of the findings in Studies IV and V was tested by assigning an independent co-examiner
- Triangulation (as described on page 28) was used continuously, both within and between the studies
- The research process in all the studies has been carefully described. The analysis of the data was performed as thoroughly as possible. The qualitative analyses in Studies IV and V were continuously supervised and discussed with senior researchers. The findings from all the studies were discussed with colleagues, other health care professionals and senior researchers at lectures, seminars etc.

The researcher’s pre-understanding

Kvale (112) argues that the validity of a study depends on the credibility and skills of the researcher, i.e. his/her character, moral integrity and workmanship. Textual data are likely to present multiple meanings and may above all be influenced by the researcher’s background and pre-understanding. The analysis therefore becomes a balancing act between ‘making the text talk’ and what the researcher adds from his/her perspective (115). According to Taylor & Bogdan (101), all observations are filtered through the researcher’s ‘selective lens’; what is seen and reported as findings depends on who the researcher is and how he/she sees the world. As a result, the avoidance of bias is impossible and critical self-reflection is essential.

My pre-understanding is based on my background as a registered paediatric nurse and diabetes educator and on my professional experience from working with immigrant families and professionals for many years. Furthermore, spending a considerable amount of time in Egypt during the last few decades, the last ten years as an associated member of an Egyptian family is also likely to have influenced my 'selective lens'.

Triangulation

All the studies in this thesis have focused on education and support, competence in diabetes management and collaboration between the immigrant families' and health care providers. These topics were studied by means of different informants and different methods. Triangulation has been used continuously, both within and between the studies.

Triangulation is defined as testing one source of information against other sources by means of various methods, or by obtaining information relevant to a topic from several informants (97,101,104). Triangulation can strengthen a study design (116). It is described as a way of obtaining a deeper and clearer understanding of the settings and individuals under study (101) and of providing increased insight into the phenomenon, including the social context (119).

Some (104,120) argue that findings and interpretations based on concurrent results from more, mutually independent sources will demonstrate validity and in particular address problems related to construct validity and objectivity, as these constitute multiple measures of the same phenomenon. In contrast, others (97,119) argue that both correspondence and discrepancies may improve the quality and accuracy of the findings. If two sources reveal the same result, they can confirm, complement and cross-validate each other. If there is a discrepancy, its investigation may help to explain or hypothesise/suggest additional points of view in relation to the phenomenon under study.

Ethical considerations

Prior to each study, the individual research plan was sent to the ethics committee in the County of Copenhagen; each time, the committee had no objections. Since there are no ethics committees in Egypt (Mrs. Laila El Sioufi, AYD in Cairo; personal communication) the study in Cairo was carried out according to Danish rules and the Declaration of Helsinki (121). Approval for the individual studies was likewise obtained from the Danish Data Protection Agency on condition that data were handled confidentially.

The participating children, adolescents, young adults and parents were all informed verbally about each study, using professional interpreters where appropriate. It was especially stressed that participation was voluntary and that personal identifiers relating to their data and statements would be removed or disguised. It may be argued that

‘volunteering’ for a project when asked by a member of the team responsible for the treatment of your child represents potential problems. Still, I perceived that most families responded in a very positive and even enthusiastic way when they were asked, just as some families actually refused to participate.

The Declaration of Helsinki (121) includes the statements of ethical principles in medical research involving human beings; the most essential being that considerations related to the well-being of human beings should take precedence over the interests of science and society. Researchers are under an obligation to protect the life, health, privacy and dignity of the individuals under study, just as the potential benefit of a research project should always be weighed up against the potential harm. It is argued (122) that moral and legal standards also play a role in guiding professional conduct, especially when ethical standards conflict with each other. Others (123) are of the opinion that ethics, research practice and the construction of knowledge/findings cannot be separated.

Some findings in this thesis have ‘merely’ emphasised that inequity in health is still a fact. Others have indicated that some health care professionals may have reduced expectations when it comes to the abilities of immigrant patients and families, suggesting that they may be discriminated against in health care. I have tried to balance my wish to draw attention to these findings and my wish to respect the confidentiality of the informants by describing the findings in a fairly ‘diplomatic’ way and without direct quotations.

Gillies & Alldred (124) emphasise the ethical concerns related to the practice of speaking for others, typically more vulnerable individuals or groups, against the morality of not speaking for them. I have closely considered whether exposing non-western immigrants as a group with a need for special educational initiatives and support may lead to further polarisation. Still, non-western immigrant families are among the most vulnerable groups in the Danish society and may thus be entitled to advocacy – not least for the sake of the immigrant children.

FINDINGS

Continuous education and support are regarded as keystones in diabetes treatment and as crucial for the child's and family's achievement of optimum selfcare and good metabolic control. In the same way, close collaboration between the child/family and the diabetes team is essential to promote adaptation to the disease and the acquisition of the knowledge and skills necessary to obtain competence in diabetes management.

The findings presented here are a summary of the main findings in Studies I-V. They primarily focus on Danish immigrant children, adolescents and parents and the Danish paediatric diabetes teams, whereas other parts are described in less detail. The findings are presented under four headings and may be viewed as a further triangulation of the findings from the individual studies. They are referred to by their Roman numerals placed in brackets.

Pre-conditions for education and collaboration

The education of immigrant families in diabetes is likely to be affected by their different background and by factors related to immigration and acculturation. The education and collaboration between the immigrant families and the diabetes team will therefore depend on the health care professionals' ability to adapt the education and support to the pre-conditions of the families. The findings presented in this paragraph mainly comprise results from Studies I and II, but they are supplemented and commented on by findings from the other studies.

The immigrant families

In March 2002, 83 children and adolescents with a non-western immigrant background were identified at the Danish paediatric diabetes centres, corresponding to 6% of the total number of paediatric patients (I). The immigrant families comprised many different groups and nationalities. Even though some had a language or country in common, these groups were still small and comprised fairly different individuals. For example, a total of 29 families spoke Arabic but came from seven different countries and included an equal mix of workforce immigrants and political refugees (I).

Structured interviews in 2001-2002 (I) showed that most families with a workforce immigrant background had lived in Denmark for 15-25 years, whereas families with a refugee background had lived in the country for 5-10 years. Three parents and 65% of the children were born in Denmark. At the time of the investigation (I) only 60% of the fathers and 50% of the mothers were working, in vocational training or attending language school. Nineteen per cent of the mothers were working at home. In Study IV, only five of the twelve Arabic parents were either working or in vocational training, while four were unemployed, one was a pensioner, one was on long-term sick leave and one was a housewife.

The immigrant parents had a more limited educational background as compared with ethnic Danish parents (I). This was most distinct among the mothers who were the main caretakers of the children. There were large variations among the parents, however, and these were also found in the subsequent studies. The average period of school/education of the Turkish and Kurdish parents (III) was 6.8 years [range 2-14 years], whereas the Arabic parents (IV), who were mostly political refugees, had an educational background of 11.4 years [range 0-20 years]. In contrast, the young adults (V) had an average period of school/education of 12.5 years – even though six (55%) had still not completed their education.

A high percentage of the parents expressed the need for an interpreter when being educated about diabetes. The need for an interpreter, however, was not ‘logically’ connected with the number of years they had lived in Denmark. Among the 36 parents who had lived in Denmark for more than 15 years, 50% expressed the need for an interpreter (I). In contrast, all the children and adolescents spoke Danish well enough to manage without an interpreter. These families were workforce immigrants, but the need for an interpreter was fairly similar among the Arabic parents (IV) who were mainly political refugees. One of the Arabic fathers, however, was able to communicate almost fluently in Danish after only three years in Denmark, whereas another could not manage without an interpreter after 19 years. The findings were consistent with the fact that many of the young adults (V) had been acting as interpreters for their parents.

The Danish paediatric diabetes teams

The immigrant children were unevenly distributed between the Danish paediatric centres: 53% of the total of 83 patients in 2002 came from the centre at Glostrup, while each of the other 19 centres had 0-5 patients (I). Few diabetes teams had special knowledge of the background of immigrant families or special educational material or programmes. The study (I) also found a large variation in the use of interpreters at the paediatric centres. It was especially notable that most centres did not use interpreters after the initial education at diagnosis if one of the parents and the child with diabetes spoke Danish. Furthermore, fewer than half the centres used interpreters after the initial education, even though none of the parents spoke Danish, if the child was 13 years or older and spoke Danish fluently (I).

Perceptions of the education and support provided

The findings presented here include experience and perceptions of various health education approaches as described by the different participants in the studies, i.e. the children/adolescents, young adults, parents and health care professionals respectively. The findings comprise overall descriptions and evaluations of the intervention programme in Study II, supplemented and commented on with results from the other studies.

Children and adolescents

The young adults (V) had perceived the paediatric educators as dedicated and supportive. Some described the initial education and support as very individually focused and said that this had been significant for them. Many in particular emphasised the fact that the education had been adapted to their age:

Especially since my parents didn't know how to handle the situation, it was nice to have a regular nurse and doctor. They were very kind and nice to me and they made things easy; they explained things in an easy way and they didn't overdo it. // I felt it was pretty much like playing.

Most adolescents had established close relationships with the paediatric doctors and nurses. For some, however, this appeared to present problems in connection with the transition to an adult department (V).

During the intervention programme (II) the members of the 'children's group' (10-13 years) showed great enthusiasm at the sessions and they had many discussions on various issues and problems related to the disease. The children's motivation for more proper education, however, was limited and most appeared not to take responsibility for the disease to any larger extent. A similar finding was made in the observation of a group session for Turkish and Kurdish families (III): the three children aged 8-9 years who participated along with their parents, appeared to be little involved in the education; most of the time they merely sat around the table drawing and painting. In addition, the observation did not find that any of the parents or educators tried to include the children, who did not appear to take any interest in the education going on around them.

Meetings in groups with the aim of providing knowledge and support are widely used for individuals with chronic diseases. This was also described by the Arabic parents (IV) as a good way of providing their adolescent children with support and acceptance of the disease. In contrast, the adolescent boys (14-17 years) refused to participate in group sessions during the intervention programme (II). The seven adolescent girls appeared to be very enthusiastic when introduced to the programme (II), but they showed little interest and only sporadically appeared to have an enjoyable time.

It was also noticeable that both the children and the adolescent girls split up into smaller groups corresponding to their ethnic background, even though the majority were born in Denmark and all of them communicated in Danish (II). When evaluating the programme, few evaluated the meeting with other children and families as the most important part. Some of the young adults (V) stated that they had benefited from attending groups, while others, mainly the younger participants, said that they disliked this approach.

The parents

Most parents were satisfied with the education provided at the centres and many felt that the health care professionals took account of the fact that they came from a different ethno-cultural background (I). The families expressed a wish both for educational material about diabetes in their native language and to meet other families with children with diabetes. Most parents were also in favour of participating in the intervention programme (II). However, even though both parents were strongly encouraged to participate, considerably fewer fathers than mothers did so, especially in certain ethnic groups.

