

Living with diabetes during transition to adult life

- Relationships, support of self-management, diabetes control and diabetes care

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ABSTRACT

The overall aim of the thesis was to illuminate main concerns related to the transition of adolescents/emerging adults with Type 1 diabetes to adult life and diabetes care and to gain a deeper understanding of how care providers, patients and their parents handle this situation.

In paper I and II, participant observations of visits to physicians, nurses and group sessions (n=51) were conducted in two paediatric (PDC) and two adult (ADC) diabetes clinics as well as interviews with care providers (n=10). Focus was to explore the care culture in the settings and its implications for care of and how care providers handle the transition in relation to adolescent needs. In paper III, 104 emerging adults were followed (18-24 years) through record audit in order to explore glycemic control and its relation to diabetes care utilization. In paper IV, interviews with young adults (n=13) and parents (n=13) were conducted to explore the meaning of interactions with and support of self-management from parents and other significant others. Internet communication between youths with diabetes was also included in the analysis. Qualitative studies (I, II, IV) were analyzed with using a constant comparative method. In paper III, parametric and non-parametric statistical methods were used and a generalized linear mixed model was used for the longitudinal data analyses.

This thesis shows that differing care culture in paediatric and adult diabetes care has implications for care providers, emerging adults and their parents' experiences of caring relationships, and diabetes care. While youths are receiving multidimensional support in paediatric care, they become less visible after transition to adult care due to differences in structural and organisational conditions and strategies. The frequency of visits declined from time in PDC to ADC and females visited ADC more than males. The glycemic control was poor during the whole study period where both males and females exceeded the recommended level. HbA_{1c} levels decreased significantly over time for females but not for males. Findings indicate that more visits in ADC are associated with worse glycemic control. The preparation phase and the transition process were facilitated in the clinic with special transition strategies where logistic problems such as lost referral letters could be prevented. Mutual understanding between care providers can be created in professional meetings which also enables integration of care. The transition to adult life for emerging adults with diabetes was found to be characterized by a relational and reflective process involving reconstruction of supportive relationships with care providers and significant others and a re-consideration of the self. This interactional process implies that an ongoing redefinition of relationships and identity occurs during the transition. In conclusion, the findings reveal that individual trust is hindered by an unsettled relationship to the new care provider and institutional trust by declining accessibility and less continuous care. Interventions at an organizational as well as individual level are required in order to meet the needs of emerging adults with diabetes in a life phase characterized by changing conditions. Patterns of diabetes care utilization are important to take into account and more forums for professional meetings might enable integration of paediatric and adult diabetes care.

Keywords; adolescents, young adults, type 1 diabetes, paediatric diabetes care, adult diabetes care, diabetes care utilization, transition, glycemic control, grounded theory.

ORIGINAL PAPERS

This thesis is based on following papers which will be referred to in the text by their Roman numerals:

- I. Sparud Lundin, C. Öhrn, I & Danielson, E (2008). From multi-dimensional support to decreasing visibility: a field study on care culture in paediatric and adult diabetes outpatient clinics. *International Journal of Nursing Studies* 45 (2), 180-190.
- II. Sparud Lundin, C. Danielson, E & Öhrn, I (2007). Handling the transition of adolescents with diabetes: participant observations and interviews with care providers in paediatric and adult diabetes outpatient clinics. *Journal of Integrated Care* 7 (15), 1-10.
- III. Sparud Lundin, C. Öhrn, I. Danielson, E & Forsander, G. Glycemic control and diabetes care utilization in young adults with Type 1 diabetes. (*Resubmitted for publication*).
- IV. Sparud Lundin, C. Öhrn, I & Danielson, E. Redefining relationships and identity in emerging adults with type 1 diabetes (*Submitted for publication*).

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ABBREVIATIONS

ADA	American Diabetes Association
ADC	Adult Diabetes Care
CAQDAS	Computer Assisted Qualitative Data Analysis Software
DCCT	Diabetes Control and Complication Trial
DKA	Diabetes Keto Acidosis
GT	Grounded theory
HbA _{1c}	Glycosated haemoglobin (outcome measure for glucose control)
IDF	International Diabetes Federation
ISPAD	International Society for Paediatric and Adolescent Diabetes
NVivo	Software for CAQDAS
PDC	Paediatric Diabetes Care
SMBG	Self-Monitoring of Blood Glucose
SVD	St Vincent Declaration
WHO	World Health Organisation

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INTRODUCTION

The focus of the present thesis is to shed light on a complex phenomenon; conditions and experiences of relationships, self-management and control of emerging adults during the transition to adult life and diabetes care. Becoming an adult with associated demands and future prospects can be a challenge for everyone. For adolescents on their way to adulthood, living with diabetes, this process can be even harder, considering the demands of taking responsibility for one's own treatment and self-care in order to avoid feared consequences. As a growing number of adolescents will experience this transition, there is a need for a deeper understanding of this phenomenon.

The relationship between glucose control and diabetes complications was proved by the Diabetes Control and Complication Trial (DCCT) (DCCT 1993; 1994; 1996) and led to recommendations to lower target glucose levels (Silverstein et al. 2005). Glycemic control is known to become worse during adolescence and several studies have shown poor diabetes outcome in terms of glycemic control and development of long term complications as retinopathy and nephropathy (Bryden et al., 2001; Bryden et al. 2003; Wills et al. 2003). Special consideration regarding care of adolescents and recommendations for target values has therefore been stated by the American Diabetes Association (ADA) and the International Society for Paediatric and Adolescent Diabetes (ISPAD) among others.

The transition to adult care during adolescence is a complex issue, which can be related to similar problems within different kinds of patient groups. Studies have shown that one of the important barriers to successful transitions are the health care systems themselves (Scal et al. 1999; Lausch & Reincke 2004). Rasmussen, Wellard & Nankervis (2001) examined which strategies people with diabetes used to access health services and the barriers they perceived. Three main barriers emerged in the interviews one of which was transition from adolescence to adulthood. Falling outside primary focus for both paediatric and adult diabetes care, the transitional phase of emerging adulthood has not been extensively explored regarding diabetes education and experiences of care (Weissberg-Benchell, Wolpert, & Anderson 2007). At the same time, this is a vulnerable time in life as many of the patterns of self-care behaviour are set (Reiss & Gibson 2002) which coincides with a struggle for independence from adults (especially parents). Few empirical studies have directed focus on family support during emerging adulthood in which primary attachment is also transferred from parents (and siblings) to other significant others such as friends and potential life partners. These significant others might play an important role in supporting self-management which requires their involvement in educational opportunities in diabetes care or elsewhere (Anderson & Wolpert 2004).

In paediatric and adult diabetes teams, several professions are involved in the care of these young people and increased knowledge can contribute to improvement of conditions for care at an organisational level and to promote caring relationships between care providers, youths and significant others. In the following section, issues related to living with diabetes from health-illness, disease, developmental and transitional aspects will be presented. Concepts with relevance for the overall aim of this thesis will be dealt with in each section and in relation to the state of knowledge.

BACKGROUND

Insulin-dependent diabetes in young people

Diabetes mellitus is a group of conditions characterized by chronic hyperglycaemia due to defects in insulin secretion, insulin action, or both. The deficient action of insulin on target tissues is related to abnormalities in carbohydrate, fat, and protein metabolism (ISPAD 2006). There are essential differences between the varying types of diabetes, but in the present thesis the focus is to describe, study and discuss the dominating type among children, adolescents and young adults; diabetes mellitus Type 1. Henceforth the term diabetes is used with this meaning.

The prevalence of diabetes in Sweden is about 14/100000 in the whole population, which implies that 0,5 % suffer from Diabetes mellitus Type 1 (Dahlquist & Mustonen 2000). In 2006, about 770 children (0-18 years) in Sweden got diabetes (SWEDIABKIDS 2006). Similar to other countries worldwide, the incidence seems to have increased over time (Onkamo et al. 1999) with the highest incidence among European countries in Finland and Sweden (EURODIAB ACE 2000). However, Pundziute-Lycka et al. (2002) did not find increasing incidence in the age group 0-34 but a shift to a younger age at diagnosis. The incidence is nearly the same for both sexes during childhood although gender differences in incidence are found in some populations (ISPAD 2006).

Main goals for treatment

The International Federation of Diabetes (IDF) accepted the Saint Vincent Declaration (SVD) in 1989, whose general objectives are to increase health condition, enable a longer life and higher quality of life for people with diabetes in all ages (ISPAD 2006). The overall aim is to prevent prevalence of acute (hypoglycaemia and ketoacidosis) and late onset complications related to diabetes; retinopathy, nephropathy and neuropathy. During the 1990s, results from the DCCT studies proved that by maintaining as near normal blood glucose levels as possible, complications could be

prevented or the development of them slower (DCCT 1993; 1994). Glycemic control is mainly evaluated by HbA_{1c} and glycemic goal for adults in general is < 7 % (ADA 2006) while the ideal target for adolescents is recommended to be < 7.5% due to the risk of increased frequency of hypoglycemia (Silverstein et al. 2005). In Sweden the Society for Diabetology has set HbA_{1c} target at 6% (Mono-S method) which is comparable to a DCCT value of 7%.

The poor diabetes outcome in adolescents and emerging adults has been reported in several studies regarding glycemic control, with higher levels of HbA_{1c} during this period than any other time (Allen et al. 2001; Bryden et al. 2001; Bryden et al. 2003; Wills et al. 2003) and Bryden et al. (2001) found a peak at the age of 18-19. The most common acute complication of type 1 diabetes is hypoglycemia which is categorized according to its severity. Mild hypoglycemia is associated with milder adrenergic, cholinergic symptoms system while moderate requires assistance to administer treatment orally. Severe hypoglycemia is associated with differing states of consciousness and requires treatment with glucagon or glucose injection (Silverstein et al. 2005). Several studies have found intensive insulin management and self-monitoring of blood glucose (SMBG) to predict hypoglycemia (DCCT 1997; Allen et al. 2001). Ketoacidosis (DKA) means insulin deficiency resulting in hyperglycemia and accumulation of ketone bodies in the blood and is also categorised to the degree of severity (mild, moderate and severe). DKA is potentially life-threatening where the risk for mortality and morbidity is higher in the severe form (Silverstein et al. 2005). Intensive insulin management also reduces the risk of long term micro vascular complications such as retinopathy and nephropathy (White et al. 2001). Development of micro vascular complications such as retinopathy is related to diabetes duration which is why the frequency of early stages of retinopathy (i.e. simplex retinopathy) is rising during adolescence and emerging adulthood while more severe complications are rare (Henricsson et al. 2003; Mohsin et al. 2005).

The cornerstones for effective treatment of diabetes are insulin, dietary restrictions and physical activity. The co-ordination of these essential parts of the treatment, are a complicated and responsible task, initiated and supported by care providers, but accomplished by the patient himself and with support from relatives. Recommended insulin therapy is a basal-bolus insulin regimen with either multiple daily insulin injections or insulin pump. All basal/bolus diabetes management regimens rely on frequent SMBG and the effect of treatment is evaluated by performing such. The overall goal for diabetes care is that patients will be able to manage their diabetes by themselves. Thus, it is of great importance that patients and their relatives have been offered proper diabetes education so adjustments can be performed according to insulin, diet and physical activity regimen (Silverstein et al. 2005; ADA 2006).

