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Master thesis

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The correlates of the health-related quality of life of paediatric patients with diabetes type 1

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DiNa

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Preface

This master thesis is the final act of graduating in health psychology/clinical psychology at the University of Twente.

I always felt home studying in the Netherlands but it was a very intensive way I went through. In the first two and a half years, I combined my studies with professional football at FC Twente which was an exceptional experience I never want to miss. Then I became a mother of two wonderful children, Finn & Mats, which is quite unconventional for a young student. I must say, it was the best way to proceed in life and now I can say “the best way is not always the easiest one!” At this point, I really want to thank all the people who made it possible for me and my husband to combine my studies with having a family.
Angelika, I'm endlessly grateful to you for being such a wonderful grandmother who has always cared for Finn and Mats with such enthusiasm!
Furthermore, I would like to thank my Mum and Dad for supporting me my entire life! A thanks goes also to Johannes for being such a nice grandfather who supported Angelika all the time caring for the children. And last but not least, a thanks goes to my husband, Ruud, who always kept people off my back so that I could study in the evening and at the weekend!

Also, I would like to thank my lectures Dr. Peter ten Klooster and Liseth Siemons for mentoring me within my final master thesis! Moreover, I would like to express my gratitude to my contact person, Dorothea Hartmann, and the whole diabetes team of the St. Agnes-Hospital! I wish them all the best for the DiNa project in future! A thanks also goes to the children and adolescents and their parents for their willingness to participate in this study!

Summary

Objective: The objective of this study was to investigate the correlates of the health-related quality of life (HRQOL) of paediatric patients with diabetes type 1. The level of congruence between the patients' self-reports and the parents' proxy reports on the patients' HRQOL was examined, too. In addition, this study investigated changes in HRQOL and self-efficacy over a period of two years (2011 vs 2013) by paediatric patients who have participated in a diabetes aftercare project, called DiNa.

Methods: Data were collected at the paediatric department of the St. Agnes-Hospital, Bocholt, Germany. Next to HRQOL of the patients, self-efficacy, stress and stress coping, quality of the communication between the patients and their parents, quality of life of the parents, treatment adherence and intellectual ability were examined. Furthermore clinical measures, financial problems of the family and school problems were investigated. In total, 94 diabetic patients, aged between 8 to 16, participated in this study. A sample of 23 patients could be examined for changes in HRQOL and self-efficacy over a period of two years.

Results: Results disclosed that metabolic control, treatment adherence, quality of the communication between patients and parents, financial problems and school problems were especially associated with the psychological and social aspects-in contrast to the physical aspect- of the HRQOL. In addition, avoidant coping proved to be a salient factor in predicting the HRQOL. This study also found that metabolic control mediates the association between the communication between patients and parents and two dimensions of the HRQOL, namely *family* and *school.* In regard to the level of congruence between the paediatric patients' self-reports and parents' proxy reports on the patients' quality of life, agreement was found to be low and assessments varied between different aspects. Parents overestimated the overall HRQOL, *psychological well-being* and the *quality with friends*. However, *self-esteem* and the *quality at school* were significantly underestimated. Parents reports achieved slightly higher reliability, though. Considering the change of the HRQOL over a period of two years, *psychological well-being* and the *quality in family* were significantly higher evaluated in 2013 than in 2011. However, the *quality with friends* was lower rated in 2013 in contrast to 2011. Self-efficacy was significantly higher judged in 2013 than in 2011.

Conclusion: Results indicate the importance of psychosocial support and the promotion of positive coping strategies for paediatric patients with diabetes type 1. Neither self-reports nor proxy-reports on HRQOL of paediatric patients with diabetes type 1 seem to be entirely superior. DiNa seems to be a useful project in strengthening the psychosocial development of the paediatric patients.

Samenvatting

Doel: Deze studie onderzocht de correlaten van de gezondheidsgerelateerde kwaliteit van leven bij pediatrische patiënten met diabetes type 1. Daarnaast werd naar de congruentie tussen de door de patiënten zelfbeoordeelde en de door de ouder(s) extern beoordeelde gezondheidgerelateerde kwaliteit van leven gekeken. Verder werd onderzocht of er significante verschillen zijn van de gezondheidsgerelateerde kwaliteit van leven en de diabetes gerelateerde zelfeffectiviteit in 2011 in vergelijking met 2013.

Methode: Data werden verzameld op de pediatrische afdeling van het St. Agnes-Hospital, Bocholt, Duitsland. In totaal namen 94 patiënten in de leeftijd van 8 tot 16 jaar deel aan deze studie. Een selectie van 23 patiënten werd onderzocht op verschillen in hun gezondheidsgerelateerde kwaliteit van leven en zelfeffectiviteit tussen 2011 en 2013.