During the intervention programme (II) all the sessions were held in a good atmosphere and comprised an exchange of experience and many spontaneous debates among the parents. The educational material was received with great enthusiasm, but whether it was actually read by the participants remained unclear. The programme (II) was evaluated positively by most parents, but the mothers in particular appeared to have profited from the design. It was notable that, even among the parents, participation in the educational sessions was evaluated considerably higher than the meeting with other families – not least by the mothers.

The parents in the subsequent studies (III,IV) similarly expressed their satisfaction with the education and support provided by the diabetes teams, just as most were positive about education in ethnic groups. The Turkish and Kurdish parents (III) described this as '*a relief*'; the Arabic parents (IV) described how meeting other families with healthy-looking children with diabetes gave them hope of a good life for their child. According to the young adults (V), most of their parents had only participated in minor parts of the education. In contrast, it was notable that a young man, who had been diagnosed in his native country at the age of 14 years, stated that his mother had stayed in hospital with him during the entire initial admission and education. The young adults (V) mainly ascribed their parents' limited participation in the education to their inability to communicate in Danish.

Despite continuous education since the time of the child's diagnosis, several parents expressed lack of knowledge of diabetes management, while some called for education in '*new and different*' topics as a result of their needs changing over time. The Turkish and Kurdish parents of adolescents (III) in particular expressed a need for guidance on problems concerning puberty and less parental control. Some of the younger informants in Study V similarly expressed a lack of knowledge about how to handle the disease after becoming adults and starting to work, going out and so on and argued that this affected their metabolic control.

The health care professionals

The general impression during the intervention programme (II) was that the children's and the parents' groups were successful and gave the participants knowledge and support by means of the education, the exchange of experience and being together. One

of the main concerns during the programme (II) was the continuous unpunctual or lacking appearance of the parents. This not only resulted in endless waiting but also meant that I, from my experience, perceived difficulties in building up the sessions.

The ‘experts’ who evaluated the intervention (II) were positive about the content and design of the educational material. The Turkish interpreter (III) said that the educational material could provide the Turkish and Kurdish families with education at a level adjusted to their background. However, both the ‘experts’ (II) and the Turkish interpreter (III) emphasised the need to activate the parents and to control comprehension and learning to a greater extent.

The simple and precise educational style, including a personal approach to the individual families, was viewed by the ‘experts’ (II) as essential for building up a relationship based on trust and respect, which might facilitate the learning process. The Turkish interpreter (III) further stressed the need for continuous close support to enable especially the Turkish and Kurdish mothers to follow recommendations:

It's a big responsibility for them to control and handle a disease, you have to support them. Education is not enough; they need support all the time.

The observation of an educational group session (III) revealed that part of the education appeared to be poorly adapted to the participants’ background; findings that also appeared in the analysis of the medical records (III). In the interview, the three members of the diabetes-team (III) explained that they showed their interest in the immigrant families by being ‘*open, curious and not prejudiced*’ and by trying not to go beyond their limits. This meant, however, that the members of the team abstained from bringing up certain topics in the education, despite their relevance to disease management, on the assumption that they were not culturally acceptable.

The impact of the disease on the life of the immigrant families

The findings presented here are primarily from the qualitative studies and related to the immigrant parents’ perceptions of the diagnosis of their child and its impact on the life of the family. Study V included the perspective of the child/adolescent/young adult and their perceptions of their parent’s reactions. In this way the findings may also help to illustrate the immigrant families’ adaptation to the disease.

Reactions and support

Most of the young adults (V) described themselves as being on their own during the time of diagnosis and the initial education, i.e. at the age of 10-17 years. This was primarily ascribed to their parents lacking the ability to communicate in Danish. One young adult, however, also related it to the parents’ immigrant background:

While I was in hospital, my entire family came to see me and they were all crying. I was thinking ‘Stop that; I am not dead or dying, I’ve just got diabetes’. But I think this is how it is with immigrants; they start crying and so on, this is how we do it. If somebody is sick: ‘Oh no’.

Most parents (V) were described as providing their children with limited emotional support. This was especially illustrated by the fact that most adolescents had eaten differently from the rest of the family, since the food recommendations for people with diabetes were perceived by the other family members as eating ‘Danish food’ and were thus inconsistent with their traditional food habits. In the same way, the fact that one or more family members had diabetes was not likely to result in changes in the traditional food served to guests. This was said to be related to the traditional practice of not informing people outside the closest family about a chronic disease due to fear of social consequences.

The children and adolescents participating in the intervention programme (II) had only expressed minor reactions when informed about the diagnosis. Most young adults (V) similarly described limited reactions and said that they were primarily related to an initial fear of needles/injections and of no longer being able to eat unrestricted amounts of sweets. In contrast, the majority of the parents (III,IV,V) had perceived the diagnosis of their child as very painful.

Parenthood and parental roles

The Arabic parents in Denmark and Egypt (IV) were found to share many reactions and concerns, but the immigrants in particular experienced the life of the child and their own parental roles in a more doubtful and negative way. Even though many children had been diagnosed years ago, some parents (III,IV) still perceived difficulty adapting the management of the disease to their principles of good parenthood – and had thus not accepted the precepts of the disease.

After two years, an Arabic mother (IV) still described her son’s diagnosis as ‘*the end of life*’. Many parents, including a father who was born in Denmark (III), perceived basic parts of diabetes management as a ‘*punishment*’ of the child. The father of a 16-year-old Turkish/Kurdish boy (III), who had been diagnosed six years prior to the interview, still felt he should treat his child differently because of the disease:

My culture tells me to treat my boy affectionately, but this is outside the disease; here I have to be hard on him. I have to react in a different way.

The parents also said that their parental roles and relationships with the child with diabetes, their other children, family and friends had changed. For the Arabic parents (IV), who were mainly political refugees, the diagnosis had brought their limited social network in Denmark into focus. Despite their perceived need for social support, however, the diagnosis of the child also meant that they saw little hope for themselves and their families to return to their native country in the future:

You're better off here (in Denmark) with this disease, because of the chances of getting insulin and all that; the material things are available here. But down there (in Iraq) I wouldn't be alone. I would have my mother, sister, aunts; family around me. This means that if I was tired, they could relieve me; take over.

The outcome of the educational programmes

The findings presented under this heading include factors that are all considered essential for the ability to live a good and reasonably 'safe' life with diabetes, i.e. with the lowest possible risk of long-term complications. These comprise knowledge and competence in diabetes management, collaboration between the child/family and the diabetes team and good metabolic control. Findings from all the studies are presented.

The families' knowledge and competence in diabetes management

Nine of the 20 Danish paediatric centres found that the immigrant families were less able to master the disease compared with ethnic Danish families; six centres did not experience any difference; five centres had no opinion (I). This did not correspond to the parents' evaluation of their knowledge of diabetes, as a large percentage of both fathers and mothers evaluated this as either 'extensive' or 'very extensive' (I).

During the intervention programme (II) many parents in particular appeared to perceive part of the topics as difficult or even to view them as 'new' knowledge, in spite of comprehensive education since the time of the child's diagnosis. In the evaluation of the intervention, knowledge of diabetes was similarly evaluated as having increased by almost all the children and parents. This corresponded to a mean increase in the number of correct answers to the test of basic knowledge of diabetes, which was carried out before and after the intervention programme (II), but with considerable variations between some of the families.

The three members of the diabetes team (III) described their general experience of educating families with a non-western immigrant background in diabetes and especially emphasised the following problems

- Many families appeared to have difficulty accepting that diabetes is a 'true' chronic disease; this influenced their motivation for education and learning
- The families appeared to understand the content of the education but failed to implement the recommendations
- Previous education was found to be either misunderstood or forgotten
- Adequate routines were said to be changed without notice as a result of recommendations from other family members or information obtained from television programmes from the immigrants' native countries

In the medical records most Turkish and Kurdish families (III) were described as having limited knowledge and compliance. In contrast, the Arabic parents (IV) whose children had been diagnosed during the past two years were described by the team as more competent in diabetes management than immigrant families in general. In spite of the team's evaluation, however, the parents (III,IV) described fairly similar perceptions and problems related to their life with a child with diabetes.

The immigrant mothers who participated in the studies were the main caretakers of the children, but the fathers stated that they would be able to take over if the mothers were unable to do so (IV). As mentioned, many parents, especially those of younger children, experienced difficulty combining disease management with their principles of good parenthood. This meant that essential parts such as insulin injections, blood glucose testing and food recommendations were perceived as a '*punishment*' of the child (III,IV). In contrast, the young adults (V) described adaptation to the food recommendations as being the most difficult aspect of having diabetes. They also expressed confidence in their competence in disease management based on their own knowledge and experience and their trust in the competence of the health care professionals.

Collaboration between the families and the diabetes team

The establishment of collaboration between the immigrant families and the diabetes team was perceived as difficult by both parties. One Arabic mother described it like this:

If you're in your native country, you're not alone and you trust the doctor; you're able to talk to the doctor, because you have the language, the understanding and the background in common.

The Turkish interpreter (III) was of the opinion that most Turkish and Kurdish families had sufficient knowledge of diabetes management but lacked the inclination to follow recommendations. He emphasised that learning, selfcare practice and the metabolic control of the child – and even the motivation to attend the regular visits to the centre – were likely to be influenced by the immigrant families' personal feelings and confidence in the health care professionals (III).

Most parents (III,IV) perceived that the diabetes team provided them with good help and support, apart from some Turkish and Kurdish parents (III) who stated that the health care professionals did not really care about them. This was linked to a high frequency of non-appearances by the Turkish and Kurdish families (III), described in the medical records. The Arabic parents' (IV) related their need to seek additional information from Arabic TV and people from their native country to insecurity or doubt about the competence of the Danish health care professionals. One Arabic mother (IV) explained that she felt the team lacked up-to-date information and that she could not trust what she was told.

Collaboration is a matter of trust but also of sufficient time and good communication. The members of the diabetes team (III) said that they experienced clear restrictions to the time and resources available. Everyday life was described as '*very, very busy*' and this meant that there was less time to go outside routines in order to find solutions to problems.

Communication with the assistance of interpreters also appeared to present problems. Many centres mainly used interpreters during the initial education at the time of the child's diagnosis (I). The young adults (V) further stated that some parents had refused the assistance of an interpreter even though this was available; instead they preferred their young children to translate for them. Interpreters may also be used in an inappropriate way, as shown in the observation of a group session (III): despite the presence of an interpreter, part of the conversation was held in Danish because the fathers in the group spoke Danish; without considering that this might prevent the mothers from participating and learning.