In between childhood and adulthood

In this thesis we have to use both adolescence (in the late sense) and emerging adults as the studies overlap both periods. The literature is not consistent in regards to this and it can sometimes seem confusing with differing terms. Sometimes the terms youths or young people is used, including our target groups of adolescents/emerging adults. Adolescence is the period between 12-19 years, sometimes also divided into early adolescence (12-15 years) and late adolescence (16-19 years) (Silverstein et al. 2005). Young adulthood has in traditional developmental psychology extended the period between 18(19)-30 years (Erikson 1968) also sometimes divided into two phases, an early phase between 18-22 years and a later between 23-30 years (Keniston 1971; Levinson 1978; Arnett 2000). A new, contemporary theory of development is proposed by Arnett (2000) extending the period from 18-25 years and differs distinctively from adolescence and young adulthood with regard to demographics features, subjective experience and identity explorations. Young people develop their identity by exploring and experiencing different love relationships and different educational and work possibilities during a longer period before they commit themselves to long-term choices. During these years, an independent exploration of possibilities in life becomes greater than any other time (Arnett 2002). Arnett labels this period in life as *emerging adulthood*, characterised by less dependency on adults but still having not yet applied to the responsibilities, traditionally normative for adulthood. Emerging adulthood is culturally related to industrialized, developing countries and urban areas and a consequence of sweeping demographic changes, allowing young people a longer period of exploring an independent role (Arnett 2000). Studies in the American society have showed that the majority of emerging adults disagree that they have reached full adulthood (Arnett 1997) and these studies have been affirmed also in European populations (Buhl 2007).

There are pure physiological differences in growing up with diabetes. The need for insulin increases when the body grows rapidly, such as in puberty, and decreases during adolescence. Therefore, it is essential to adjust the insulin regimen according to these changes (Silverstein et al. 2005). Insulin resistance increases in both sexes during puberty, resulting in increased insulin secretion in healthy individuals. Growth hormone secretion increases more in girls than in boys and as girls of all pubertal stages have a higher body fat mass, the insulin resistance is higher (Travers et al. 1995) and insulin action is less effective in girls with diabetes compared to boys (Arslanian et al. 1991). Adolescent girls with diabetes have disturbances in the growth hormone system irrespective of the glycemic control (Halldin et al. 1998).

Additionally, the glycemic control can also decrease during puberty, due to developmental psychological and psychosocial factors (NSF 2001; Silverstein et al. 2005). Several developmental psychological demands are placed on the youth during late adolescence/emerging adulthood; leaving the origin family, developing intimate

relationships with other people, outside the family (including attitude to his/her sexuality) and becoming responsible for his /her financial situation (balancing economy, plans for the future regarding studies and/or occupation) (Roisman et al. 2004; Silverstein et al. 2005). A recent study found that emerging adults with diabetes are as psychosocially mature regarding responsibility and independence as their age-matched peers (Pacaud et al. 2007).

A fundamental behaviour during puberty and adolescence is risk-taking, which implies experimenting with adult behaviour such as alcohol and tobacco usage. These behaviours are more harmful and perilous for the youth with diabetes than for other teenagers, due to both short and long term complications (NSF 2001; Anderson & Wolpert 2004; Silverstein et al. 2005). In the phase of emerging adulthood, youths are often still less receptive to changes due to feelings of invulnerability which has implications for care providers, parents and other supportive relations (Arnett 2000). There is a need to further explore the interaction between developmental tasks in emerging adulthood and the challenges of living with diabetes.

Health, illness and disease

Humans are active beings who attach meanings to and have perceptions of health and illness situations (Meleis et al. 2000). According to the Ottawa Charter for Health Promotion (WHO 1986) individuals or groups must be able to identify and to attain the object of their wishes, to satisfy their needs, and cope with environmental changes in order to reach health, in terms of physical, mental and social wellbeing. Health is not the objective of living but a source for everyday life which emphasizes social, personal resources and physical capacities. Thus, health has to be promoted throughout life in order to ensure that the full benefits are enjoyed in later years. Good health is vital to maintain an acceptable quality of life at all ages and as stated in the definition there is a close relation between health and wellbeing. While illness can be experienced as changes in the state of being, bodily processes and in social function, disease is defined in terms of disorders in bodily structure and functions (Eisenberg 1977; Kleinman 1988). For most people, health care can not be limited to "disease care" which forces care providers to adopt the wider definition of health stated by WHO. Consequently, in order to promote patients' well-being, these concepts, health, illness and disease have to be encompassed by care providers.

For people living with chronic conditions, illness and suffering often intrude all aspects of daily life implying that many ordinary things can no longer be taken for granted. The control over self, identity and situations is threatened leading to uncertainty (Charmaz 1997) which is why experiences of living with chronic illness puts personal beliefs in a different context compared to healthy individuals (Skinner, Hampson, & Fife-Schaw 2002). Adolescents' personal models of illness representations (i.e. beliefs about the efficacy of treatment and seriousness of

diabetes) are important determinants for well-being and self-care (Skinner, John, & Hampson 2000; Law et al. 2002; Skinner et al. 2002). The research is inconsistent regarding the direction of these associations where Skinner et al. (2000) showed that greater perceived seriousness was significantly related to poorer dietary self-care and Glasgow et al. (1997) to better self-care. Girls have been shown to perceive diabetes implying (having) greater influence on their life (Skinner et al. 2000) and psychological adjustment mediates the gender-glycemic control relationship (La Greca et al. 1995).

Self-management and control

As stated previously, self-management is a fundamental part of daily life in living with diabetes. Kyngäs & Hentinen (1995) and Kyngäs (2000) have illuminated the concept compliance in the context of adolescents with diabetes by examining the meaning and conditions attached to compliance with self-care. They conclude from their findings that patients must view the compliance and its goal as meaningful and possible to combine with their lifestyle. This supports previous research and is of great importance for care providers to deal with. However, the concept compliance has been questioned due to the meaning of “following prescribed orders” which is why self-management can imply a more dynamic means of maintaining health (Coates & Boore 1998). Schilling et al. (2002) have performed an evolutionary concept analysis in order to clarify how the concept *self-management* of Type 1 diabetes in children and adolescents has been used and changed over time in different scientific areas. They agree with the previous notion that self-management describes the complexity of living with diabetes in a better way. They found the following variables repeatedly connected to self-management: age, gender, motivation, cognitive ability, skills and knowledge. After performing a review of definitions they suggested that: “*self-management of type 1 diabetes in children and adolescents is an active, daily and flexible process in which youths and their parents share responsibility and decision-making for achieving disease control, health and well-being through a wide range of illness-related activities*” (Schilling et al. 2002 p. 92). This definition seems to be more comprehensive than earlier stated and can therefore partly serve as a definition of self-management within this project, but with the addition that it includes emerging adults with diabetes as well as significant people other than parents.

Law et al. (2002) have found self-management to be an important predictor of psychological well-being while illness beliefs did not significantly affect diabetes self-management. Cotes and Boore (1998) found perceived control, knowledge and health beliefs to have no demonstrable influence on diabetes self-management. However, one of the outcome measures for self-management in this study was clinic attendance which can be questioned as a reliable representation of self-management.

The concept *control* shall in this project be understood as a way to evaluate diabetes control concerning blood glucose levels mainly in quantitative perspectives (i.e. HbA_{1c}). Other aspects of control are further elaborated in relation to self-management.

Relationships with significant others

Social interactions with other people that contribute to the reflexive project of the self can imply that these people become significant “others” for the individual (Giddens 1991). This can be compared to how Mayeroff (1971) describes an “appropriate other” as someone cared for and who enables me to be complete, creating a better position for further growth. A study by Jacobson et al. (1997) showed no differences in loneliness between young people with diabetes (19-26 years) and a control group. Young people with diabetes had fewer friends but no serious problems in forming social relationships during the transition to young adulthood. The two groups had similar patterns and experiences of close peer relationships although the diabetes group showed a lower level of trust and intimacy within a primary love relationship.

Social support from significant others has been shown to be important for individual success of managing diabetes in daily life (La Greca et al. 1995; Weissberg-Benchell et al. 2007). Diabetes control is promoted in families where parents continue to guide and supervise adolescents in diabetes management (Grey et al. 1998) although it is a challenge to find a suitable level of parental involvement for all involved (Seiffge-Krenke 1998). Several studies have shown conflicts between parents and child to be associated with poorer diabetes control (Wysocki et al. 1992; Anderson 1995). However, Viikinsalo et al. (2005) found that having diabetes did not increase conflicts with parents compared to a comparable group without diabetes (Reisch, Bush, & Nelson 2000). In this study, general conflict issues were examined and not diabetes management related issues which might explain the findings. Moreover, as glycemic control was not measured, no relation between the level of conflict scores and glycemic control could be assessed. Davidson, Penney, Muller et al. (2004) found that relations to parents also can imply a source of stress for teens when they nag, overprotect, worry and lay blame about diabetes self-management issues.

Hanna et al. (2003) have examined the relationship between parental involvement in terms of communication and support, diabetes management responsibility and metabolic control. They found, consistent to previous research; less communication agreement (particularly if the diabetes management implied family conflicts) was related to poorer metabolic control and that parent-adolescent communication affects metabolic control. Furthermore, the adolescents appeared to be less autonomous in their decisions if they received more parental support, which might be negative in the long run. They need to be more independent decision makers by the time they leave home as young adults. However, as long as adolescents live with their parents,

they will be affected by their family's lifestyle and habits, which in turn has an impact on individual self-management of diabetes issues (Öhrn 2000). Kyngäs, Hentinen & Barlow (1998) showed that parental actions perceived by adolescents as motivating or accepting, implied better compliance with self-care. Hence, it is not just the parental support that matters; the kind of support they receive seems to influence as well. These findings are in line with Skinner et al. (2000) who showed that social support, consisting acceptance and emotional support provided by both friends and family, was a predictor for dietary behaviour. Gender differences in support from friends has also been reported, where adolescent girls perceive significantly more support from friends regarding blood glucose testing and emotional support than boys (Bearman & La Greca 2002). The authors conclude that essential for optimal dietary self-care and well-being, the adolescents need to adopt constructive illness representations supported by both family and peer group. This will be much easier if these groups have a lifestyle which complies with the demands of diabetes. In addition, Kyngäs et al. (1998) found a relationship between good compliance among the adolescents and perceiving silent support from their friends while others have not found the support of friends to be related to adherence to diabetes treatment (La Greca et al. 1995; Bearman & La Greca 2002).

Although with some inconsistency, support from significant others appears to influence compliance, well-being and/or glycemic control in young people living with the demands of diabetes. However, this research is mainly conducted in adolescents and does not entail so much knowledge about the support from friends and parents in emerging adulthood.

Care culture

People acting together within a specific context will together learn and create patterns of beliefs, behaviours and actions characterising that particular place. These patterns are social constructions, shaping a culture and can strongly differ between one place to another (Leininger 1985). Edvardsson (2005) claims that the existing conceptual heterogeneity in describing the environmental field in different research traditions contributes to the challenge of describing its aspects and how these aspects affect people. Atmosphere in care settings, place, space, caring culture, enriched, supportive and healing environments are all close concepts in these efforts. The term culture shall here be understood as attitudes, beliefs, patterns of relationships, traditions and the psychosocial context in which work is done as well as how people collaborate in doing it (Menziés 1990; Öhlander 2005).

In acknowledging that there are people who do not apply to the assumptions stated above, my standpoint is that health care settings can represent different care cultures. Öhlander (2005) presents the variety of using culture as a concept with no given sorting principle and that culture can be handled at both individual and group levels.

According to this view, the transition from PDC to ADC can be described as a passage between two care subcultures (different social categories) situated in different contexts within the overall health care context. It is therefore inevitable that there are also many commonalities. However, an important assumption when exploring paediatric and adult care contexts is that children and adults are regarded as having different needs which forces people around them to relate to this in interactions and practices. PDC and ADC culture has been assumed to be constituted of well-defined social categories, specific strategies and the result of these strategies. Culture is used relatively in the meaning that each culture must be assessed on their own premise, but also with a judging ambition when comparing the similarities and differences between two cultures. This way of using the concept can work as an explanation of people's way of thinking and acting in different contexts (Öhlander 2005).

Diabetes outpatient care

Differing care cultures in paediatric and adult diabetes settings have been found in previous studies where adolescents and young adults report differences between the services (Eiser et al. 1993; Pascaud et al. 1996; Lausch & Reincke 2004; Reiss, Gibson, & Walker 2005). Fleming et al. (2002) have in their literature review described PDC as having a family centred, socially orientated and informal mode of service while ADC provides a more individual centred, disease orientated and a formal, direct mode. Another major difference is the role of parents. Many care providers assume youths to be more independent if parents are not present at visits (Visentin, Koch & Kralik 2006). Similar differences have also been found in other areas, such as adolescents with inflammatory bowel disease, (Baldassano et al. 2002) cystic fibrosis (Westwood, Henley, & Willcox 1999) and sickle cell disease (Hauser & Dorn 1999) etc. Even if there are several general similarities due to developmental and psychosocial issues in emerging adulthood, there are also disease-specific aspects to take into account. The differing national (and even regional) conditions and regulations also require research in different countries and/or regions. Moreover, the DIABUDSTUDY2 (2001) demonstrated considerable variation in HbA_{1c} between paediatric centres in a national study and found that after adjustment of factors affecting the individual child's glycemic control other factors must explain the different performance levels of HbA_{1c} between the centres. Their findings showed that clinics with best overall glycemic control provided frequent contact with nurses or physicians, flexible insulin regimen and aimed for almost normal levels for HbA_{1c} and rapid service in case of problems. They speculated that a key factor for achieving good glycemic control might be how care providers utilize resources. A "care ambassador" intervention implying increased number of visits was shown to reduce acute adverse outcomes (hypoglycaemic events and hospital stays) in children between 7-16 years but did not improve glycemic control for the whole group (Svoren et al. 2003). When separating youths with poor control, significant improvement in glycemic control was found in

this group. Hence, these findings suggest that “general” interventions can benefit different groups of patients. The overall result of the intervention here was shown to be cost-effective in the short run but can also be expected to contribute to savings in a longer perspective. Association between better glycemic control and more frequent visits during care in PDC has also been found in other studies (Kaufman, Halvorson, & Carpenter 1999; Nordly et al. 2005). In ADC on the other hand, fewer visits seem to be associated with worse glycemic control (Kipps et al. 2002; Wills et al. 2003; Busse et al. 2007).

The role of diabetes care providers

Although physical care environment is of importance, patients value qualities of care provider’s personal characteristics as more important (Farrant & Watson 2004). Kyngäs et al. (1998) examined how adolescents with diabetes perceived the actions of care providers in relation to compliance with self-care. The findings showed that adolescents referred more to actions of physicians than nurses. The nurses were described as motivating, acting according to physicians’ instructions and routine acting. The authors conclude that motivating actions of both nurses and physicians were perceived as supportive, and the category describing a combination of following routines and acting negligently was representative for the group with poor compliance. These findings are confirmed by Williams, Freedman & Deci (1998) who showed that care providers being perceived as autonomy supportive would predict decreasing HbA_{1c} among adults with diabetes over the 12-month maintenance period and the following 4 months. The author stresses the fact that autonomy support implies a health climate which closely relates to patient centeredness. According to the self-determination theory of human motivation they hypothesized that this autonomy support could have significant influence on diabetics’ autonomous motivation to improve their condition, i.e. glucose control (Williams et al. 1998). However, one could criticize the lacking information on how the intervention (i.e. the autonomous support) was performed during this study. The measure outcomes are well defined and described but not how the self-determination model was applied to promote changes in patients’ autonomy, competence and finally, increased glucose control.

According to adolescents living with chronic illness and their parents, the highest ranked qualities for care providers are honesty, confidentiality, good listening skills and good medical knowledge (Farrant & Watson 2004). A trusting and reciprocal relationship between care provider and family/adolescents/emerging adults plays an important role in their evaluation of satisfaction with care and care provider’s competence. As such a relationship was not experienced after transition to adult medical care, negative aspects of the contacts with care providers was found (Reiss et al. 2005). However, both these studies included youths with a wide range of chronic conditions in which diabetes was one of several.

Transition

Transition is a significant concept in this thesis, embracing a process and a wider concept than transfer, which is more of an event (Department of Health 2006), and even if some authors have used transfer, at least previously, the focus here is not a single event but several processes ongoing simultaneously. Giddens (1991) describes transitions as critical situations and settings, which will influence the life course and the life project. Transitions involve loss and also most often potential gain, and the losses has to be mourned before self-actualisation can proceed. Transition has also been used as a perspective and framework. Transition is considered to be a central concept in the nursing domain where people's perceptions of and how they attach meaning to the situation influence the conditions for transition (Chick & Meleis 1986; Schumacher & Meleis 1994; Meleis et al. 2000). They define transition as a change in health status, ability, roles and denote changes in all human systems. It implies a need to incorporate new skills and knowledge in order to change behaviour which is why a changed definition of self is necessary. This is in line with Kralik et al. (2006) who claim that self-identity is challenged during transitions and requires reorientation or reconstruction of the sense of self. In the context of adolescents with diabetes, different types of transitions occur simultaneously: developmental, changes in health-illness experiences as well as organizational and situational ones. The suggested definition of transition by Blum et al. (1993); "*a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic and medical conditions as they move from child-centred to adult-oriented health care systems*" (Blum et al. 1993 p. 570) has been acknowledged within a wide spectrum of clinical practice/guidelines and research studies (Department of Health 2006). All these definitions have their place in this thesis, complementing each other in organisational and individual aspects according to the different levels of simultaneously ongoing transitions. However, the individual's transitional process of inner re-orientation has to be taken into account in order to fulfil the goal of conducting holistic research and care which is in line with Kralik et al. (2006) and Meleis et al. (1986; 1994).

Transition between diabetes care settings

Insufficient preparation for transition, lack of bridging strategies and no evaluation of transition outcomes have been reported in previous studies (Fleming, Carter & Gillbrand 2002; Reiss, Gibson & Walker 2005; Visentin et al. 2006). Lack of interest in transition issues among adult care providers seems to constitute the main hindrance for developing effective transition health programs (Scal et al. 1999). The transition has to be well planned to enable uninterrupted quality care and diabetes care which can influence glycemetic control (Rosilio et al. 1998; DIABUDSTUDY2 2001). Clinic attendance decreased notably after transition to ADC in the study of Kipps et al. (2002) and low frequency of visits was associated with poor glycemetic control. Some

studies have examined factors related to transition mode (Kipps et al. 2002) and clinic attendance rates (Kipps et al. 2002; Wills et al. 2003; Busse et al. 2007) but the relationship between diabetes care variables and glycaemic control has been less explored. The appropriate time for transition has been debated and in a recent study the mean transition age was 17.8 years (Busse et al. 2007) while Kipps et al. (2002) reported a great variation in transition age between districts (mean 16.3-19.2).

Different ways to overcome this identified problem has been presented in the literature. Kipps et al. (2002) describe four slightly different modes of transfer methods. Some methods include introduction of adult physician or joint visits before the transfer from PDC to ADC. Several authors emphasize that one way to increase transition outcomes is to organize special "young adult clinics", in order to bridge the gap between two parts in the diabetes care systems (Betts, Jefferson, & Swift 2002; Kipps et al. 2002; Rasmussen et al. 2001). Although Kipps et al. (2002) advocate young adult clinics and conclude that transfer mode is of greater importance than the age when it occurs, it will not solve all problems related to this issue. Emerging adults could benefit from being provided care with specialist knowledge based in paediatric and adult diabetes care as well as awareness of developmental psychology (Dovey-Pearce et al. 2005).

What remains to explore?

It is not easy to summarize what we already know about emerging adults' transition to adult life in living with diabetes. The most crucial reason is the vague distinction related to age classification, i.e. adolescents versus adults. The main problem is that much of the research is conducted in either paediatric care (adolescents) or adult care (adults > 19 years). Findings in such studies can sometimes, but far from always be transferred to the group of emerging adults, which is a decisive rationale for this thesis. The vulnerability characterising this period regarding glycaemic control and a sometimes reduced motivation for constructive self-management of diabetes contributes to a challenging time for the youth, their family and friends and not least for diabetes care providers. The literature review has revealed that there still remain a lot of questions on how to best support emerging adults with diabetes during several simultaneously ongoing transitions. However, the past decade's increased focus on the needs of adolescents and health care transitions have entailed a growing body of knowledge. Several countries have recently worked out ambitious policy statements, standards and guidelines. The recommendations in these standards and guidelines are based on best available evidence, in most cases as a result of conducted research and sometimes based on clinical expertise. Different countries, or regions within a country, also have such disparities concerning financial and organisational conditions for diabetes care which makes generalisations difficult. It is also important to follow changes in transition strategies over time as new problems

can arise when the old ones seems to be solved. A limited amount of qualitative research studies concerning adolescent care and health care transitions have been reported of which a few have examined diabetes mellitus exclusively. Thus, following issues still needs to be further explored:

- Implications of differences in the diabetes care system in relation to adolescents/ emerging adults needs
- Factors enabling and hindering transition conditions, experiences and outcome
- Relationship between diabetes care variables and glycemic control during the overlapping period of adolescence and emerging adulthood
- How emerging adults with diabetes experience and handle transition issues
- In what way significant others support self-management during emerging adulthood.

AIMS

The overall aim of this thesis was to illuminate main concerns related to the transition of adolescents/ emerging adults with type 1 diabetes to adult life and adult diabetes care and to gain a deeper understanding of how care providers, patients and their parents handle this situation.

The overall aim was investigated in four separate studies with specific aims:

Paper I

The aim was to describe care culture in paediatric and adult diabetes outpatient clinics and implications for care of adolescents in those settings.

Paper II

The aim was to explore how care providers handle the transition process from paediatric to adult diabetes outpatient clinic and to describe their perception of adolescents' needs during this process.

Paper III

The aim was to explore during the transition to adult diabetes care and for several subsequent years: 1) How glycemic control in young adults is related to diabetes care utilization; 2) If those variables differ between males and females.

Paper IV

The aim was to explore the meaning of interactions with and support of self-management from parents, care providers and other significant others for emerging adults with type I diabetes during the transition to adult life and care.

THEORETICAL AND METHODOLOGICAL VIEWPOINTS

The phenomenon under investigation has been the transitional phase when young people are supposed to become “grown-ups” and take more responsibility for their own health related issues although still in need of support from significant others. The transition has thereby been illuminated from the perspectives of adolescents /emerging adults, their parents and care providers in both paediatric and adult diabetes care. It was necessary to include all these perspectives in order to clarify how meaning is created in this interaction process. With this background, it became natural to apply a theoretical base which has its focus on interaction and using research methods congruent with such theoretical assumptions.

Caring

The present thesis has its foundation in the discipline of caring sciences which is based on the humanistic science. Human beings are considered as wholes and human science deals with how meanings are seen and experienced by its members. Focus is caring in relation to people’s needs and problems in daily life and in relation to illness/disease/disability (Meleis, 1985/2007). Caring can be described as a human trait, moral imperative and affect, manifested through emotional feelings of empathy and dedication (Morse et al. 1990; 1991). The essence of caring is the relation, between care providers and patients and their relatives. The American philosopher Mayeroff (1971) points out that building a trustful relationship is central in caring and involves real engagement, commitment and to truly see the other as he/she is and with a humble attitude try to understand the person’s world (Mayeroff 1971). This could be compared with how Leininger (2002) stresses the need for culturally based caring which can only occur if diversities and commonalities regarding values, expressions and patterns are known and used. Caring is also seen as therapeutic interventions (Morse et al. 1990; 1991) i.e. actions and strategies, based on patients’ needs, problems and wishes and how they are planned, accomplished and evaluated in clinical practice. Caring is supposed to lead people to find their place in the world by being “in place” in contrast to be “out of place” (Mayeroff 1971) and care providers have an important role in promoting the other to grow. Although several professions are caring for patients, the nursing discipline is the one most concerned with studying caring attitudes, caring processes and caring relationships (Leininger 1988). Thus, the term nursing relates to profession oriented caring. The intention with this thesis has been to generate clinical as well as theoretical contribution to caring sciences.