Metabolic control

Due to the recent diagnosis of the children and the lack of and/or incomparable data on the children in Egypt, data on metabolic control were not included in Study IV. Findings from the other four studies showed that most Danish children, adolescents and young adults with a non-western immigrant background did not have optimum metabolic control (recommendation $\leq 7-8\%$). The mean HbA_{1c} values of the various immigrants who participated in the studies were:

- I (N=58) 9.05% \pm 1.4%
- II (after the intervention; N=37) 8.6% \pm 1.0%
- III (N=8) 9.7% [range 8.5-12.0]
- V (2006; N=9) 8.8% \pm 0.3-0.6%

In Study I, the group of non-western immigrants was compared with the total group of Danish/western patients. The study found a significantly higher HbA_{1c} among the immigrants ($p=0.018$) whereas no differences were found in the prevalence of severe hypoglycaemia or ketoacidosis. No significant differences in HbA_{1c} were found between the different ethnic groups, a fact that may be explained by the limited number of children in each group. The linear regression analysis, although not significant, suggested that the difference in HbA_{1c} between ethnic Danish and immigrant children was likely to increase as they grew older. This result may perhaps be considered in the light of the findings in Study V in which many of the young adults said that their families had not provided them with sufficient support, especially during adolescence.

DISCUSSION

This thesis has focused on type 1 diabetes in children and adolescents from non-western immigrant families and has aimed at exploring pre-conditions and potential barriers to diabetes education and collaboration in a cross-cultural relationship. This was done to provide knowledge of the way health education and support should be given to ensure the immigrant families adequate competence in disease management and their children optimum metabolic control. The discussion is presented in accordance with the research questions.

Pre-conditions and barriers to education and learning

In spite of years of continuous diabetes education, most families included in the studies lacked sufficient competence in disease management, as is also indicated by the fact that the majority of the immigrant children and adolescents had non-optimum metabolic control. This might suggest that the families did not learn from the health education provided. Marton (82) argues that the contents of an education need to become part of what the person already knows; that genuine learning is likely to fail if the contents are not related to the reality of the learner. This may pose difficulties, not least in a cross-cultural relationship.

Somewhat in contrast to this, the immigrant families stated that the paediatric teams provided them with good help and support and a large percentage of the parents evaluated their knowledge of diabetes as 'extensive'. The intervention also showed that an educational programme adapted to the background and qualifications of the immigrants could improve the outcome and thereby metabolic control. As has also been found by others (94,125,126), however, the long-term effect of the intervention was doubtful and the effect among some participants limited. It is therefore evident to argue that the education did not result in learning; that education and good discussions of relevant topics do not necessarily result in subsequent reflection and implementation into practice and adequate routines – and that the contents of the education may therefore quickly be forgotten.

Educational, linguistic and social barriers

The immigrant families were mutually different in terms of country of origin, reasons for coming to Denmark, length of residence and in the qualifications they brought with them. Most of the parents, however, had somewhat different pre-conditions for diabetes education than ethnic Danish parents; the most obvious barriers being their limited educational background and inability to communicate in Danish. This was especially prevalent among the mothers and was thus a matter of great concern, since they were also the main care-takers of the children. In contrast, the immigrant children and adolescents either had or were likely to acquire fairly different pre-conditions compared with their parents.

It has also clearly been shown that the immigrants' length of residence in Denmark did not 'logically' reflect their level of acculturation as evaluated by their need for an interpreter for diabetes education. Most Danish paediatric diabetes centres used interpreters to a lesser extent than requested by the families. Instead, the immigrant children functioned as interpreters for their parents, even though this is strongly advised against (31,127). The majority of the centres had few immigrant patients and may therefore also have had limited knowledge of the evident communicational problems that have been identified between immigrants and 'western' health care professionals. These include a lack of understanding of the information provided despite relevant linguistic skills (128), and a lack of learning despite a linguistic understanding of the contents of the information (128-130) and consequently a clear need for professional assistance.

The fact that some parents/families refused the assistance of an interpreter and preferred their young children to translate for them should therefore not be accepted but should result in dialogue and motivation towards the use of professional interpreters. Finding the right interpreters and establishing collaboration may require both time and practice, but it should be regarded as a means of enabling a far better understanding of the background and situation of a family (8) and the basis for a better treatment outcome.

It should also be remembered that non-western immigrants frequently originate from countries where orthodoxy is widespread and criticising and questioning authorities uncommon (31,43). This could explain the families' expressed satisfaction with the education and the parents' evaluation of having an extensive knowledge of diabetes – in obvious contrast to the children's poor metabolic control – and therefore spotlights the immigrants' vulnerability as regards critical communication (5,31). This further emphasises the need for the assistance of interpreters in order not merely to have words translated but also to promote an understanding of the contents of an education and the intentions behind it (128).

Furthermore, most non-western immigrants have a socially marginalised position in the Danish society; a fact which may in itself affect learning and selfcare practices (60). Several studies have tried to evaluate whether another cultural background or a low social position respectively have the greatest effect on the poor disease outcome of immigrant patients. Some (9,34,131) have concluded that poor metabolic control is primarily related to a low social position, while others (8,10,57) have emphasised the importance of also considering different beliefs about health and disease in diabetes care for immigrants. A recent Swedish study (132) found that immigrant men with diabetes in a socially low position had more distressed and emotionally oriented coping strategies as compared to ethnic Swedes. It was therefore recommended that both psychosocial and cultural approaches should be applied.

Culture and traditions

Different cultures and traditions are important aspects to consider in the care of a chronic disease. Murphy et al. (133) point out that while culture often plays a minor role

in the treatment of emergencies and acute conditions cultural dynamics are likely to influence the outcome of chronic disease management. Since the immigrant parents have grown up in another (distant) country, they may still be greatly influenced by the norms and values there (23) and therefore less likely to benefit from health education designed for the general population in the new country (134).

A large part of the families in this thesis lacked sufficient knowledge and competence in diabetes management. It is argued, however, that the concept of selfcare is based on western ideas of individualism and autonomy (31) and is thus counter to the cultural beliefs, values and norms in non-western cultures (10,56). Hansen (31) further states that autonomy presupposes that the person is able to make decisions and that this requires that he/she is mentally and socially prepared.

Different traditions regarding parenthood and the upbringing of children may help explain why some immigrant parents perceived that they were ‘punishing’ their children when giving them insulin injections for example, and why the younger children were not encouraged to take responsibility for their disease. First-generation immigrants have been found to have less ability to cope with a chronic disease (132), a fact that may be related to a less optimum utilisation of adequate medical care (135). It was noticeable, however, that some perceptions were shared by a father who was born in Denmark. This suggests that cultural attitudes and norms are influenced not only by the level of acculturation (12,27) but also simply by growing up in an immigrant family (31).

Differences in health and illness beliefs also mean that diseases may be viewed differently within various cultures (31). A Canadian study (136) found that ethnic Canadian and Chinese parents took different views of a chronic disease in childhood. The Canadians viewed the disease as a limited part of the child and tried to normalise life by minimising the effect of the disease. In contrast, the Chinese parents did not separate the disease from the child but perceived that it influenced the function of the whole person; finding a cure was therefore the only way to establish normality. This could explain why the immigrant families did not consider adapting their traditional food habits, for example, as a way of supporting their child.

The influence of culture, however, should not be overestimated (8,43,127). Just as ethnicity is not a static concept, culture should instead be viewed as a meaning-generating concept (137). It is therefore important that health educators come to understand the individual patient’s life situation, including the impact of the disease (35,138) as a basis for optimum health education and collaboration.

Pre-conditions and barriers to establishing collaboration

Due to the long-lasting course of a chronic disease, health care professionals should be actively involved in the individual patient and thereby able to inform, encourage and support him/her in the complex process towards competence and adaptation (50,93). In the same way, they should enable the establishment of a trusting relationship in which the patient/family feels appreciated and safe (54,87).

Confidence, collaboration and compliance

All the participants in the studies stated that the paediatric diabetes teams provided them with good help and support. Some, however, also emphasised the importance of being able to trust, talk to and understand the doctor. In the same way, the fact that some parents were active in seeking additional knowledge from television channels and people from their native country was explained by doubt as to whether the competence of the Danish health care professionals could be fully trusted.

The young adults had profited from a close relationship with the paediatric teams, whereas the collaboration between their parents and the health care professionals was described as fairly limited. This is a matter of concern, since most non-western immigrants originate from countries with an authoritarian view of health care professionals: disease is viewed as the doctor's area, indicating that there is little tradition for involving the patient/family in the treatment and decision-making (43). In the same way, patients from ethnic groups socialised in the norms of paternalism have been found to be less disposed towards partnership with health care professionals (87).

The immigrant families' personal feelings and confidence in the health care professionals were described as essential for selfcare, learning and attendance at the diabetes centre. Members of the diabetes team further stated that the families often failed to implement the given recommendations and also changed adequate routines as a result of information obtained from media or persons from their native countries. Non-compliance, however, may be related to the fact that a chronic disease like diabetes involves so much more than a disturbance of the metabolism (139). Scherman (140) argues that non-compliance may be a suitable way for a patient to address his/her socio-cultural context and that the context, society and culture of the individual patient should be carefully considered.

The use of the term 'compliance' may be especially problematic if a patient has widely different values compared with the educator (133). Dunn (37) emphasises that the goal in any patient-provider interaction is to increase the patients' control of the situation and include them in the decision-making process around their disease. In the same way, patient-centred encounters including a knowledge of the life world, expectations and anxieties of the individual patient/family are described (77) as vital for optimum collaboration. Meeting individuals with a different ethno-cultural background thus requires that health care professionals combine a professional expert role with a caring and empathic attitude (141) and practise individualised care and intercultural competence (142).

Professional attitudes and intercultural competence

Like other health care professionals, the Danish paediatric diabetes teams described difficulty caring for immigrant patients. Others (143,144) have found that this may result in an inability to develop a therapeutic relationship and may thereby lead to mutual stress and frustration. Ethno-cultural differences may furthermore result in

inadequate or ineffective assistance (137) – and thus inequality in health. Even though the origin of the problems lies with both the immigrant families and health care professionals, Hansen (31) argues that, as professionals, nurses and others have a duty to initiate ways to resolve them.

The establishment of a relationship that facilitates active collaboration requires a genuine interest in the patient and confidence in his/her ability to participate; pedagogic strategies, sufficient time and provider-patient continuity are described as essential factors for achieving a good result (145). Fagerli et al. (141) further argue that successful patient-encounters are impossible to establish without trust. In contrast, members of the diabetes team described working days as very busy and said that this meant that they had less time to go beyond routines in order to find solutions to perceived problems related to the immigrant families.

Some findings from the studies such as the acceptance of continuously poor metabolic control and limited use of more intensive insulin regimens for example, could indicate that health care professionals may have reduced expectations of the abilities of immigrant patients/families; a fact that may lead to suboptimum care (131,146). In the same way, others (130,147) have found that the patients' ethnicity affected physicians' satisfaction with the clinical encounter and that this was especially associated with perceptions of immigrant patients as being less able to understand chronic disease management.

Anderson (128) argues that, while the culture of the patients is often problematised, the culture of health care providers is usually not questioned. She (128) further emphasises the importance of realising the unequal power relationships in health education based upon assumptions relating to race, ethnicity or class relations and thus in contrast to facilitating a mutual learning process:

Health education is usually conceptualized as imparting a body of knowledge; the health professional is the 'knower' and the patient is the 'receiver' – an empty vessel to be filled with knowledge. His/her culture is usually seen as standing in the way of knowledge acquisition (128).