Symbolic interactionism

The interpretive tradition and assumptions of symbolic interaction theory conceptualized by George Herbert Mead (1934) and elaborated by Herbert Blumer (1969) is a social-psychological approach that emphasizes the importance of meaning and interpretation as essential human processes. People act according to the meaning that things and situations have for them. They attach meanings to things and situations and respond on the basis of this meaning. The individual interpret and define the situation through reflection and understanding of the others response to his/her actions. Meaning is created in the interaction process among people in the way that one individual's meaning emerges in relation to how other people acts (attach meaning to things). Furthermore, the meanings are redefined and modified through an ongoing interactive process. Even if there is a freedom of choice in people's behaviour, cultural and societal norms affect and constrain this freedom. According to peoples cognitive capacity they can reflect abstractly and learn without experiencing everything by them selves. Through the symbolic use of gestures and language, meanings are created and communicated which implies a common response or a shared meaning, in the interaction with other people. Peoples acting are therefore based on the meaning they individually or collectively have given things and situations. A main assumption of the symbolic interactionism is that individual and context can not be separated. As the social world exists through creation of human interactions, the nature of being is best explored by examining individual interpretation of reality in the social context (Benzies & Allen 2001). In the context of emerging adults with diabetes in transition from childhood to adult life there is, what Mead outlines as; stages of interactive learning by which the individual acquire social understanding.

Grounded theory

Grounded theory methods aims at explore how people handles and understands a phenomenon of interest (Patton 2002). In concordance with the assumption of symbolic interactionism, it was therefore natural to use the latter as the research method for the qualitative studies in this thesis. Grounded theory has developed in different directions since the 1960s when Barney Glaser and Anselm Strauss developed the classic version, which has been widely used in different scientific fields ever since that. They argued for the use of qualitative research as a credible methodological approach on its own and not simply in order to develop instruments as questionnaires etc (Glaser & Strauss 1967). Later on, they went in different directions and developed their own versions of grounded theory. Strauss and Corbin (1998) applied a more pragmatic approach, formulating methodological guidelines and moved the method toward verification and new technical procedures in analyzing data. Charmaz (1995b; 2006) has thereafter presented a constructivist

version of grounded theory with theoretical underpinnings in symbolic interactionism and the pragmatic philosophical tradition. A distinguishing assumption from the classic version is that *"we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices"* (Charmaz 2006 p. 10). This constructivist version of grounded theory with focus on action and meaning has guided the qualitative analyses in this thesis although Strauss & Corbins (1998) guidelines methodologically served the purpose of paper II. Basic principles for GT are data collection simultaneously with analysis in order to direct further data collection; hierarchical coding; constant comparisons of codes, data and emerging categories and memo-writing during all steps. Theoretical sampling aims to saturate categories and to develop properties of elaborated categories in contrast to sample for a representative population. The analysis process can be summarized to involve conceptualizing, searching for patterns and theory generation. Grounded theories may serve different purposes and can either offer a theoretical interpretation or explanation of a delimited problem in a particular area (substantive theory) or a cut across several substantive areas of study (formal theory). Theories can differ regarding their level, precision, generality and applicability theoretically or in clinical practice (Charmaz 2006). According to Charmaz (2006), quality aspects of a GT study is evaluated by assessing the *credibility, originality, resonance* and the *usefulness* of the presented findings. These aspects refer to more traditional quality standards in qualitative research; *trustworthiness* and *transferability* (Malterud 2001).

According to the assumptions of symbolic interactionism, the main focus for this thesis is to shed light on what is of utmost importance for emerging adults, their parents and care providers and how particular interactions give rise to meaning and understanding. And furthermore, how can caring processes and relationships facilitate or hinder personal growth during this transitional process?

MATERIAL AND METHODS

Design

The overall phenomenon under investigation is the transition from adolescence to adult life in relation to diabetes care and living with diabetes. Such a complex research area requires multiple approaches and the design has been descriptive, explorative, comparative and correlational (see Table 1). Referring to each study's research questions, considerations have been taken from a methodological, pragmatic point of view. Accordingly, whenever the purpose was to study the subjective meaning of the transition, i.e. adopting assumptions based in interpretivism, a qualitative method was chosen (**I, II, IV**). Study **III** has a retrospective, longitudinal design with the purpose of examining groups of subjects in various stages of development simultaneously. In this study, correlation between different variables was the objective which is why statistical analysis with assumptions grounded in positivism/post positivism was conducted. This study complemented the three others by contributing with a more general picture of conditions for organisational issues and outcome of diabetes control during the transition. Although theoretical assumptions underlying qualitative and quantitative methods are differing, the benefits include emerging different, sometimes overlapping facets of a phenomenon, in order to understand the complexity of many medical and care related topics (Malterud 2001). Patton (2002) states that it can be fruitful to combine qualitative and quantitative data to elucidate complementary aspects of the same phenomenon. This illustrates a simple and somewhat pragmatic view of using different research methods in order to achieve the overall aim for this thesis.

Settings

Two different hospitals within the same politically and financially managed region were chosen in order to gain variation of conditions and strategies and still make it possible to conduct the studies. One of the hospitals is located in an urban area (clinic A+B) and has a larger amount of patients with a wide scope of nationalities and other demographic conditions. The PDC unit in this hospital has about six different ADC units in the area to refer their patients to when time has come for transition to adult care. The other hospital (clinic C+D) is located in a smaller town with one main referring clinic. Occasionally, both PDC units have to refer patients to ADC units further away and outside the region due to emerging adults shifting occupational and living conditions. Clinical practice of time for transition to adult care was similar in both hospitals. The diabetes teams in all settings were composed of nurses, physicians, dieticians, counsellors/ psychologists and chiropodists (in ADC). The

access to each of these professions differs between the clinics as do organisation of the visits. Diabetes nurses and physicians constitute the basis of diabetes care, which is why such visits were chosen as the main focus when collecting data. The involvement of other professionals is therefore only described through the participating nurses and physicians or by following patients' contacts with other members of the team. In Table 1 an overview of the clinics participation in the different studies is outlined.

Table 1 Research design overview.

Paper	I-II	III	IV
Design	Explorative, comparative, descriptive	Retrospective, longitudinal, correlational	Explorative, descriptive
Data Collection	-Participant observations -Formal interviews	Record audit	Intensive interviews Internet communication
Setting	Four different diabetes outpatient clinics, two PDC (A+C) and two ADC (B+D).	One PDC (A) and 6 different ADC	Patients connected to 6 different ADC (and previously treated at PDC A+C)
Participants/data	Participant observations of visits to diabetes nurse / physician and group meetings (n=51) -Formal interviews with care providers (n=10)	Five age groups of young diabetics (n=104) Data collected between 18-24 years age	- Emerging adults with diabetes aged 21-22 (n= 13) - Parents of emerging adults with diabetes (n=13) - Internet communication chats (n= 180)
Inclusion criteria	<u>Participant observations</u> : - Adolescents in PDC - > 15 years of age -Emerging adults in ADC - < 25 years of age <u>Interviews</u> : - Care providers with significant experience of adolescents/emerging adults in diabetes care	-Identifiable record in PDC - Primary referral to ADC in the region	-Time of debut in diabetes before the age of 15 - Able to speak and understand Swedish
Analysis	Constant comparative analysis	Descriptive statistics, inferential, parametric and non-parametric statistical analysis	Constant comparative analysis

Sampling and participants

The whole investigation period for paper I and II extended over seven months during 2004-2005, where each setting was examined during approximately two months. Fifty-one participant observations (Taylor & Bogdan 1998; Roper & Shapira 2000) were carried out by attending the patient visits to the diabetic nurse or physician and four observations of group sessions with patients within the settings. For inclusion criterion of patients visits see Table 1. Patient visits were selected consecutively as they appeared after discussion with care providers in the settings. Observation of patient visits to nearly all employed nurses and physicians in each setting were conducted in order to achieve a variation of encounters between patients and care providers (Table 2).

Table 2 Number of observations and interviews in each setting.

Data collection	PDC (A)	ADC (B)	PDC (C)	ADC (D)
Observations	16	14	11	10
Nurse	8	7	4	6
Physician	7	7	4	2
Nurse+Physician			2	
Other group sessions	1		1	2
Formal interviews	3	2	3*	3*
Nurse	2	1	2*	3*
Physician	1	1	1	

* One nurse works part-time in both PDC and ADC and was asked questions about both settings.

Ten formal semi-structured interviews were also conducted with care providers during time spent in each outpatient clinic (Paper I+II). The participants were chosen according to their experience of diabetes care in relation to adolescents/emerging adults and both nurses and physicians in three of the four settings were interviewed. In one adult setting there was a lack of continuity regarding available employed physicians at the time of data collection due to sick leave, which is why three nurses were chosen instead.

In paper III, data in medical and nursing records of all patients born between 1978-1982 (n=121) was examined for several variables, with starting point one year before common time for transfer (18) and subsequently until the age of 24. The exclusion and inclusion process is shown in Figure 1. According to the medical records, those 18 participants in the last step of the figure were referred to other regions directly after completed care in PDC or later during the follow-up period.

For paper I, II and IV the number of participants/observations were not determined before the study, according to the goal of reaching theoretical saturation which refers to the moment when gathering additional data does not yield any further theoretical insights about the emerging theory (Strauss & Corbin 1998; Charmaz 2006).

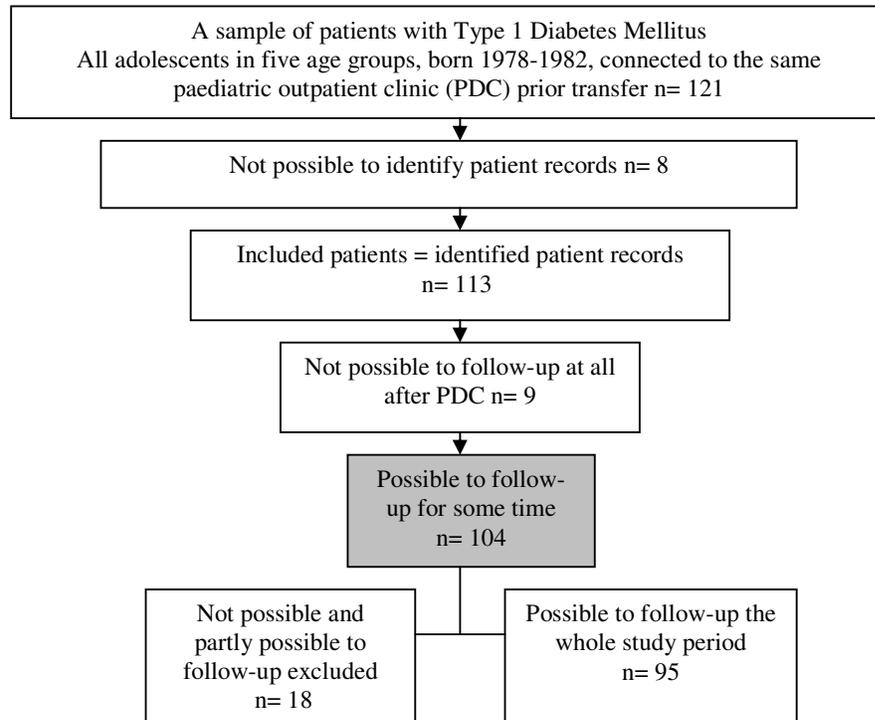


Figure 1 Flowchart of the reduction of individuals when excluding patients not possible to follow-up partly or the whole study period.

In paper IV twenty-six individual interviews with emerging adults and parents were conducted during 2006-2007 in order to examine how they handle and understand support of self-management from and relationships with significant others during transition to adult life and diabetes care. A group of patients born the same year were chosen. Twenty youths and parents (10+10) originally connected to setting A were included and finally an additional six youths and parents (3+3) from setting C. For inclusion criterion see Table 1. Demographic data of participants are shown in Table 3.

Table 3 Demographic information of participants in Paper IV.