Since Danish health care services are designed for ethnic Danes, it should also be evaluated whether the existing options can be used by persons with an immigrant background or whether alternatives are needed – otherwise immigrants are likely to be discriminated against (127). According to Rhodes & Nocon (146), some health care professionals have become so accustomed to working without the proper resources that they appear to have accepted this as an unchanging fact rather than an issue to be challenged. It is also pointed out (39,148) that working with immigrants calls for openness and acceptance of other cultures; that health care providers should acquire adequate knowledge to enable the provision of care, based on respect for the values of patients with a different ethno-cultural background.

The development and use of adapted strategies should therefore be considered (35,95,134). This includes finding solutions to identified problems such as how certain

educational topics could be provided in a ‘culturally acceptable’ way instead of merely abstaining from bringing them up as described in one of the studies.

How can diabetes education and support be improved?

Several findings from the studies show that the Danish immigrant families, in particular the parents, have different pre-conditions for diabetes education compared with ethnic Danes. Different social and ethno-cultural pre-conditions are likely to affect behaviour and ways of thinking and may thus create barriers to education and learning (95,133) and influence selfcare practice and care-seeking behaviour (10). The educator’s ability to provide appropriately adapted education that yields meaning and relevance to the learner is therefore likely to determine its success (35). The studies have identified several factors to be considered when providing diabetes education to non-western immigrant families in order to establish collaboration and provide a basis for a successful outcome. They are summarised in Figure 2.

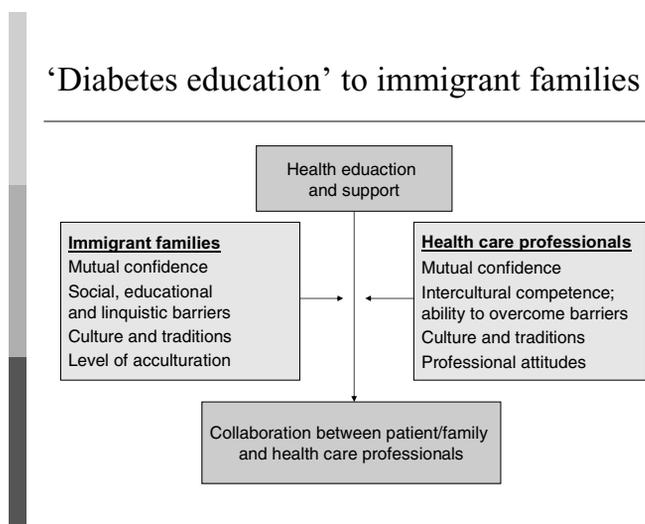


Figure 2. Factors to be considered when providing diabetes education and establishing collaboration with immigrant families.

The Ottawa Charter (16) emphasises that the health care sector should move *beyond* its responsibility for providing care and focus on the *total* needs of the individual. In the same way, the goals of health promotion are to pursue equity and eradicate existing differences in order to achieve health. Factors such as social inequalities and structural barriers related to immigration and acculturation should therefore be addressed. Treating all patients/families equally is likely to lead to discrimination; individuals with

different pre-conditions – whether they are ethnic Danes or non-western immigrants – should be treated individually and differently in order to achieve equal opportunities. The successful care and health education of immigrant patients and their families therefore primarily requires an ability to handle dissimilarity and diversity including openness towards and acceptance of other values, i.e. intercultural competence (35-39).

Educational strategies that are designed and used for ethnic Danes may not result in an optimum outcome if they are merely adapted to individuals with a widely differing background. Like the intervention programme, recent large controlled studies (149-151) have focused on finding more optimum ways to provide diabetes education to immigrant patients. In spite of the use of culturally adapted educational strategies, enhanced care and the use of trained link workers from other cultures, however, they were unsuccessful in achieving a significant effect on metabolic control.

Watts et al. (152) argue that in providing information/education to patients from ethnic minorities, their needs appear to have been an ‘add-on’. They suggest that health care providers should instead collaborate with the individual immigrant or ethnic group in identifying and developing appropriate strategies. Special attention should be paid to the way the patient, based upon his/her pre-conditions, understands and lives with the disease (37,138,153,154). It should be noted, however, that the informants in the qualitative studies identified specific areas in which they perceived a need for additional knowledge, indicating that the therapeutic patient education (89) may still be an option. According to Clerk (154) excellent listening skills, involvement and an interest in promoting open communication are essential for facilitating a patient-centred educational approach.

This thesis has clearly shown that Danish non-western immigrants are mutually very different individuals and that the acculturation of the individual members of a family or ethnic group is likely to vary – not least as regards the mothers. Accordingly, the pre-conditions of the individual family members should be thoroughly evaluated prior to initiating diabetes education. In the same way, the appropriate way to provide the education should be carefully planned in collaboration with the individual family. Moreover, continuous psycho-social support, control of learning and implementation of knowledge should form an integral part of the educational sessions.

Special attention should be paid to the education and learning of the mothers since they were found to be the main care-takers of the children. Findings from this thesis clearly indicate that some mothers had only participated in small parts of the education and that their limited ability to communicate in Danish was not sufficiently acknowledged in the educational sessions. Within health promotion it is emphasised that policies that embrace gender differences and similarly acknowledge that women are often assigned as the care-givers of the family are more likely to be successful in promoting health (155).

The fact that many immigrant families had limited social relationships also indicates that there is a need for more optimum emotional and psychosocial care and support, not least for the parents who were found to receive less support compared with their

children. A trust-filled relationship is described as essential (54,87) for achieving the aim of diabetes care – that is providing the patient/family with optimum competence in disease management in order to promote adaptation and coming to terms with the disease (59,60) and thus gradually build up empowerment (73). Sessions in groups may be especially relevant for dealing with problems related to culture and traditions (156) and being unfamiliar with chronic disease management or feeling insecure about the competence of culturally different health care providers. The uneven distribution of immigrant families between the Danish paediatric centres represents an obvious obstacle to establishing groups and calls for closer collaboration between centres with few immigrant families.

Education and support on the basis of accepted social values and cultural norms are described as being effective when it comes to integrating new information into practices and thereby influencing lifestyle and adaptation (157). A wide range of alternative approaches such as the involvement of significant others, songs and storytelling are suggested as alternative ways of providing immigrants with competence in disease management and a forum for discussing, negotiating and challenging difficulties related to new phenomena (157,158). The inclusion of grandparents and other significant family members is described as a way of acknowledging the structure of many ethnic minority families (159). Groups may also be appropriate for dealing with problems relating to parental roles and traditions in the upbringing of children and ways of providing them with support and handing over responsibility for disease management.

It is, however, important to consider whether group sessions should include all the individuals who speak the same language or belong to a specific ethnic group, or whether a carefully selected group of more homogeneous participants would be more suitable. It might also be appropriate for the sessions to be either primarily or entirely conducted by persons with a cultural and linguistic background similar to that of the participants, indicating the involvement of peer education or bilingual health educators (94-96). These should not just be fluent in the same language but should understand and be familiar with the cultural and social context of the participants (160). Due to the limited social network of many immigrant families, England et al. (129) further suggest the attachment of ‘mentors’, i.e. more experienced immigrants with a similar background to the most vulnerable families or individual family members.

In contrast, findings from this thesis show that immigrant children and adolescents have or are likely to achieve an extended educational background and ability to communicate in Danish compared with most parents. The young adults described the initial education and support as very individually focused and that this had been significant for them – not least the ones with good metabolic control. This suggests that special attention should be paid to the immigrant children and adolescents and that they should be provided with special education and support, especially prior to and during adolescence. However, special initiatives for the younger immigrant children, separately from the parents, should also be considered. Similar to clinical practice at the AYD in Cairo (personal observation), this training/education might be provided in small groups and should mainly focus on psycho-social topics related to diabetes management and be conducted at an age-adapted level.

Study validity and limitations

This thesis has focused on exploring potential barriers to be considered when providing diabetes education and support for Danish non-western immigrant families. Since the phenomenon under study was complex and multi-factorial, both quantitative and qualitative research methods were included (98,104). As described in the methods section, several measures were taken to validate the findings and establish trustworthiness (115-20). Accordingly, this paragraph comprises a more general discussion of the participants and methods applied and the overall validity of the findings.

The number of participants in the studies is limited, but a large percentage of the children and adolescents with an immigrant background at the Danish paediatric diabetes centres were nevertheless included. Particularly in Studies I and II it was considered problematic that the immigrant families were described as a group and their mutual differences thereby not acknowledged. This was redressed to some extent in the subsequent studies, even though it might be argued that studies including other large ethnic groups such as the Pakistanis and the Somalis could also have contributed valuable knowledge. Due to the limited number of participants, the findings cannot be transferred to apply to all immigrant children, adolescents and young adults with diabetes and their families. Still, the findings may provide nurses and health educators with a deeper understanding. Furthermore, the findings may not be unique to the diabetes field, but may be applicable to other immigrant families, not least the ones affected by a chronic disease in childhood or adolescence.

The majority of the participants in Studies I-IV were followed at the paediatric diabetes centre in Glostrup. In spite of this, there is no reason to believe that the families at Glostrup, who comprised 53% of the total number in 2002, were considerably different from immigrant families in other parts of Denmark. The structured interviews in Study I mainly included families from Glostrup but comprised data on all large ethnic groups and on 46% of the total number of Danish immigrant families with children with diabetes. Since so many immigrant children and adolescents are followed at Glostrup, however, this is the only centre offering special educational programmes on a larger scale, just as the team is more experienced in providing care for these families than Danish paediatric centres in general. The fact that the majority of the participants came from Glostrup may therefore have influenced the families' perceptions and evaluations of the education and support provided – but it is impossible to say whether this was in a positive or negative way. In Study V, in which young adults from centres all over Denmark were included, no major differences were identified between the centres.

The inclusion of a group of ethnic Danish children/families in a qualitative study for comparison and control was considered. Matching such a group, however, would have presented serious difficulties as it would only have been possible to attempt to match educational background and socio-economic factors. This means that a large variety of factors including culture, traditions, communicational problems, limited acquaintance with the Danish social agencies and health care services would simply be labelled 'a different ethnic background'. Instead, it was considered more appropriate to include

different groups of immigrants and immigrants/non-immigrants as in Studies III, IV and V, thereby acknowledging that immigrant families are not homogeneous.

The inclusion of interviews with immigrant children and adolescents was also considered. Throughout the studies, however, the immigrant parents were perceived as the ones with the most obvious difficulty acquiring competence in diabetes management and adapting their parental roles accordingly. Furthermore, the adaptation of the parents is described (59) as having a major influence on the coping and well-being of the ill child and other family members. In the same way, social support has been closely connected with the mental well-being and good selfcare practice of people with diabetes (161).

It was originally planned to include elements of action research in the intervention in Study II. This was strongly advised against by the interpreters, however, who said that the immigrant families, due to the traditional orthodoxy in their native countries, would feel uncomfortable with this approach. This could help to explain why almost all the parents, despite strong and repeated requests for comments and possible amendments, continuously expressed their extreme satisfaction with every single part of the intervention programme – and were thus perceived as not really collaborating. In the same way, it can be argued that the families, especially in Studies I and II, were too satisfied with every part of the education and support provided. Still, it cannot be excluded that the families, from their background and pre-conditions, actually perceived that their needs and expectations were met.

Most interviews with the parents were carried out in small groups. Bowling (113) argues that individual interviews are likely to provide a basis for richer data. In contrast, others (101,102) describe groups as more appropriate when exploring specific topics including cultural values. According to Kitzinger (156), (focus) groups are 'ideal for exploring people's talk, experiences, opinions, beliefs, wishes and concerns' and are likely to reveal a deeper understanding of the informants' different perspectives because they 'operate within a social network'.

The fact that I initially worked as a diabetes educator at Glostrup and was therefore familiar with most of the participants in Study II may be questioned, just as my personal experience and attitudes may have affected the analysis of the findings. Taylor & Bogdan (101) argue that the researcher's 'selective lens' makes avoiding bias impossible and critical self-reflection essential. This indicates that he/she must provide the reader with a clear impression of the rigour and trustworthiness of the process, the findings and conclusions reached (115,117). Berg (102) furthermore recommends that the interviewer should be familiar with the background and culture of the informants and also describes it as beneficial that the interviewer is able to use his/her professional insight during the interview. Practitioners and educators are likewise encouraged (97) to take an active part in the intervention process to ensure that relevant problems are identified, new strategies initiated and the findings subsequently implemented.

The fact that data relating to the participants' need for an interpreter were used in the analyses as an indication of their level of acculturation could be questioned, since this

might also be interpreted as the parents' perceived difficulties relating to diabetes education. In the 'assessment' of the acculturation, however, the need for an interpreter was closely related to the number of years during which the immigrants had lived in Denmark.

Finally, it may be argued that learning to live with diabetes in a child or adolescent is a complex process and is therefore likely to include more than 'merely' the acquisition of the knowledge, skills and support necessary for adaptation, selfcare and good metabolic control. In relation to immigrants and refugees, it is particularly important to consider whether conditions related to acculturative stress (11-13,162) and PTSD (25,26) may present additional barriers to learning and adaptation.

CONCLUSIONS AND IMPLICATIONS

This thesis first of all leads to the conclusion that the needs of non-western immigrant families are quite similar to those of ethnic Danish families – namely 1) a trust-filled relationship with health care professionals, 2) being provided with health education and support adapted to individual pre-conditions and needs and 3) conducted in a language that facilitates dialogue and learning. Some of the findings could be related to the socially marginalised position of most non-western immigrants, which may in itself result in less energy to comply with the huge demands imposed by a chronic disease in a child or adolescent. Other findings suggest that the immigrants' level of acculturation is also likely to influence the outcome of health education. Special attention should above all be paid to the fact that different individuals may have achieved different levels of acculturation, indicating that immigrant families, and even individual family members, may be more mutually different than Danish families in general.

Viewed from a public health perspective, this thesis confirms that non-western immigrant families represent a different and vulnerable group within the Danish society and that inequality/inequity in health among immigrant children and adolescents with type 1 diabetes is a fact. It may therefore be argued that Denmark's ongoing transformation into a multicultural society has exposed the health care services' difficulty adapting to people with different traditions and values. The findings of the studies clearly indicate that the care and health education that have been provided have been insufficient in overcoming the multiple barriers to learning and adaptation that were identified, in particular among immigrant parents.

The implications listed below originate from the findings and should be considered when providing care and health education for immigrant children, adolescents and their families

- It is important to recognise that culture and traditions affect behaviour and ways of thinking and are likely to create barriers to health education and collaboration in a cross-cultural relationship
- Non-western immigrant families should not be viewed as a group. Their non-homogeneity requires educational initiatives that are closely adapted and tailored to the pre-conditions and needs of the individual family members
- Special attention should be paid to the immigrant mothers, as they are the main care-takers of the children
- Immigrant parents should be carefully introduced to Danish principles on the treatment of diabetes in childhood. The parents may especially require assistance and support in order to learn to deal with problems related to parental roles and how to provide their child with optimum support. The use of peer education should be considered
- Professional interpreters should be included whenever requested

- Special educational initiatives should be provided to immigrant children and adolescents. Training of the younger children at an age-adapted level should be considered
- A close, supportive and trust-filled relationship between the families and health care professionals is necessary to facilitate learning, adaptation and collaboration
- Health care professionals should acquire intercultural competence. Collaboration between centres with few immigrant families may be an option in order to provide more optimum education and support

The implications may be applied in future intervention programmes for immigrant families. When planning new projects, however, immigrants from the various ethnic groups, both men and women with a varied social, educational and acculturative background should be actively involved in the design.

Furthermore, it would be interesting to explore how the diagnosis of diabetes in a child or adolescent may have influenced non-western immigrant families in terms of family life, pattern of sexual roles, parental roles, the parents' ability to communicate in Danish and their familiarity with the Danish society and health care services.

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REFERENCES

1. Statistics Denmark. Statistisk Tiårsoversigt 1999 (Statistical ten years' survey 1999). Copenhagen, 1999.
2. Statistics Denmark. <http://www.statistikbanken.dk/statbank5a/default.asp?w=1024>
3. Carballo M, Divino JJ, Zeric D. Migration and health in the European Union. *Trop Med Int Health* 1998;3:936-44.
4. The Danish National Board of Health. Etniske minoriteters sundhed og sygelighed (Health and ill health of ethnic minorities). Copenhagen: Sundhedsstyrelsen, 2005.
5. Dyhr L. Udfordringer i mødet med patienter med anden etnisk baggrund (Challenges in the meeting with patients with another ethnic background). *Ugeskr Læger* 2000;162/46:6307-9.
6. Ekblad S. Migration och hälsofrämjande integration (Migration and health promoting integration). In: Theorell T (Ed.). *Psykosocial miljö och stress (Psychosocial environment and stress)*. Lund: Studentlitteratur, 2003:199-258.
7. Sundquist J, Johansson SE. Sämre somatisk hälsa hos utlandsfödda (Poorer somatic health in people born abroad). *Lakartidningen* 1998;95:1000-6.
8. Hawthorne K, Mello M, Tomlinson S. Cultural and religious influences in diabetes care in Great Britain. *Diabet Med* 1993;10:8-12.
9. Anderson RM, Herman WH, Davis JM, Freedman RP, Funnell MM, Neighbors HW. Barriers to improving diabetes care for Blacks. *Diabetes Care* 1991;14:605-9.
10. Hjelm K, Bard K, Nyberg P, Apelqvist J. Religious and cultural distance in beliefs about health and illness in women with diabetes mellitus of different origin living in Sweden. *Int J Nurs Stud* 2003;40:627-43.
11. Bengi-Arslan L, Verhulst FC, Crijnen AAM. Prevalence and determinants of minor psychiatric disorder in Turkish immigrants living in the Netherlands. *Soc Psychiatry Psychiatr Epidemiol* 2002;37:118-24.
12. Sam DL, Berry JW. Acculturative stress among young immigrants in Norway. *Scand J Psychol* 1995;36:10-24.
13. Samarasinghe K, Arvidsson B. 'It is a different war to fight here in Sweden' – the impact of involuntary migration on health of refugee families in transition. *Scand J Caring Sci* 2002;16:292-301.
14. Beaglehole R, Bonita R. *Public health at the crossroads. Achievements and prospects*. Cambridge: Cambridge University Press, 1999.
15. The Acheson Report. *Public health in England: the report of the committee of inquiry into the future development of the public health function*. London: Her Majesty's Stationary Office, 1988:1-3.

16. World Health Organization. Ottawa Charter for Health Promotion. Copenhagen: WHO Europe, 1986.
17. Rose G. The strategy of preventive medicine. Oxford: Oxford University Press, 2000:1-5,107-29.
18. World Health Organization, Regional committee for Europe. Health 21 – the introduction to the health for all policy for the WHO European region. Copenhagen: WHO Europe, 1998.
19. Statistics Finland. http://www.stat.fi/tup/kirjasto_tieto/info_sv.html [May 29, 2007].
20. Statistics Norway. <http://www.ssb.no/> [May 29, 2007].
21. Statistics Sweden. <http://www.scb.se/> [May 29, 2007].
22. Bing V. Små, få och fattiga – om barn och folkhälsa (Small, few and poor – about children and public health). Lund: Studentlitteratur, 2003:233-61.
23. Franzén EC. Att bryta upp och byta land (Breaking up and changing country). Stockholm: Natur och Kultur, 2001.
24. Carballo M, Nerukar A. Migration, refugees and health risks. *Emerg Infect Dis* 2001;7(3Suppl):556-60.
25. Eisenbruch M. From post-traumatic stress disorder to cultural bereavement. Diagnosis of Southeast Asian refugees. In: Van der Geest S, Rienks A (Eds.). *The art of medical anthropology*. Amsterdam: Het Spinhuis Publishers, 1998:251-60.
26. Richman N. Looking before and after: Refugees and asylum seekers in the West. In: Bracken PJ, Petty C (Eds.). *Rethinking the trauma of war*. London: Free Association Books 1998:170-86.
27. Neufeldt V, Guralnik DB (Eds.). *Webster's New World Dictionary of American English*. New York: Prentice Hall, 1994.
28. Guarnaccia PJ, Lopez S. The mental health and adjustment of immigrant and refugee children. *Child Adolesc Psychiatr Clin N AM* 1998;7:537-53.
29. Janson S. Faktorer som påverkar hälsan hos invandrar- och flyktingbarn (Factors influencing the health of children with immigrant and refugee background). *Lakartidningen* 1998;95:1951-5.
30. Keesing RM, Strathern AJ. *Cultural anthropology. A contemporary perspective*. Orlando: Harcourt Brace and Company, 1998:14-25.
31. Hanssen I. Facing differentness. An empirical inquiry into ethical challenges in intercultural nursing. (Doctoral dissertation). Oslo: Institute of Nursing, University of Oslo, 2002.
32. Helman CG. *Culture, health and illness*. Oxford: Butterworth-Heinemann, 2000: 79-91,218-29.
33. Ogden J. *Health Psychology, a textbook*. Buckingham: Open University Press, 2000:13-97.