Participants (n=26)	Youth (n=13)	Parents (n=13)
Female	7	10
Male	6	3
Occupation		
Student	6	
Employed	7	12
On sick-leave		1
Living conditions		
With parent/parents	6	
Alone	3*	2
Cohabit/married	5*	11

*one girl is living partly alone and partly with her boyfriend due to studying elsewhere

Data collection

Participant observations (I+II)

The foundation for paper I and II lays in the ethnographic tradition. A central assumption in this tradition states that a group of people interacting together evolves a culture (Roper & Shapira 2000). The method for generating data was participant observations in order to explore the care culture by exploring prerequisites for the settings, current care provider strategies and how attitudes and beliefs influence relationships and care. Total observation time was 100 hours, approximately 60 hours of which were visits and group sessions, with the remaining time in waiting room area or together with care providers in relation to planned visits. Focus during observations was directed to events and care providers' actions/ strategies in relation to transitional issues and adolescents/emerging adults' needs. All observations were conducted by CSL who did not participate in the conversation during the visit unless directly addressed by the patients. During other observations, i.e. informal conversations with care providers, patients and parents, the level of participation was higher, by conducting attendant questions in order to explore significant data. Field notes were dictated directly after observations and transcribed later the same or in some cases the following day.

Interviews (I,II,IV)

During observations, care providers with the most significant experience of encounters with adolescents' /emerging adults' were identified. In these formal interviews they were asked to give their view of the youths' needs at time before/after transition (Paper I+II) and current strategies related to the transition process as well as hinders and possibilities related to this process (Paper II). For

distribution of interviews with different professionals see Table 2. After agreement on devoted time to formal interview, these took place in a secluded room at the clinics. The interviews lasted for 30-70 minutes.

In paper **IV** the voice of emerging adults and parents were focused upon by exploring their meaning of supporting relationships in relation to living with diabetes. Information about the study was sent to them by mail and one week later they were asked (by telephone) if they would consider participation in the study, 2 years after transfer to ADC. If they approved, they were called after 1 ½- 2 years, information about the study was repeated and they were then asked again if they were willing to participate. All interviews were conducted separately in the participant's home or at the university. After initial information about the topics, they were asked to freely narrate and reflect on their experiences of: the time of diabetes onset, how they have handled self management and diabetes control issues over time, the meaning of living with diabetes and support from family, friends and care providers in these matters. Follow-up question were posed in order to get more detailed descriptions or explanations. The interviews lasted between 30-75 minutes.

All interviews in study **I**, **II** and **IV** were tape-recorded and transcribed to text. Throughout the whole process, theoretical ideas were formulated and documented in memos which directed the focus of the following observations and interviews.

Internet communication (IV)

In study **IV**, Internet communication between youths with diabetes in a national diabetes website for young people was used as an additional context of social construction. By observing the process of exchanging messages it was possible to explore how complex and transformative understandings of self identity, the other and reality are negotiated (Markham 2004). A total number of 180 chat contributions with 584 reply contributions (range 0-15 /chat contribution), published during 6 months and spread over one year were included (every other month starting in June 2006) were collected through "cut and paste" into the NVivo software for further sorting and analysis together with interview data.

Record audit (III)

In study **III**, a study-protocol was conducted in order to document the following investigation independent variables; age for diabetes onset and transition to ADC, sex, BMI, documented acute complications (Ketoacidosis, Hypoglycemia) and long term complications, diabetes care utilization, diabetes-related diseases, and as a dependent variable; HbA_{1c} (outcome measure for glycemc (disease) control). The data collection started with gathering data from records in PDC (A) and was continued by following each participant to the ADC they had been referred to. Data

was collected by CSL in five of the six outpatient clinics and an employed research nurse collected data according to instructions from the remaining clinic.

Data analysis

Constant comparative method (I,II,IV)

The constant comparative method developed in the grounded theory tradition (Charmaz 1995b, 2006; Strauss & Corbin 1998) has guided the analysis which started during data collection in setting A and B and was carried out simultaneously with remaining data collection in setting C and D (I+II). The first step, open coding was carried out by examining each paragraph of data in order to identify care providers' meaning, events and actions in data, and segmented into smaller units, i.e. codes. The codes were labeled concretely and after comparison similar phenomenon were given the same code-label. Data from interviews were compared with field notes from observations and vice versa. Comparison of similarities and differences between codes were systematically conducted, gradually grouped into potential categories and thereafter cross compared. The recurrent visits to each outpatient clinic made it possible to accomplish systematic checks of generated categories by gathering more data in return visits. In this phase all three authors considered, discussed and revised the categories on a more abstract level and according to their hierarchical order until a consensus were reached. Properties and dimensions of categories were specified and related to each other in order to describe the emerging data pattern by integrating and explaining relationship between categories. Four categories were developed and saturated; describing similar and differing aspects of care culture, and finally one core category was identified which all categories are related to (I). In Paper II, the categories were finally integrated into a framework where causal and intervening conditions and consequences of events, actions and beliefs in the settings and the transition process were sought after and specified. In this phase, the core phenomenon was identified as central to all generated data and generated categories. In paper IV, the initial coding phase was fairly similar; the most significant and/or frequent codes were synthesized in order to explain different parts of the study areas, i.e. interactions with and support of self-management from parents, care providers and other significant others. After a more focused coding, new threads arose and in this phase some former codes shifted in hierarchical order to a higher analytical level (from code to category). The two main categories were first developed and explored to define its properties. Data obtained from internet communication complemented the interview data by developing subcategories to a varying extent within the main categories. In this phase, we tried to challenge our preconceptions and also look for contrasting and unique reflective accounts of meaning, situations and actions among participants and in internet communications. A core category was created when analyzing the theoretical links between subcategories and main categories. An analytic model was finally constructed showing how the categories are related to

each other in the context of living with diabetes during emerging adulthood. The software NVivo (Gibbs 2002) for computerized qualitative data analysis software (CAQDAS) was used in all studies to sort and manage data and memos. Thoughts and reflections after interviews, during initial and further analysis were formulated in memos and linked to documents and categories in the hierarchical tree-structure. Comparing earlier memos and writing new ones in order to develop emerging categories facilitated the analyses in all studies.

Statistical methods (III)

In paper **III**, descriptive statistics were used to describe the sample and occurrence of acute and micro vascular complications. Generalized Linear Mixed Model (Brown & Prescott 2006) was performed in order to determine change in HbA_{1c} and BMI over time. When comparing independent group means with continuous variables, the Mann Whitney U- test (MW) was used to examine statistical significance. For dependent groups in which variables were not normally distributed the Wilcoxon Signed Rank Test was used while the Student's T-test was used where the variables were normally distributed. The Chi-Squared test was chosen when comparing categorical variables. Friedman's test was applied when exploring development over time in variables which were not normally distributed. Pearson's product-moment correlation coefficient was used in the case of linear relationship in order to investigate association between continuous variables. Unless otherwise specified, a p-value below 0.05 was considered to be statistically significant.

Ethical aspects

The Ethics Committee at University of Gothenburg performed a counselling statement (Dnr 381-04) regarding study **I**, **II** and **IV** according to current guidelines. All informants participated voluntary and verbal and informed consent was obtained from all participants in interviews. Verbal consent was obtained from the adolescents / emerging adults / parents visiting the diabetes outpatient clinics just before the visit (study **I-II**) to give them opportunity to decline participation. In similar ways care providers were asked before the patients were introduced.

Written informed consent was obtained from the participants in study **IV**. Care providers in ADC were not aware of the emerging adults' participation in the study as the names were identified in PDC, which encouraged them to speak freely in the interviews as patient-care provider relationship could not be jeopardized. The researcher is not connected to any of the participating clinics, therefore no impact on the relation between patients and care providers can be expected.

A contemporary ethical problem to handle has been the use of internet communication in study **IV** as the chatters could not leave their informed consent in the traditional way. Specific recommendations for using "open access" data are presented by the organisation, Association of Internet Research (2002), which we have tried to follow by using a utilitarian approach. This means weighing risks against benefits and as it is hardly possible for anyone to recognize individuals from the chats (they are even anonymous for the researcher), a decision was made that the risk was minor compared to the potential benefits for others in similar situations. The text was transferred to the CAQDAS software without any nicknames included to further assure confidentiality.

Study **III** was approved by the Ethics Committee at University of Gothenburg (Dnr 639-05). Informed consent was not obtained in this study due to the retrospective, longitudinal design implying risk for large reduction of sample. Specific caution when handling protocols and code lists has therefore been conducted in order to ensure patients' confidentiality. Moreover, data has been analysed on a group level and presented so it is impossible to identify any participant or clinic.

FINDINGS

Conditions for paediatric and adult diabetes care

The findings in Paper I showed shifting aspects of diabetes care culture with both similarities and differences in conditions, attitudes and strategies between PDC and ADC. An *unfocused behaviour* was observed during visits in both care cultures related to interaction disturbing strategies such as using a computer and telephone simultaneously with patient communication. Lack of compliance to patients' statements and needs occurred when care providers did not pay attention to the implicit meaning of the conversation (I).

The differences in characteristics of care culture implied that adolescents with diabetes are provided a *multi-dimensional support* as long as they belong to the paediatric settings regarding higher accessibility in care, a larger extent of complementary resources and an often long continuous contact (I), which is in line with the mean age for diabetes onset in paper III which was 9.6 years (SD 1.28). In ADC, patients appear to be exposed to a *decreasing visibility* in comparison with PDC, according to several concrete structural and organisational conditions and strategies (I). Furthermore, these findings were congruent with significant differences in the number of visits ($p < 0.001$), in PDC mean 3.6 (SD 1.11) and in ADC 2.7 (SD 1.08) found in paper III, where females were shown to visit ADC significantly more often than males ($p=0.04$) with no differences in PDC. Twenty-four percent of the youths changed care provider once or more after transition with no significant differences between males and females (III). Perceptions of discontinuity in care contacts were also expressed by the emerging adults as well as less accessibility and frequency of contacts (IV). Other factors related to the decreased visibility were found to be constituted of a more distant physical environment in ADC; waiting room not located in direct connection with the reception; strategies implying less contact with care providers as more formal ways to follow-up cancelled visits increasing the risk for unawareness of poor clinic attendance; taking blood tests at the laboratory instead of in relation to visits (I).

With the adolescent's growing independence, parents' presence and participation in care decreases during the last years in PDC. Parents can still be "present" when care providers relate to family issues as family members are often known to them even if they do not take part in the visit physically. The absence of the parental participation in ADC makes the family unfamiliar to care providers and can in this way be conducive to a decreasing visibility (I). Parents experience the declining involvement in visits differently; some youths refuse to allow their parents to join them at visits in ADC while others still want them present, which are rarely occurring in ADC. Mothers in particular miss the former insight into current strategies and responses to

diabetes control. To contact care providers they have never met does not feel natural for them why some of them express a need of being updated afterwards (IV).

The glyceemic control was shown to be poor during the whole study period in both males and females (Figure 2) where they all exceeded the recommended level for their age (HbA_{1c} <19 years = < 7.5%; >19 years = < 7%). HbA_{1c} levels decreased significantly over time for females ($p= 0.014$) but not for males and a higher level of mean HbA_{1c} among females in PDC (mean=9.24, SD=1.54) compared to males (mean=8.88, SD=13.8, $p=0.046$) but no difference in ADC ($p=0.550$). The findings indicate that more visits in ADC were associated with higher HbA_{1c} i.e. worse glyceemic control ($p=0.005$) in both sexes (III).

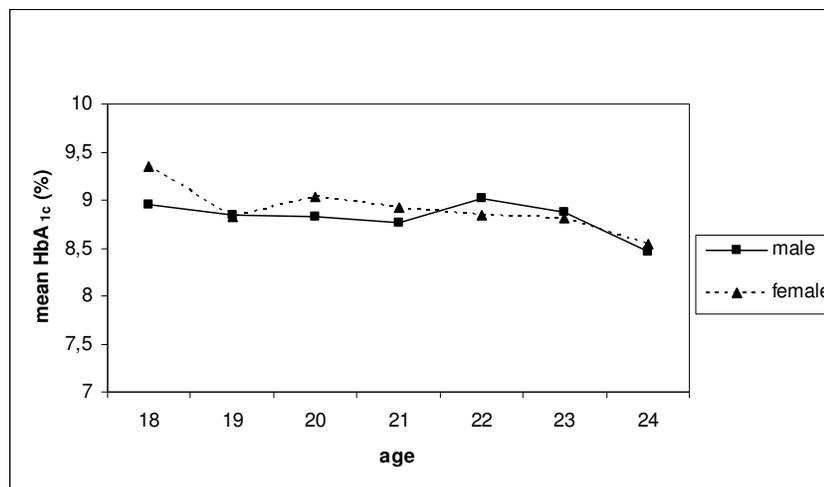


Figure 2 Mean HbA_{1c} in males and females with type 1 diabetes between 18-24 years of age.

Issues related to transition processes

A social psychological process of reconsidering self-identity occurs during this transitional period in which the emerging adults are *fighting identity threats*. They have become aware of feelings of shame and shyness related to their diabetes and can now see these reactions in another perspective. Most of them still dislike being deviant although a few like to be special due to having diabetes. A growing awareness of lacking personal qualities compatible with diabetes management is also illustrated. Increased acceptance of having diabetes is apparent as they mature although the level of acceptance varies among participants. The youths whose diabetes started in pre-school-age seem to have integrated illness into their self-identity more than the others (IV).

The organizational transition process of changing care provider embraces three phases. The first phase, *preparing transition requires modified strategies* such as

transition meetings and/or possibilities for ADC providers to encounter patients before transition but also to gain extended knowledge of the other care culture (II). This was confirmed by one male who expressed a lack of common understanding in regards to appropriate insulin dosages between his physicians in PDC and ADC. The emerging adults felt that they were *ready to leave but yet unprepared* for ADC and expressed a need for bridging activities. Parents sometimes felt a resistance towards leaving the familiar PDC but had no recollections of preparation strategies despite being assured that these were in place (IV).

The next phase implied *transferring responsibility and changing care relations* which involves relinquishing the youth from PDC and receiving them in ADC. The first action was to decide a time for transition, a decision made in collaboration with the patient and his/her family. Both hospitals had similar routines of transferring patients in relation to high school graduation (II) which is consistent to the findings in paper III where the mean age for transfer was 19.8 years. PDC providers were hesitant to transfer youths with unstable glycemic control. ADC providers sympathized with these doubts, although they preferred to receive the patients as soon as possible. The routine in one setting of introducing a diabetes nurse from ADC at the last visit in PDC indicated that logistic problems with lost referral letters could be avoided (II). This was confirmed in paper IV by participants who had experienced prolonged waiting time for first visit in ADC and through the findings in paper III in which mean time between last –first visit was 7 months (range 0-39) with no statistical differences between sexes. Care providers in all settings agreed that PDC retain responsibility for patients until first visit in ADC (II).

In the evaluation phase, findings revealed that care providers are *creating mutual understanding through appraisal*. Care providers expressed a need for increasing contact between care cultures in order to understand each others strategies. The clinic with one diabetes nurse employed half time in both PDC and ADC had brought about a number of positive effects leading to improved knowledge and better understanding of some patients' situation. Although some problems were eliminated due to the combined post, there was congruence among care providers that more could be done to improve transition strategies (II). The overall findings of paper II indicate that *enabling integration through professional meetings* is related to the degree of contact and routines for feedback and influence the possibility to bridge uncertainty, insufficient knowledge, routines and strategies. These meetings mediate between two different care cultures and improve clinical practice of transition. Professional meetings establish relations between care providers and may contribute to increased comprehension of adolescents' needs during transition.

Support of self-management

Parents are still giving some practical, problem solving, comforting support and are the main choice when the youths need emergency support, even if they are no longer living together. Mainly those siblings who have diabetes as well serve as an active support in sharing diabetes experiences. The results indicate that other siblings do not have a very prominent role in supporting self-management, thus applying to a *standing by* function. However, they do have to adapt to the special consideration of their sibling's needs that sometimes occur in daily family life **(IV)**.

Strategies promoting self-care and diabetes management were shown to be mainly similar in PDC and ADC culture. The content of visits to nurses and physicians respectively were congruent although the clinics organised the visits differently **(I)**. According to the emerging adults, the diabetes nurse played a more prominent role in ADC than the physician compared to in PDC **(IV)**. In order to support self-management, care providers in both care cultures applied a confirming attitude towards improved control as well as expressing understanding for life circumstances that have impaired the self-management capacity. A patient centred attitude was apparent during observation of most visits where care providers emanate recommendations from patients' description of reasons for and reactions to current glyceamic control. In PDC, an authoritative attitude is sometimes applied mainly when adolescents were lacking self-responsibility and showed poor disease control **(I)**. However, care providers in both care cultures expressed uncertainty of how to best support the special needs of youths with diabetes during emerging adulthood. Although the youth often knows what to do to manage their diabetes, motivation seem to be the problematic issue **(II)**.

With less involved parents (family) and care providers, other significant others get a more prominent role in supporting self-management during emerging adulthood. The findings show that emerging adults view their partners as *concerning but unqualified* in diabetes related issues. Some partners are invited to support self-management and take responsibility for dietary habits after they start living together. The youths are *managing friends' involvement* according to the degree of that involvement. Some incorporate friends in diabetes related issues; others let them take control in critical situations while others resist support from friends. The analysis of internet communication show how adolescents and emerging adults can apply to new self-management strategies by *learning from others experiences*. Some uses the website to raise questions on how to handle specific situations and replies gratefully when valuable advice is given. Similar experiences contribute in such way to a confirming support **(IV)**.

Relationship with significant others

Emerging adulthood for youths with diabetes and transition to adult diabetes care is characterized by a relational and reflexive process involving reconstruction of supportive relationships with significant others and reconsideration of self leading to an *ongoing redefinition of relationships and self-identity*. During emerging adulthood, parents have become *guiding agents* contributing with specific knowledge, reminders, encouraging confidence and by showing a humble attitude towards their youth struggling with diabetes in daily life. Parents who have diabetes serve as models and show by examples how to handle self-management and by genuine confirmation of illness related experiences. *Transferred responsibility* was found due to an increasing trust in the youth's capacity although some parents perceived more resistance than others. Emerging adults longing for independence or changed social conditions in the family have in those cases forced them to relinquish responsibility. A parental *conflict-creating concern* sometimes leads to consequences that influence the relationship negatively. The emerging adults on the other hand, are no longer as challenged by this concern and can at this time express empathy towards their parents and show respect for their concerns (IV).

Care providers in PDC express a need to end the contacts properly in order to complete relationships with the families, an opportunity sometimes lacking in one clinic (II). This was confirmed by emerging adults and parents who also felt a need to say goodbye. They were *recalling trustful relations* in PDC where they experienced continuous contact with care providers who sometimes complimented each other and/or compensated lacking quality in relations to nurses versus physicians. Getting complimentary support from care providers in times of medical, developmental or psychosocial challenges contributed to feelings of being acknowledged in the paediatric care culture. The unsettled relation to ADC provider is characterized by *unestablished trust* due to the aggravated circumstances for contacts and feelings of not being recognized and objectified in the adult diabetes care culture. Simultaneously, entering adult care has also entailed *new possibilities* where some emerging adults received helpful support and appreciates the honest, confirming and future orientated approach provided in ADC (IV).

Self identity is often challenged during this period due to changing and unsettled relationships with new friends and partners. The emerging adults express ambivalent feelings about diabetes influence on their relationship to partners. Concern is appreciated as this indicates that they are being accepted with their illness, but in new relationship it appears to be important to diminish needs related to diabetes. Some youths desire greater understanding from friends while others appreciate their empathy of the demands related to living with diabetes. Findings show that having reliable friends creates feelings of safety and trust (IV).

DISCUSSION

General discussion of the findings

The main concerns related to emerging adults' transition to adult life and diabetes care in living with diabetes was in this thesis, found to be characterized by several changing conditions on institutional as well as individual levels. In this section the interplay between organizational conditions and the consequences for encounters between emerging adults and care providers will be discussed as well as the prerequisites for integration and outcome of diabetes care and the implications of dividing life periods in socially constructed categories. Added to this, how other significant interactions influence the social-psychological transition during emerging adulthood. By doing so, this thesis might contribute to some new insights for young people and their significant others, including former, present and future diabetes care providers.

The interplay between organizational conditions and caring relationships

Bridging macro and micro levels of human conditions and interaction are not simple. An endeavour in these matters will be discussed here by using the multi scientifically shared concept *trust*, an essential feature for caring as stated previously (Mayeroff 1971; Morse et al. 1991). In the disciplines of nursing and medicine, trust is mainly handling the interpersonal trust between nurse/physician-patient although nursing also often involves relationships with the family. Psychology and sociology in general, regard trust as developed over time, influenced by personal traits or social interactions. These disciplines address, to differing degrees, the individual perspectives of personal trust or institutional trust (Hupcey et al. 2001) which is why it may be fruitful to use this approach when discussing our empirical findings.

The preconditions to trust in this context are that the individual 1) must be in a situation with an identified need of another; here support from diabetes care providers 2) has some experience or knowledge of that care provider and 3) who is trusting is taking a risk of becoming vulnerable and dependent (Hupcey et al. 2001). In the light of the differences in care culture between PDC and ADC found in our results and other studies (Fleming et al. 2002; Visentin et al. 2006) the emerging adults being less visible in adult care, and experiencing unestablished trust to new care providers could be at risk of avoiding contacts and decreased clinic attendance as a result. Declining clinic attendance has also been shown in studies by Kipps et al. (2002) and Wills et al. (2003) which is in line with the findings in paper III where the number of visits declined significantly after transition to ADC. But these results do not tell us anything about the reasons. It would be easy to say that it is because the parents do not handle appointments anymore or that adult care provider expect and

accept less frequent visits. This is probably one side of the coin, but I will argue that how the youth experience the caring relationship with care providers is of utmost significance in this matter. The findings in paper IV indicate that the emerging adults (and their parents) asked for the major ingredients of caring stated by Mayeroff (1971). These essential ingredients include knowing, alternating rhythms, patience, honesty, trust, humility, hope and finally courage which is a process of helping another grow and actualize himself. The “carer” has to know that and how, direct and indirectly, all with the purpose of helping the other to grow. Being unfamiliar with family and social conditions as a care provider in ADC hinders development of a relationship built on trust and humility for demanding situations and is in line with a study of Reiss et al. (2005) as well. Moreover, adult care providers can not yet learn from earlier actions and their outcome why possibility to modify behaviour to better support the youth is limited due to the short, unsettled and not yet trustful relationship. This might explain the contradictory findings of patient centred care, observed in paper I, and experiences of being a “nobody” or a “HbA1c” in paper IV. On the other hand, perhaps the emerging adults have to mourn the loss of former relationship to care providers in PDC before they can benefit from the potential gains that the transitions can bring (cf. Giddens 1991).

The observations of patients visits revealed that care providers sometimes showed an unfocused behaviour in PDC and ADC which seems to be expressions of a deficient ability to let the other grow in his own time and way by giving the youth (and sometimes parents) time as well as space (cf. Mayeroff 1971). Without conducting participant observation, this behaviour would not have emerged, at least not in interviews with care providers. Although this behaviour is not unique for diabetes care, this example can illustrate hindrance for alternating care providers’ behaviour according to the needs of the patient. New technology makes us reachable and we can access information simultaneously as we are supposed to be present and sensitive to what the patients says or needs, which implies a contemporary problem in caring encounters.