34. Hjelm K. Migration, health and diabetes mellitus. (Doctoral dissertation). Lund: Department of Medicine, University of Lund, 1998.
35. Svederberg E. Lyhörddhet för tidigare erfarenheter (Responsiveness to previous experiences). In: Svederberg E, Svensson L, Kindeberg T. (Eds.). *Pedagogik i hälsofrämjande arbete (Education in health promotion)*. Lund: Studentlitteratur, 2001:207-31.
36. Wiseman RL. Intercultural communication competence. In: Gudykunst WB (Ed.). *Cross-cultural and intercultural communication*. Thousand Oaks: Sage Publications, 2003:191-208.
37. Dunn AM. Culture competence and the primary health provider. *J Pediatr Health Care* 2002;16:105-11.
38. Lundberg P. Utbildning och träning för interkulturell kommunikativ kompetens (Education and practice in intercultural communicative competence). (Doctoral dissertation). Lund: Department of Social Science, University of Lund, 1991.
39. Chenoweth L, Jeon YH, Goff M, Burke C. Cultural competency and nursing care: an Australian perspective. *Int Nurs Rev* 2006;53:34-40.
40. World Health Organization. Facts related to chronic diseases. <http://www.who.int/dietphysicalactivity/publications/facts/chronic/en/> [May 13, 2004].
41. The Danish National Board of Health. *Kronisk sygdom. Patient, sundhedsvæsen og samfund (Chronic disease. Patient, health services and society)*. Copenhagen: Sundhedsstyrelsen, 2005.
42. World Health Organization. *International migration, health and human rights*. Health and Human Rights Publication Series 2003;4:29.
43. Dyhr L. *Det almene i det anderledes. Belysning af problemer i mødet mellem praktiserende læger og tyrkiske indvandrerkvinder i Danmark, set fra en klinisk synsvinkel (The general in the different. Examining problems in the meeting between general practitioners and Turkish immigrant women in Denmark from a clinical perspective)*. (Ph.d. dissertation). Copenhagen: Department of Social Medicine, University of Copenhagen, 1997.
44. Gujral JS, McNally PG, Botha JL, Burden AC. Childhood-onset diabetes in the white and South Asian population in Leicestershire, UK. *Diabet Med* 1994;11:570-2.
45. Raymond NT, Jones JR, Swift PG, Davies MJ, Lawrence G, McNally PG, Burden ML, Gregory R, Burden AC, Botha JL. Comparative incidence of type 1 diabetes in children aged under 15 years from South Asian and white or other ethnic background in Leicestershire, UK 1989 to 1998. *Diabetologia* 2001;44:B32-6.
46. Staines A, Hanif S, Ahmed S, McKinney PA, Shera S, Bodansky HJ. Incidence of insulin dependent diabetes mellitus in Karachi, Pakistan. *Arch Dis Child* 1997;76:121-3.
47. Feltbower RG, Bodansky HJ, Mckinney PA, Houghton J, Stephenson CR, Haigh D. Trends in the incidence of childhood diabetes in South Asians and other children in Bradford, UK. *Diabet Med* 2002;19:162-6.

48. Povlsen L, Olsen BS, Ladelund S. Diabetes in children and adolescents from ethnic minorities in Denmark – barriers to education, treatment and good metabolic control. *J Adv Nurs* 2005;50:576-82.
49. Swift P (Ed.) *ISPAD Guidelines 2000*. Zeist: Medical Forum International, 2000: 11-20,24-39.
50. Assal JP. Revisiting the approach to treatment of long-term illness: from the acute to the chronic state. A need for educational and managerial skills for long-term follow-up. *Patient Educ Couns* 1999;37:99-111.
51. The Diabetes Control and Complications Trial Research Group. Effects of intensive treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus. *J Pediatr* 1994;125:177-88.
52. Hoey H, Aanstoot HJ, Chiarelli F, Daneman D, Danne T, Dorchy H, Fitzgerald M, Garandeau P, Greene S, Holl R, Hougaard P, Kaprio E, Kocova M, Lynggaard H, Martul P, Matsuura N, McGee HM, Mortensen HB, Robertson K, Schoenle E, Sovik O, Swift P, Tsou RM, Vanelli M, Åman J. Good metabolic control is associated with better quality of life in 2.101 adolescents with type 1 diabetes. *Diabetes Care* 2001; 24:1923-8.
53. Nordly S, Jørgensen T, Andreasen AH, Hermann N, Mortensen HB. Quality of diabetes management in children and adolescents in Denmark. *Diabet Med* 2003; 20:568-74.
54. Funnell MM, Anderson RM, Arnold MS, Barr PA, Donnelly M, Johnson PD, Taylor-Moon D, White NH. Empowerment: An idea whose time has come in diabetes education. *Diabetes Educ* 1991;17:37-41.
55. Dørfler L, Hansen HP. Egenomsorg – en litteraturbaseret udredning af begrebet (Selfcare – a literature based analysis of the concept). Copenhagen: Sundhedsstyrelsen (The National Board of Health), 2005.
56. Leininger M. Selfcare ideology and cultural incongruities: some critical issues. *J Transcult Nurs* 1992;4:2-4.
57. Anderson JM, Wiggins S, Rajwani R, Holbrook A, Blue C, Ng M. Living with a chronic illness: Chinese-Canadian and Euro-Canadian women with diabetes – exploring factors that influence management. *Soc Sci Med* 1995;41:181-95.
58. Seppänen SM, Kyngäs HA, Nikkonen MJ. Coping and social support of parents with a diabetic child. *Nurs Health Sci* 1999;1:63-70.
59. Canam C. Common adaptive tasks facing parents of children with chronic conditions. *J Adv Nurs* 1993;18:46-53.
60. Hentinen M, Kyngäs H. Factors associated with the adaptation of parents with a chronically ill child. *J Clin Nurs* 1998;7:316-24.
61. Lazarus RS. Coping theory and research: past, present and future. *Psychosom Med* 1993;55:234-247.

62. Garwick AW, Kohrman CH, Titus JC, Wolman C, Blum RW. Variations in families' explanations of childhood chronic conditions: A cross-cultural perspective. In: McCubbin HI, Thompson EA, Thompson AI, Futrell JA (Eds.). *The dynamics of resilient families*. Thousand Oaks: Sage Publications, 1999:165-202.
63. Kleinman A. *Patients and healers in the context of culture*. Berkeley: University of California Press, 1980:24-45.
64. Lowes L, Lyne P. Chronic sorrow in parents of children with newly diagnosed diabetes: a review of the literature and discussion of the implications for nursing practice. *J Adv Nurs* 2000;32:41-8.
65. Mæland JG. *Forebyggende helsearbejde i teori og praksis (Preventive health care in theory and practice)*. Oslo: Tano Aschehough, 1999:63-73.
66. Tones K, Tilford S. *Health promotion. Effectiveness, efficiency and equity*. Cheltenham: Nelson Thornes Ltd., 2001:18-73,101-6.
67. WHO. Constitution. http://www.who.int/governance/eb/who_constitution_en.pdf [February 27, 2007].
68. Medin J, Alexanderson K. Begreppen hälsa och hälsofrämjande – en litteraturstudie (The concepts of health and health promotion – a review). *Lund: Studentlitteratur*, 2000:40-50.
69. Antonovsky A. The salutogenic model as a theory to guide health promotion. *Health Promot Int* 1996;11:11-8.
70. Hanson A. *Hälsopromotion i arbetslivet (Health promotion in working life)*. Lund: Studentlitteratur, 2004:107-31.
71. Ekblad S. Inledning (Introduction). *Socialmedicinsk Tidskrift* 2006;3:3-5.
72. Wallerstein N, Bernstein B. Empowerment education: Freire's ideas adapted to health education. *Health Educ Q* 1988;15:379-94.
73. Gibson CH. A concept analysis of empowerment. *J Adv Nurs* 1991;16:354-61.
74. Gabrielsen TS, Mach-Zagal R. *Sundhedspædagogik for praktikere (Health education for practitioners)*. Copenhagen: Munksgaard, 2001:13-24.
75. Lund AB. *Sundhedsformidling (Health promotion)*. In: Kamper-Jørgensen F, Almind G (Eds.). *Forebyggende sundhedsarbejde (Preventive health care)*. Copenhagen: Munksgård, 1998:239-54.
76. Marks DF, Murray M, Evans B, Willig C, Woodall C, Sykes CM. *Health psychology. Theory, research and practice*. London: Sage Publications, 2005:272-90.
77. Fossum B. *Communication in the health service: two examples. (Doctoral dissertation)*. Stockholm: Department of Public Health Science, Division of Social Medicine, Karolinska Institutet, 2003.

78. Egelind S. Patientundervisning (Education of patients). In: Hounsgaard L, Eriksen JJ (Eds.). *Læring i sundhedsvæsenet (Learning in the health services)*. Copenhagen: Gyldendal, 2000:157-70.
79. Vég A. Teaching and learning in type 2 diabetes. The importance of self-perceived roles in disease management. (Doctoral thesis). Uppsala: Department of Medicine, Uppsala University, 2006.
80. Musaeus L. Sygeplejerskens rolle i diabetesomsorgen (The nurse's role in diabetes care). In: Borrild LK, Musaeus L (Eds.). *Sygepleje til mennesker med diabetes (Nursing for people with diabetes)*. Copenhagen: Munksgaard, 2001:40-54.
81. Säljö R. *Læring i praksis: et sociokulturelt perspektiv (Learning in practice: a socio-cultural perspective)*. Copenhagen: Hans Reitzel, 2003.
82. Marton F, Booth S. *Om lärande (About learning)*. Lund: Studentlitteratur, 2002.
83. Dall'Alba G. Reflections on phenomenography – an introduction. In: Dall'Alba G, Hasselgren B (Eds.). *Reflections on phenomenography – towards a methodology?* Göteborg: Acta Universitatis Gothoburgensis, 1996:7-11
84. Willemann M, Hanak ML. Egenomsorg – et særligt perspektiv på forebyggelse og sundhedsfremme (Selfcare – a special perspective on prevention and health promotion). Copenhagen: Sundhedsstyrelsen (The National Board of Health), 2006.
85. Jensen BB. Handlekompetence, sundhedsbegreber og sundhedsviden (Action competence, health concepts and knowledge of health). In: Hounsgaard L, Eriksen JJ (Eds.). *Læring i sundhedsvæsenet (Learning in the health services)*. Copenhagen: Gyldendal, 2000:191-212.
86. Gibson CH. Facilitating critical reflection in mothers of chronically ill children. *J Clin Nurs* 1999;8:305-12.
87. Gallant MH, Beaulieu MC, Carnevale FA. Partnership: an analysis of the concept within the nurse-client relationship. *J Adv Nurs* 2002;40:149-57.
88. Funnell M, Anderson R. Patient empowerment: A look back, a look ahead. *Diabetes Educ* 2003;29:454-62.
89. Lacroix A, Assal JP. Therapeutic education of patients. New approaches to chronic illness. Paris: Maloine, 2003.
90. Wennick A, Hallström I. Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus. An ongoing learning process. *J Fam Nurs* 2006;12:368-89.
91. Atkinson RL, Atkinson RC, Smith EE, Bem DJ, Nolen-Hoeksema S. *Introduction to psychology*. Fort Worth: Harcourt Brace Jovanovich College Publishers, 1993:83-91.
92. Sarkadi A, Rosenqvist U. Study circles at the pharmacy – a new model for diabetes education in groups. *Patient Educ Couns* 1999;37:89-96.