Another caring aspect to deal with is honesty (cf. Mayeroff 1971), which can be really challenging for care providers as it implies to see the other as he/she is and not as I would like him/her to be. When encountering emerging adults with such poor glycaemic control as were many of the participants in paper III, care providers have to deal with patience, honesty, hope and courage to successfully support them and simultaneously build a relationship. It is however important to acknowledge that the association between good glycaemic control and better quality of life is not self-evident (DCCT 1996; Grey, Davidson, & Boland 2001a; 2001b) which is why these issues may have to be considered separately. Actually the findings indicated that at the time for transition, the smallest proportion of patients were in good control which demonstrates their vulnerability and the challenge for a new care provider to “take over” these patients. Although care providers in PDC also have to deal with

poor control they can often rely on a previously formed trustful relationship and the multi-dimensional support available in PDC. It was obvious in the interviews with care providers that they had difficulties in properly meeting the needs of emerging adults, despite long experience. The findings indicate also that there is a need for modified strategies and behaviour so youths can feel prepared for, acknowledged and recognized in the adult settings which is in line with what other studies have found (Farrant & Watson 2004; Kralik et al. 2006). According to Hupcey et al. (2001) the outcome of trust is"- *an evaluation of the congruence between expectations of the trusted person and actions*" (Hupcey et al. 2001 p. 290), expectations which were not experienced to be met among the participants in study IV. Mayeroff (1971) claims that being accessible is an expression of trust and institutional trust appeared in our studies to be hindered by declined accessibility after transition to ADC.

Integration and outcome of diabetes care

Another finding worthwhile to discuss is the prerequisites for integrated diabetes care. In the definition of Blum et al. (1993) transition between paediatric and adult care settings is supposed to be a purposeful and planned process. The findings did not support this goal to be fulfilled which is in line with insufficient implementation of the three phases; preparation, formal transition and evaluation found by Visentin et al. (2006). However, there were differences between the involved settings and the findings indicating that some barriers are easier to overcome in smaller hospitals with fewer receiving adult clinics. Similar to what Kipps et al. (2002) found, joint visits with a diabetes nurse present at the last visit in PDC seemed to influence the transition process on both an organisational and individual level. This strategy also increased the contact between care providers in PDC and ADC and contributed thereby to promoting transition preparation and increased understanding of individual needs during transition.

Another bridging factor appearing in paper II was the combined post, held by a diabetes nurse who was working part-time in both PDC and ADC which was also creating a feeling of safety for those participants who had such experiences. Although this organisation is not applicable in all hospitals, it obviously contributed to integrating the diabetes care in this hospital. With some contact between care providers it seems to be easier to find more and other forms of collaborative strategies as there are "natural" and recurring times and places to discuss common issues. Building trust between the different parts of the system through creating relations between individual care providers could mediate institutional and individual levels of care. According to the care providers (II) and the participants in paper IV there were a lot of problems with lost referral letters and prolonged waiting time and mean time of seven months (III) seems to be a long time for a youth in a vulnerable phase. A suggestion for clinical practice could be to use "the time between last-first visits" as one quality indicator and evaluation of the transition process. As

Scal et al. (1999) have already pointed out; the barriers for providing collaborative, coordinated and integrated care mostly lay in the health care system itself. Unfortunately, in paper III we only followed youths between 18-24 years of age in one of the two hospitals (without any transition strategies) which makes it impossible to know if time between visits in PDC and ADC had been influenced by transition strategies.

Some of the PDC providers expressed worries about handing over adolescents with poor control to ADC due to their fewer resources and less frequent visits which also demonstrates a lack of trust in the diabetes care system. Previous findings have shown better glyceamic control to be associated with more frequent visits in PDC (Kaufman et al. 1999; Nordly et al. 2005) and less clinic attendance with worse glyceamic control in ADC (Kipps et al. 2002; Busse et al. 2007). It was therefore especially interesting that we found more visits in ADC to be associated with higher HbA_{1c} i.e. worse glyceamic control which suggests that ADC allocates their resources to those most in need. Even if ADC does not succeed in improving the overall control (during the examined period), the emerging adults seem to be prioritized when needed. On the reverse side, this might explain why some youths did not feel prioritized in ADC. As we did not examine the youth's glyceamic control in that study we can not conclude that there is a relationship between these experiences and the number of visits for those individuals. This needs to be further explored but can serve as one example of how results from qualitative studies can give plausible explanations to statistical significant findings and thereby contribute to refining further research questions in future studies. Another finding that needs to be explained in such a way is why women visited ADC more often than males.

Implications of socially constructed categories

Considering childhood and adulthood as social constructions which permeate most social milieus in society, is one way to reflect on the appropriateness of dividing diabetes care into two different static environments. Perhaps it is time to loosen up these essentially old-fashioned borders and create care environments with flowing "departures and arrivals". But this requires that diabetes settings have what Giddens labels as institutional reflexivity which means "*the use of knowledge about social circumstances of social life as constitutive element in its organisation and transformation*" (Giddens 1991 p. 20). However, the developmental context for this thesis, emerging adulthood, can also be regarded as a social construction, although reflecting the group from a more contemporary perspective. This period is characterized by extremely changing conditions regarding living and occupation which entails different implications for individuals and also for ADC due to a quite often occurring need to change care provider after transition to ADC, as shown in paper III. The diversity of characteristics must be acknowledged when regarding them as one group (Arnett 2000). Schwartz, Cote and Arnett (2005) describe different

developmental routes in the individualisation process where forms and degrees of agency are suggested to be important for the development of identity in emerging adulthood. According to the care providers' perceptions of emerging adults as being preoccupied with other things than their diabetes, those with lack of commitment to set goals, values and beliefs ought to need more external support from care providers. Schwartz et al. (2005) recommend that those emerging adults need to be assisted in developing an agentic orientation, facilitating effective decision-making and problem-solving, to better navigate in this unstructured developmental period. The definition of self-management (Schilling et al. 2002) stated in the background section seems to be in concordance with how paediatric care providers view the involvement of parents in daily life of youths with diabetes. However, the definition does not take other significant others into account and according to our findings, it is difficult to assert that the definition is in line with how adult care providers view self-management in emerging adults. It seems problematic with a definition that fortifies differences in the two different contexts of diabetes care. A suggestion for care providers can therefore entail a common discussion of how support from significant others can be maintained and promoted in the diabetes care system. This could mediate the fact that care culture is partly formed by its conditions which implies that different needs in children, emerging adults and adults could be acknowledged explicitly in interactions and practices.

Entering adult care also entailed new possibilities for some of the emerging adults. Anderson and Wolpert (2004) suggest this time as a "window of opportunity" which some of our participants also expressed by their growing awareness of their own strengths and limitations and compatibility to manage diabetes. This awareness seems also to be signs of a response to the transition process where indicators of being located and situating themselves in terms of time and space can help them explain who they are by creating new meanings and perceptions (Meleis et al. 2000). By creating care environments that overlap the transition process it might be easier to follow the development of self-management capacities and need for support without risking a break in the chain of "trust" (between patient-care provider but also to significant others, especially parents).

Developing self through interactions with others

The emerging adults were still fighting identity threats although they also demonstrated a growing self-consciousness which is presumed for development of self-identity, incorporated and maintained by reflexive activities of the individual according to Giddens (1991). The social-psychological process was shown to entail a redefinition of self-identity which others have also pointed out. Meleis et al. (2000) state that transition requires changes of self-identity and Kralik et al. (2006) emphasize the need for inner re-orientation caused by challenged self-identity. Even if those authors also acknowledge the influence of relationships during transitions,

we are focusing more on how the meaning of supportive relationships is reconstructed during the organisational, social and developmental nature of transitions. This leads to a redefinition of not only self-identity but also of former and new relationships in an ongoing process. This is in line with how Charmaz (1983; 1995a) describes that shifting social experiences lead to a change in self identity as a result of how the individual is defining, locating and differentiating the self from others. According to the developmental transition for emerging adults, identity is less based on prescribed roles and more on individual choices as a result of globalisation (Arnett 2002) and identity can therefore be assumed to be created and recreated more actively than previously (Giddens 2000).

Parents appeared to be more or less resistant towards handing over responsibility to the emerging adults. Especially the mothers in our studies seemed to have difficulties in "letting go". On the other hand, studies have shown that the personality traits of mothers influence glycemic control. Mothers' agreeableness has been found to predict good glycemic control in children 6-16 years (Vollrath et al. 2007) and adolescents showed better control if they had mothers who were actively involved in diabetes management (Wiebe et al. 2005). However, parents caring too much can also display a lack of trust in the others ability which is negative for construction of self-identity (Mayeroff 1971). The mothers who expressed this, of themselves undesired behaviour appeared to be very aware of these consequences. Two mothers talked about the worry as the negative side of concern. Hopefully, the emerging adults' maturation seemed to have entailed an increased understanding for their parents' concern as several statements of trust in their mothers' competence in diabetes issues emerged in paper IV. These findings can be explained by the fact that our participants are some years older (about 21-22) than in other studies where parent-adolescent relationship regarding communication (Hanna & Guthrie 2001; Hanna & Guthrie 2003) and conflicts (Viikinsalo et al. 2005) were examined. The other side of concern seems to be more positively valued, including trust, hope and courage which can be important messages to parents, partners and other significant others of how to best support the other. An unexpected finding was the supportive role of siblings which seemed to be rather insignificant in daily life according to both parents and emerging adults. Exception from this occurred in the three families who had two children diabetes where these youths seemed to support each other considerably. However, having two children with diabetes was recognised as laborious work implying a heavy burden on the family, especially the mothers.

Developing intimate relationships to a partner is one of the tasks expected to be initiated or at least tried out in emerging adulthood (Roisman et al. 2004). As in most new romantic relationships there is a period of getting to know each other and implicitly evaluate feelings and compatibility. For emerging adults with diabetes in study IV this seemed to be accompanied with uncertainty of diabetes impact on relationship before a more settled stage of the relationship could occur. The meaning

of the relationship with partners is thereby forced to be redefined with regard to supportive aspects. There are also gender differences regarding expectations of what a relationship should include where females in the study of Jacobson et al. (1997) tended to ask for more care from their partner which is in line with our findings. However, this was found in emerging adults both with and without diabetes but might come more to the fore in the context of living with diabetes.

The emerging adults need to have control over diabetes related disclosure and the degree of support from friends and partners are in line with the findings in a study of Doveay-Pearce, Doherty and May (2007). Also some of the others (in chats) distinctively asked for a particular kind of helpful support in favour of other, less helpful support. The contribution of support from others on the website adds new and important knowledge to this problem area. First, care providers can acquire knowledge of important issues for youths through the “read-only” access without challenging the integrity of the youths. This might give them a broader understanding of contemporary problems such as both generation and gender differences between care providers and youths which can then be bridged. Secondly, the usefulness of internet communication as supportive and confirming strategy can be considered when planning interventions, hopefully more effectively due to its contemporary approach. Moreover, problems with accessibility might be bridged by using alternative ways for care providers to communicate with emerging adults.

Methodological considerations

This thesis embraces several perspectives which were necessary to apply as focus was to explore meaning of transition experiences at both the subjective and the social level. Accordingly, it has been challenging to examine a phenomenon which occurs in several different dimensions; socially, physiologically and psychologically and on shifting levels of diabetes care; the organisational conditions in each hospital/ clinic and the interaction level between individuals. A multi-scientific approach was therefore applied by considering socio-psychological, medical and caring aspects of the transition to adult life and diabetes care. Although it can be hard to grasp all perspectives on a deeper level, a more comprehensive knowledge can be gained by letting different conditions and experiences be included in a systematic analysis of how diabetes self-management issues in emerging adults are understood, facilitated and sometimes hindered in everyday life and in diabetes care. Additionally, the researcher “tells a story about people, social processes and situations, the researcher composes the story and accordingly the story reflects the viewer as well as the viewed” (Charmaz 2000). The researcher can hereby contribute with an analytical perspective which is a social construction. No perspective is supposed to be superior

why it is of utmost importance that “the story” has been conducted with a critical and reflexive stance.

It was beneficial not being employed or connected to any of the involved settings which contributed to equal relations with care providers. The observer role is not uncomplicated. By not being a clinical “expert” in the studied area it was possible to pose certain questions and try to alter between care providers and patients/ parents perspective during visits. Long clinical experience as a paediatric nurse facilitated understanding that different conditions and many influencing factors may bring undesired shortcomings in care strategies. However, it was of great value to have previous experience of young adults with diabetes when accomplishing interviews and analysing data and for being aware of how the findings could be explained and applied in clinical practice. Personal experience of three adolescents emerging to adulthood has also brought many insights of the challenges young people face in modern society, with or without having diabetes.

Quality aspects concerning data collection and analysis in paper I, II and IV will be discussed by referring to the quality criteria for GT as formulated by Charmaz (2006). One way to ensure *credibility* in paper I + II was the possibility to follow-up statements and hunches which emerged during observations of patients’ visits in PDC and ADC. Through the memos and the concurrent analysis, other angles could be examined and new questions posed during the next observation or in the coming outpatient clinic. The interviews were also conducted at the end of time spent in each setting which contributed to establishing a good contact with care providers and selecting those nurses and physicians who could communicate significant experiences. In concordance with Hall & Callery (2001) I believe that *relationality* in terms of trustful relationship between participant and researcher also has to be addressed as one quality standard in qualitative studies. In paper IV this was in some cases facilitated by conducting interviews in the participant’s home which entailed a personal and relaxed environment for the interview. However, one of the most extensive and touching interviews with the mother of a young man with diabetes took place in the university. In this case the atmosphere and relation between interviewer and the mother become very empathic with a rich, detailed story about experiences of raising a child with diabetes to adulthood. *Resonance* is another quality criterion in GT and getting access to both emerging adults and one of the parent’s perspectives enriched the stories about issues in daily living and sometimes taken-for-granted meanings among the participants. As it became obvious during data collection of paper IV that it was difficult to get access to in what way the emerging adults got support from other young people, data with internet communication from a national diabetes website were explored and included in the analysis. This observation of interaction turned out to reveal surprisingly rich and interesting information about the way youths communicate and give/receive support from each others knowledge and experiences in both diabetes related and existential

issues. In accordance with Charmaz (2006) recommendations for gathering qualitative data, multiple views of the youth's range of actions could thereby be obtained which also contributed to meet the quality criterion of *usefulness*. The care providers did not seem to be aware of the knowledge transferring in this unique discursive milieu, a contemporary "diabetes caring arena". These findings can therefore entail new knowledge of social and clinical significance and in some way also entail *originality*. The concept of saturation is commonly used when motivating the number of participants in qualitative studies (particularly GT studies). In line with Charmaz (2006) and others, I doubt the value and trustworthiness of referring to this as justification of the data amount. Although *theoretical saturation* should be understood in another way than just simply "have enough data", it is reasonable to question if any researcher can ever be sure of having saturated his/her categories. When considering the researcher as participating in the socially constructed findings, new threads and hunches could be followed and explored in qualitative different ways.

In paper III, other methodological issues need to be addressed. First, the retrospective design implies certain problems as you can not influence data quality. You have the data you have and the access to these data can also hinder the data collection. Insufficient documentation was also apparent during record audit which precluded differentiating of specification of visits and phone calls. However, by preparing the data collection thoroughly by contacting all involved seven units, it was possible to identify variables more or less possible to follow longitudinally. A limitation with this study is the rather small sample of 104 individuals initially decreasing to 95 at the end of the study period. On the other hand, this is a well known problem in all longitudinal studies. Yet, it is possible that with a larger sample we could have found other differences. An approximate power calculation was performed where 100 individuals were suggested to be included. It might have been a good decision from the beginning to include the other hospital in this study as well (as in paper I, II and partly IV). Then we would have had a total greater sample and statistical correlations between the two settings with differing transition strategies regarding diabetes care variables and glycemic control might have been possible. However, using a generalised linear mixed model (Brown & Prescott 2006) was a preferable choice for the longitudinal analysis as all measurements could be taken into account in contrast to conventional regression models. The possibility to generalise our findings is contextual depending on the way that different regions and countries have such diverse policies and practices which makes it hard to compare without taking local conditions into account.

CONCLUSIONS AND CLINICAL IMPLICATIONS

This thesis shows that differing care culture in paediatric and adult diabetes care has implications for care providers, emerging adults and their parents' experiences of caring relationships, and diabetes care. The organizational transition revealed that relations with diabetes care providers in ADC are vulnerable because of unsettlement but sometimes promising with new opportunities. Establishing trustful relationships with adult care providers might prevent poor clinic attendance but requires changes in strategies and behaviour in ADC. Joint visits in PDC seem to prevent risk for lost referral letters and prolonged waiting time for first visit in ADC. Glycemic control was shown to be poor between 18-24 years of age in both males and female and worse glycemic control was associated with more visits in ADC. Females appeared to visit ADC more frequently than males which have to be further investigated. Professional meetings between care providers in PDC and ADC can bridge differences in care cultures, create shared understanding of their patients' condition and influencing factors, increase knowledge of more or less effective strategies and promote continuity and integration of care.

The youths growing reflexive awareness has led to identity development and that the meaning of supportive relationships transforms during transition to adult life. The findings shows how parents are still important in daily management but with less involvement and control although perceived as the most trusted in case of need, compared to partners, siblings and other significant others. The analysis also revealed some new findings including how chat-friends can contribute with a contemporary, valuable and confirming support without any commitments.

It may differ between diabetes care settings to which extent they can apply conclusions and recommendations drawn from these findings in clinical practice. According to what was found in all four studies, the hindrance for promoting trust at individual and institutional levels seems to lay in the system itself which in turn is represented by the bearers of the diabetes care culture, the care providers. Using the findings as a starting point for discussion of what can be done to improve the care of emerging adults with diabetes is a desired goal for this thesis. This calls for institutional (diabetes care as a system) and individual (care providers) reflexivity.

Further exploration of gender-specific needs in emerging adulthood, utilization and effectiveness of diabetes related care is desired to provide additional contribution to this explorative developmental period of life. As interactions in internet communication appeared to entail a special and often supportive form of relationship to others, new contemporary web-based interventions could be introduced, tested and evaluated for applicability. The special needs of families who have several children with diabetes also need to be further investigated.

SVENSK SAMMANFATTNING

Att leva med diabetes i övergången till vuxenliv

Det är väl känt att ungdomstiden innebär en extra utmaning för människor som har kroniska sjukdomar. Högre grad av risk beteende är vanligare under denna tid och för ungdomar med typ 1 diabetes kan det utgöra ett allvarligt hot mot deras hälsa både på kort och på lång sikt. Det tillhör också den naturliga utvecklingen att ungdomar skall frigöra sig från vuxna vilket kan utgöra ett problem när man är beroende av andra för vägledning och stöd i det dagliga livet med diabetes. Att ha kontroll på sjukdomen vid diabetes ställer stora krav på aktiv egenvård för att upprätthålla så normala blodsockernivåer som möjligt och därigenom minska risken för komplikationer. Många studier har visat att sjukdomskontrollen är sämre under ungdomstiden och tidig vuxenålder. Sjukvården har svårt att möta de särskilda behov som ungdomar har i övergången till vuxenliv och överföringen till nya vårdgivare kan öka sårbarheten pga ändrade förutsättningar för vård och stöd inom vuxenvården.

I detta avhandlingsarbete har fyra olika studier genomförts i syfte att belysa övergången från barn till vuxenliv och vuxenvård för ungdomar med diabetes samt få en djupare förståelse för hur vårdgivare, ungdomar och deras föräldrar hanterar denna situation. Även betydelsen av dessa relationer avseende stöd för egenvård och sjukdomskontroll har studerats.

Observationer av patientbesök hos läkare och sjuksköterskor har genomförts på fyra olika barnmedicinska och vuxenmedicinska diabetesmottagningar. Intervjuer har gjorts med vårdgivarna på de olika enheterna samt med ungdomar och föräldrar två år efter övergången till vuxenvård. För att komma åt hur ungdomar med diabetes kan stödja varandra användes också chatt-inlägg från en nationell hemsida för ungdomar och unga vuxna med diabetes. I en studie som omfattar 104 ungdomar har journaluppgifter avseende sjukdomskontroll och utnyttjande av diabetesvård mellan 18-24 år kartlagts och analyserats.

Studierna visar att det finns både likheter och skillnader mellan barn och vuxenmedicinsk diabetesvård. På barnsidan erbjuds ett multidimensionellt stöd med bättre tillgänglighet och komplementära resurser, en vårdmiljö som inbjuder till informella kontakter samt högre grad av föräldrars delaktighet i vården. Efter övergången till vuxenvård blir ungdomarna sedan mindre synliga pga skillnader i organisatoriska villkor och strategier. Frekvensen av besök minskar efter övergången och inom vuxenvården gör kvinnorna fler besök än männen. Kvinnor och män med sämre glykemisk kontroll besökte vuxenmottagningen i större utsträckning än de

med bättre kontroll vilket skiljer sig från flera tidigare studier. Sjukdomskontrollen för gruppen av ungdomar som följdes mellan 18-24 år var mycket otillfredsställande och översteg vida rekommenderad nivå under hela undersökningsperioden. Endast kvinnornas glykemiska kontroll förbättrades signifikant under perioden.

Förberedelsefasen inför övergången visade sig kräva förändrade strategier, delvis pga vårdgivarnas osäkerhet om lämpliga metoder för att möta ungdomars specifika behov under denna tid men också pga bristande kunskap om arbetssätt i den andra mottagningskulturen. Under överföringen överlämnas ansvar och relationen till vårdgivarna förändras. Ungdomar och deras föräldrar minns tillitsfulla relationer på barnsidan medan en oetablerad relation med sämre tillit till den nya vårdgivaren framkommer vid tidpunkten för studien. Logistiska problem som borttappade remisser mm visade sig dock kunna överbryggas av särskilda överföringsstrategier som förekom på ett av de två involverade sjukhusen. Förutsättningar för ömsesidig förståelse genom utvärdering av övergången kräver att mötesarenor för vårdgivare från både barn och vuxenvård skapas.

För ungdomarna innebär övergången till vuxenlivet också att de genomgår en relationell och reflexiv process som innebär att innebörden av relationer till närstående som föräldrar, vänner och partners förändras. Föräldrar utgör fortfarande det viktigaste stödet, i synnerhet vid akuta situationer, men har inte längre själva tillgång till information och stöd från vårdgivarna. I denna process framkommer en pågående omvärdering av både den egna identiteten och relationen till dessa stödjande närstående. En ökad medvetenhet om egna styrkor och svagheter avseende egenvårdskapacitet framkommer hos ungdomarna och många uttrycker också en gradvis tilltagande anpassning till sjukdomen. I nya relationer är det inte lika självklart att vara öppen med sin diabetes. De ungas kontakter på Internet visade sig kunna utgöra ett kravlöst, bekräftande och ofta lärande stöd i strävandena att hantera diabetes i det dagliga livet.

Slutsatsen av dessa studier är att för att kunna möta dessa "begränsade vuxnas" behov i en omvälvande livsfas, behövs förändrade strategier på organisatorisk nivå såväl som på individuell nivå. Genom att öka antalet professionella mötesarenor skapas förutsättningar för integrerad diabetesvård vilket vårdgivare, ungdomar och deras föräldrar efterfrågar. Vidare skulle ett mer utvecklingsanpassat bemötande kunna förbättra ungdomar och närståendes tillfredsställelse med vården samt skapa långvariga och ömsesidiga relationer med bättre förutsättningar för stöd i sjukdomskontroll och egenvårdskapacitet. Vårdgivare kan ta del av interaktionen mellan ungdomar i chatt-forum utan att de ungas integritet hotas och lära mer om ungdomars samtida problem som inte alltid framkommer vid besöken samt utveckla alternativa former för Internet-baserat stöd.

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