93. Thorne SE, Paterson BL. Health care professional support for selfcare management in chronic illness: insights from diabetes research. *Patient Educ Couns* 2001;42:81-90.
94. Brown SA, Garcia AA, Kouzekanani K, Hanis CL. Culturally competent diabetes self-management education for Mexican Americans. *Diabetes Care* 2002;25:259-68.
95. Chachkes E, Christ G. Cross cultural issues in patient education. *Patient Educ Couns* 1996;27:13-21.
96. Kocken P, Voorham T, Brandsma J, Swart W. Effects of peer-led AIDS education aimed at Turkish and Moroccan male immigrants in The Netherlands. *Eur J Public Health* 2001;11:153-9.
97. Robson C. *Real World Research*. Oxford: Blackwell, 1999.
98. Karlberg I, Hallberg LR-M, Sarvimäki A. Introduction and aims at the book – health, public health and research on public health. In: Hallberg LRM (Ed.). *Qualitative methods in public health research. Theoretical foundations and practical examples*. Lund: Studentlitteratur, 2002:13-31.
99. Kjærgaard J, Mainz J, Jørgensen T, Willaing I. *Kvalitetsudvikling i sundhedsvæsenet (Quality development in the health services)*. Copenhagen: Munksgaard, 2001.
100. Denzin NK, Lincoln YS (Eds.). *Collecting and interpreting qualitative materials*. Thousand Oaks: Sage Publications, 2003.
101. Taylor SJ, Bogdan R. *Introduction to qualitative research methods. A guidebook and resource*. New York: John Wiley & Sons Inc., 1998.
102. Berg BL. *Qualitative research methods for the social sciences*. Boston: Pearson Education International, 2004.
103. Povlsen L. 'Mener du, jeg skal være mit barns læge?' Kronisk sygdom hos børn fra etniske minoriteter i det danske sundhedsvæsen ('Are you saying that I should be my child's doctor?' Chronic disease in children from ethnic minorities in the Danish health services). (Master of Science thesis). Göteborg: The Nordic School of Public Health, 2005.
104. Yin RK. *Case study research: design and methods*. Thousand Oaks: Sage Publications, 2003.
105. Stake RE. *The art of case study research*. Thousand Oaks: Sage Publications, 1995.
106. Sjöström B, Dahlgren LO. Applying phenomenography in nursing research. *J Adv Nurs* 2002;40:339-45.
107. Lepp M, Ringsberg KC. Phenomenography – a qualitative research approach. In: Hallberg LRM (Ed.). *Qualitative methods in public health research. Theoretical foundations and practical examples*. Lund: Studentlitteratur, 2002:105-35.

108. Alexandersson M. Metod och medvetande (Method and consciousness). (Doctoral dissertation). Göteborg: Acta Universitatis Gothoburgensis, Göteborg studies in educational sciences, 1994.
109. Pang MF. Two faces of variation: on continuity in the phenomenographic movement. *Scandinavian Journal of Educational Research* 2003;47:145-56.
110. Sioufi L, Shaltout A. Improving the quality of life of young people with diabetes in Egypt. *Diabetes Voice* 2005;50(2):35-9.
111. Polit DF, Beck CT. *Nursing Research: Principles and methods*. Philadelphia: Lippincott Williams & Wilkins, 2004:375-85.
112. Kvale S. *Interviews. An Introduction to Qualitative Research Interviewing*. Thousand Oaks: Sage Publications, 1996.
113. Bowling A. *Research methods in health. Investigating health and health services*. Buckingham: Open University Press, 2002:394-8.
114. Altman DG. *Practical statistics for medical research*. London: Chapman and Hall, 1991:167-73,179-228,299-321.
115. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 2004;24:105-12.
116. Patton MQ. *Qualitative evaluation and research methods*. Newbury Park: Sage Publications, 1990:186-95,380-9,460-70.
117. Sandelowski M. The problem of rigor in qualitative research. *Adv Nurs Sci* 1986; 8:27-37.
118. Larsson S. Om kvalitetskriterier i kvalitativa studier (Quality criteria in qualitative studies). In: Starrin B, Svensson PG (Eds.). *Kvalitativ metod och vetenskapsteori (Qualitative methods and theory of science)*. Lund: Studentlitteratur, 1994:163-89.
119. Holstein B. Triangulering – metoderedskab og validitetsinstrument (Triangulation – a methodological tool and validation instrument). In: Lunde IM, Ramshøj P. *Humanistisk forskning inden for sundhedsvidenskab (Humanistic research in the health sciences)*. Copenhagen: Akademisk Forlag, 1996:329-38.
120. Mays N, Pope C. Assessing quality in qualitative research. *BMJ* 2000;320:50-2.
121. World Medical Association. The Declaration of Helsinki. 2000. <http://www.wma.net/e/ethicsunit/Helsinki.html> [February 12, 2007].
122. Resnik DB. *The ethics of science: an introduction*. London: Routledge, 2001:14-33.
123. Doucet A, Mauthner N. Knowing responsibly: Linking ethics, research practice and epistemology. In: Mauthner M, Birch M, Jessop J, Miller T. (Eds.). *Ethics in qualitative research*. London: Sage Publications, 2002:123-45.
124. Gillies V, Alldred P. The ethics of intention: Research as a political tool. In: Mauthner M, Birch M, Jessop J, Miller T. (Eds.). *Ethics in qualitative research*. London: Sage Publications, 2002:32-52.

125. Hawthorne K. Effect of culturally appropriate health education on glycaemic control and knowledge of diabetes in British Pakistani women with type 2 diabetes mellitus. *Health Educ Res* 2001;16:373-81.
126. Ford S, Mai F, Manson A, Rukin N, Dunne F. Diabetes knowledge – are patients getting the message? *Int J Clin Pract* 2000;54:535-6.
127. Zarrehparvar M. Den danske sundhedssektor og de etniske minoriteter (The Danish health sector and the ethnic minorities). In: Hanssen I. *Sundhedsarbejde i et flerkulturelt samfund (Health care in a multi-cultural society)*. Copenhagen: Gads Forlag, 2000:225-38.
128. Anderson JM: Speaking of illness: Issues of first generation Canadian women – implications for patient education and counselling. *Patient Educ Couns* 1998;33: 197-207.
129. England R, Doughty K, Genc S, Putkeli Z. Working with refugees: Health education and communication issues in a child health clinic. *Health Educ J* 2003; 62:359-68.
130. Kamath CC, O’Fallon WM, Offord KP, Yawn BP, Bowen JM. Provider satisfaction in clinical encounters with ethnic immigrant patients. *Mayo Clin Proc* 2003;78:1353-60.
131. Hjelm K, Isacson A, Apelqvist J, Sundquist J, Nyberg P. Foreign- and Swedish-born diabetic patients – a population-based study of prevalence, glycaemic control and social position. *Scand J Soc Med* 1996;24:243-52.
132. Gåfväls C, Wändell PE. Coping strategies in immigrant men and women with type 2 diabetes. *Diabetes Res Clin Pract* 2006; Sep 26 [Epub ahead of print].
133. Murphy FG, Satterfield D, Anderson RM, Lyons AE. Diabetes educators as cultural translators. *Diabetes Educ* 1993;19:113-8.
134. Moreno C, Alvarado M, Balcazar H, Lane C, Newman E, Ortiz G, Forrest M. Heart disease education and prevention program targeting immigrant Latinos: Using focus group responses to develop effective interventions. *J Community Health* 1997;22:435-50.
135. Kavuk I, Weimar C, Kim BT, Gueneyli G, Araz M, Klieser E, Limmroth V, Diener HC, Katsarava Z. One-year prevalence and socio-cultural aspects of chronic headache in Turkish immigrants and German natives. *Cephalalgia* 2006; 26:1177-81.
136. Elfert H, Anderson JM, Lai M. Parents’ perceptions of children with chronic illness: a study of immigrant Chinese families. *J Pediatr Nurs* 1991;6:114-20.
137. Dijk RV. Culture as excuse. The failures of health care to migrants in the Netherlands. In: Geest S, Rienks A (Eds.). *The art of medical anthropology*. Amsterdam: Het Spinhuis Publishers, 1998:243-50.
138. Stattin NS. Immigrant patients with diabetes. How they understand, learn to manage and live with their diabetes. (Doctoral dissertation). Uppsala: Department of Medicine, University of Uppsala, 2001.

139. Richt B. Mellan två världar. Om konflikten mellan livets krav og doktors önsknigar (Between two worlds. The conflict between the demands of life and the doctor's wishes). (Doctoral dissertation). Linköping: Department of Health and Society, University of Linköping, 1991.
140. Scherman MH. Att vägra vara sjuk. En longitudinell studie av förhållningssätt till astma/allergi (Refusing to be ill. A longitudinal study of attitudes to asthma/allergy). (Doctoral dissertation). Gothenburg: Department of Educational Sciences, University of Göteborg, 1994.
141. Fagerli RA, Lien ME, Wandel M. Health worker style and trustworthiness as perceived by Pakistani-born persons with type 2 diabetes in Oslo, Norway. *Health* 2007;11:109-29.
142. Eshiett M, Parry E. Migrants and health: a cultural dilemma. *Clin Med* 2003;3: 229-31.
143. Murphy K, Clark JM. Nurses' experiences of caring for ethnic-minority clients. *J Adv Nurs* 1993;18:442-50.
144. Michaelsen JJ, Krasnik A, Nielsen AS, Norredam M, Torres AM. Health professionals' knowledge, attitudes and experiences in relation to immigrant patients: a questionnaire study at a Danish hospital. *Scand J Public Health* 2004; 32:287-95.
145. Sahlsten MJM, Larsson IE, Lindencrona CSC, Plos KAE. Patient participation in nursing care: an interpretation by Swedish registered nurses. *J Clin Nurs* 2005;14: 35-42.
146. Rhodes P, Nocon A. A problem of communication? Diabetes care among Bangladeshi people in Bradford. *Health Soc Care Community* 2003;11:45-54.
147. Rhodes P, Nocon A, Wright J. Access to diabetes services: The experiences of Bangladeshi people in Bradford, UK. *Ethn Health* 2003;8:171-88.
148. Zanchetta MS, Poureslami IM. Health literacy within the reality of immigrants' culture and language. *Can J Public Health* 2006;97:S26-30.
149. Baradaran HR, Knill-Jones RP, Wallia S, Rodgers A. A controlled trial of the effectiveness of a diabetes education programme in a multi-ethnic community in Glasgow. *BMC Public Health* 2006;6:134.
150. Uitewaal PJM, Voorham AJJ, Bruijnzeels MA, Berghout A, Bernsen RMD, Trienekens PH, Hoes AW, Thomas S. No clear effect of diabetes education on glycaemic control for Turkish type 2 diabetes patients: a controlled experiment in general practice. *Neth J Med* 2005;63:428-34.
151. O'Hare JP, Raymond NT, Mughal S, Dodd L, Hanif W, Ahmad Y, Mishra K, Jones A, Kumar S, Szczepura A, Hillhouse EW, Barnett AH. Evaluation of delivery of enhanced diabetes care to patients of South Asian ethnicity: the United Kingdom Asian Diabetes Study (UKADS). *Diabet Med* 2004;21:1357-65.
152. Watts T, Merrell J, Murphy F, Williams A. Breast health information needs of women from minority ethnic groups. *J Adv Nurs* 2004;47:526-35.

153. Rosenqvist U. Diabetes service management training and the need for a patient perspective: a 10-year evolution of training strategies and goals. *Patient Educ Couns* 1995;26:209-13.
154. Clerck M. Diabetes education in Africa: what we need to know. *Diabetes Voice* 2005;50(3),12-4.
155. Östlin P, Eckermann E, Mishra US, Nkowane M, Wallstam E. Gender and health promotion: A multisectorial policy approach. *Health Promot Int* 2006;21(Suppl 1):25-35.
156. Kitzinger J. Focus group research: using group dynamics to explore perceptions, experiences and understandings. In: Holloway I (Ed.). *Qualitative research in health care*. Buckingham: Open University Press, 2005:56-70.
157. Aubel J, Touré I, Diagne M. Senegalese grandmothers promote improved maternal and child nutrition practices: the guardians of tradition are not averse to change. *Soc Sci Med* 2004;59:945-59.
158. Greenhalgh T, Collard A, Begum Noorjahan. Sharing stories: complex intervention for diabetes education in minority ethnic groups who do not speak English. *BMJ* 2005;330:628.
159. Ochieng BMN. Minority ethnic families and family-centred care. *J Child Health Care* 2003;7:123-32.
160. Eng E, Parker E, Harlan C. Lay health advisor intervention strategies: a continuum from natural helping to paraprofessional helping. *Health Educ Behav* 1997;24:413-7.
161. Skovlund S. Diabetes attitudes, wishes and needs. *Diabetes Voice* 2004;49(S):4-11.
162. Sowa H, Crijnen AAM, Bengi-Arslan L, Verhulst FC. Factors associated with problem behaviours in Turkish immigrant children in the Netherlands. *Soc Psychiatry Psychiatr Epidemiol* 2000;35:177-84.

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1983

- 1983:1 Hälsa för alla i Norden år 2000. Föredrag presenterade på en konferens vid Nordiska hälsovårdshögskolan 7–10 september 1982.
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1984

- 1984:1 Långvarigt sjuka barn – sjukvårdens effekter på barn och familj. Andersson, Harwe, Hellberg & Syrén. (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. Märten Lagergren (red).
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1986

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1987

- 1987:1 Children's Health and Well-being in the Nordic Countries. Lennart Köhler & Gunborg Jakobsson. Ingår i serien Clinics in Developmental Medicine, No 98 och distribueras av Blackwell Scientific Publications Ltd, Oxford. ISBN (UK) 0 632 01797X.
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1989

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- 1990**
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- 1991**
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- 1991:2 Health Policy Assessment – Proceedings of an International Workshop in Göteborg, Sweden, February 26 – March 1, 1990. Carl-Gunnar Eriksson (ed). Distributed by Almqvist & Wiksell International, Box 638, SE-101 28 Stockholm.
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Förteckning över NHV-rapporter

1992

- 1992:1 Forskning om psykiatrisk vårdorganisation – ett nordiskt komparativt perspektiv. Mats Brommels, Lars-Olof Ljungberg & Claes-Göran Westin (red). sou 1992:4. Distribueras av Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna förlaget).
- 1992:2 Hepatitis virus and human immunodeficiency virus infection in dental care: occupational risk versus patient care. Flemming Scheutz. Avhandling.
- 1992:3 Att leda vård – utveckling i nordiskt perspektiv. Inga-Maja Rydholm. Distribueras av shstf-material, Box 49023, SE-100 28 Stockholm.
- 1992:4 Aktion mot alkohol och narkotika 1989–1991. Utvärderingsrapport. Athena. Ulla Marklund.
- 1992:5 Abortion from cultural, social and individual aspects. A comparative study, Italy – Sweden. Marianne Bengtsson Agostino. Avhandling.

1993

- 1993:1 Kronisk syke og funksjonshemmede barn. Mot en bedre fremtid? Arvid Heiberg (red). Distribueras av Tano Forlag, Stortorget 10, NO-0155 Oslo.
- 1993:2 3 Nordiske Konference om Sundhedsfremme i Aalborg 13 – 16 september 1992. Carl-Gunnar Eriksson (red).
- 1993:3 Reumatikernas situation i Norden. Kartläggning och rapport från en konferens på Nordiska hälsovårdshögskolan 9 – 10 november 1992. Bjarne Jansson & Dag S. Thelle (red).
- 1993:4 Peace, Health and Development. A Nobel seminar held in Göteborg, Sweden, December 5, 1991. Jointly organized by the Nordic School of Public Health and the University of Göteborg with financial support from SAREC. Lennart Köhler & Lars-Åke Hansson (eds).
- 1993:5 Hälsopolitiska jämlikhetsmål. Diskussionsunderlag utarbetat av WHOs regionkontor för Europa i Köpenhamn. Göran Dahlgren & Margret Whitehead. Distribueras gratis.

1994

- 1994:1 Innovation in Primary Health Care of Elderly People in Denmark. – Two Action Research Projects. Lis Wagner. Avhandling.
- 1994:2 Psychological stress and coping in hospitalized chronically ill elderly. Mary Kalfoss. Avhandling.
- 1994:3 The Essence of Existence. On the Quality of Life of Children in the Nordic countries. Theory and Practice. Bengt Lindström. Avhandling.

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1995

- 1995:1 Psykiatrisk sykepleie i et folkehelseperspektiv. En studie av hvordan en holistisk-eksistensiell psykiatrisk sykepleiemodell bidrar til folkehelsearbeid. Jan Kåre Hummelvoll. Avhandling.
- 1995:2 Child Health in a Swedish City – Mortality and birth weight as indicators of health and social inequality. Håkan Elmén. Avhandling.
- 1995:3 Forebyggende arbeid for eldre – om screening, funn, kostnader og opplevd verdi. Grethe Johansen. Avhandling.
- 1995:4 Clinical Nursing Supervision in Health Care. Elisabeth Severinsson. Avhandling.
- 1995:5 Prioriteringsarbeid inom hälso- och sjukvården i Sverige och i andra länder. Stefan Holmström & Johan Calltorp. Sprit 1995. Distribueras av Spris förlag, Box 70487, SE-107 26 Stockholm.

1996

- 1996:1 Socialt stöd, livskontroll och hälsa. Raili Peltonen. Socialpolitiska institutionen, Åbo Akademi, Åbo, 1996.
- 1996:2 Recurrent Pains – A Public Health Concern in School – Age Children. An Investigation of Headache, Stomach Pain and Back Pain. Guðrún Kristjánsdóttir. Avhandling.
- 1996:3 AIDS and the Grassroots. Frants Staugård, David Pitt & Claudia Cabrera (red).
- 1996:4 Postgraduate public health training in the Nordic countries. Proceedings of seminar held at The Nordic School of Public Health, Göteborg, January 11 – 12, 1996.

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).
- 1997:3 Edgar Borgenhammar – 65 år. Bengt Rosengren & Hans Wedel (red).

1998

- 1998:1 Protection and Promotion of Children's Health – experiences from the East and the West. Yimin Wang & Lennart Köhler (eds).
- 1998:2 EU and Public Health. Future effects on policy, teaching and research. Lennart Köhler & Keith Barnard (eds) 1998:3 Gender and Tuberculosis. Vinod K. Diwan, Anna Thorson, Anna Winkvist (eds)

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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.
- 1999:3 Learning about health: The pupils' and the school health nurses' assessment of 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. Kristján Sigurdsson. DrPH-avhandling.

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. DrPH-avhandling.
- 2000:4 ASPHER Peer Review 1999. Review Team: Jacques Bury, ASPHER, Franco 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.

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- 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.
- 2001:5 Protection – Prevention – Promotion. The development and future of Child Health Services. Proceedings from a conference. Lennart Köhler, Gunnar Norvenius, Jan Johansson, Göran Wennergren (eds).
- 2001:6 Ett pionjärarbete för ensamvargar
Enkät- och intervjuundersökning av nordiska folkhälsodoktorer examinerade vid Nordiska hälsovårdshögskolan under åren 1987 – 2000.
Lillemor Hallberg (red).

2002

- 2002:1 Attitudes to prioritisation in health services. The views of citizens, patients, health care politicians, personnel, and administrators. Per Rosén. DrPH-avhandling.
- 2002:2 Getting to cooperation: Conflict and conflict management in a Norwegian hospital. Morten Skjørshammer. DrPH-avhandling.
- 2002:3 Annual Research Report 2001. Lillemor Hallberg (ed).
- 2002:4 Health sector reforms: What about Hospitals? Pär Eriksson, Ingvar Karlberg, Vinod Diwan (ed).

2003

- 2003:1 Kvalitetsmåling i Sundhedsvæsenet.
Rapport fra Nordisk Ministerråds Arbejdsgruppe.
- 2003:3 NHV 50 år (Festboken)
- 2003:4 Pain, Coping and Well-Being in Children with Chronic Arthritis.
Christina Sällfors. DrPH-avhandling.
- 2003:5 A Grounded Theory of Dental Treatments and Oral Health Related Quality of Life.
Ulrika Trulsson. DrPH-avhandling.

2004

- 2004:1 Brimhealth 1993-2003
- 2004:2 Experienced quality of the intimate relationship in first-time parents – qualitative and quantitative studies. Tone Ahlborg. DrPH-avhandling.

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2005

- 2005:1 Kärlek och Hälsa – Par-behandling i ett folkhälsoperspektiv.
Ann-Marie Lundblad. DrPH-avhandling.
- 2005:2 1990 - 2000:A Decade of Health Sector Reform in Developing Countries
- Why, and What Did we Learn?
Erik Blas. DrPH-avhandling
- 2005:3 Socio-economic Status and Health in Women
Population-based studies with emphasis on lifestyle and cardiovascular disease
Claudia Cabrera. DrPH-avhandling

2006

- 2006:1 "Säker Vård -patientskador, rapportering och prevention"
Synnöve Ödegård. DrPH-avhandling
- 2006:2 Interprofessional Collaboration in Residential Childcare
Elisabeth Willumsen. DrPH-avhandling
- 2006:3 Innkøst-CTG: En vurdering av testens prediktive verdier, reliabilitet og
effekt. Betydning for jordmødre i deres daglige arbeide
Ellen Blix. DrPH-avhandling

2007

- 2007:1 Health reforms in Estonia - acceptability, satisfaction and impact
Kaja Põlluste. DrPH-avhandling
- 2007:2 Creating Integrated Health Care
Bengt Åhgren. DrPH-avhandling
- 2007:3 Alkoholbruk i tilknytning til arbeid – Ein kvalitativ studie i eit folkehelsevitskapeleg
perspektiv
Hildegunn Sagvaag. DrPH-avhandling
- 2007:4 Public Health Aspects of Pharmaceutical Prescription Patterns – Exemplified by
Treatments for Prevention of Cardiovascular Disease
Louise Silwer. DrPH-avhandling
- 2007:5 Å fremme den eldre sykehuspasientens helse I lys av et folkehelse og holistisk-
eksistensielt sykeleieperspektiv
Geir V Berg. DrPH-avhandling

2008

- 2008:1 Diabetes in children and adolescents from non-western immigrant families –
health education, support and collaboration
Lene Povlsen. DrPH-avhandling