Resultaten: Resultaten lieten zien dat in het bijzonder de psychologische en sociale aspekten van de gezondheidsgerelateerde kwaliteit van leven met de *metabolische controle*, *adherentie*, *kwaliteit van de communicatie tussen patiënten en hun ouders*, *financiële problemen in de familie* en *problemen op school* geassociëerd waren. Bovendien kwam naar voren dat vooral *vermijdende coping* een goede voorspeller was van de gezondheidsgerelateerde kwaliteit van leven. Verder werden met behulp van mediatie-analyses significante resultaten gevonden waarin metabolische controle de relatie tussen de kwaliteit van de communicatie en de dimensies *familie* en *school* (subschalen van gezondheidsgerelateerde kwaliteit van leven) volledig mediëert. De congruentie tussen de door de patiënten zelfbeoordeelde en de door de ouder(s) extern beoordeelde gezondheidgerelateerde kwaliteit van leven was laag. Ouders overschatten de totale *kwaliteit van leven*, *psychologische wellbevinden* en de *kwaliteit met vrienden*. Daarentegen werden het *gevoel van eigenwaarde* en de *kwaliteit op school* onderschat. De ouders bereikten echter een hogere interne consistentie. Verder beoordeelden de patiënten hun *psychologische welbevinden* en hun *kwaliteit met familie* in 2013 significant hoger dan in 2011. De *kwaliteit met vrienden* was echter significant slechter beoordeeld in 2013. Met betrekking tot de diabetes gerelateerde zelfeffectiviteit scoorden de patiënten in 2013 systematisch hoger dan in 2011.

Conclusie: Deze studie geeft het belang van psychosociale ondersteuning en de bevordering van positieve coping strategiëen voor de pediatrische patienten met diabetes type 1 aan. De zelfbeoordeelde noch de extern beoordeelde kwaliteit van leven bleken superieur. DiNa blijkt een nuttig project te zijn om de psychosociale ontwikkeling van de pediatrische patiënten met diabetes type 1 te versterken.

1 Introduction

1.1 Diabetes Mellitus Type 1

Type 1 diabetes (T1D) is one of the most common chronic illnesses in childhood (Nouwen, Law, Hussain, McGovern & Napier, 2009). Its origin can be defined as a lack of insulin following autoimmune destruction of the insulin-producing pancreatic beta cells. It is a severe metabolic disorder characterized by the body's inability to produce insulin, the hormone responsible for metabolizing glucose, which means that the muscle and liver cells take up glucose from the blood in order to store it as glycogen in muscle and liver tissue (Levitsky & Misra, 2010). To date, the exact mechanisms of this disease and the advancement of the disease are not fully understood yet (Levitsky & Misra, 2010). Without treatment, patients with diabetes suffer from a condition called hyperglycemia which is an abnormally high blood glucose level which can result in fainting and unconsciousness (Sacco & Bykowski, 2010). In addition insufficient insulin levels force the body to break down fat for energy, which can produce dangerously high levels of ketones (ketoacidosis) leading to diabetic coma or even death (Sacco & Bykowski, 2010). In order to survive people with T1D rely completely on exogenous forms of insulin by means of injections (Sacco & Bykowski, 2010).

The age of onset of T1D has a bimodal distribution which has its peak first at the age of 4 to 6 and its second at the beginning of puberty at the age of 10 to 14 years (Levitsky & Misra, 2010). In the overall incidence rate of T1D no gender difference are manifested (Levitsky & Misra, 2010). In Germany, roughly 25,000 children and adolescents under the age of 20 are affected by T1D (Bartus & Holder, 2012). The highest reported incidence rate is found in Finland and Sardinia (37 to 45 per 100.000 children younger than the age of 15 years) compared to the 400 times lower incidence rates in Venezuela and parts of China (0,1 to 0,5 per 100.000 children) (Levitsky & Misra, 2010).

Over the past 20 years, a steady increase in the annual incidence rate of roughly 3 to 5% has been observed. It is estimated that by 2020 the new incidence rate in Germany will be twice as high as in 2001 (Neu, Ehehalt, Willasch, Hub & Ranke, 2001). The reasons for this increasing incidence are not known yet (Levitsky & Misra, 2010). According to Rosenbauer et al. (1999) there is a rising risk analogous to the geographical latitude. That is, the more the distance from the equator the greater the risk of obtaining T1D. It is a striking fact that people

moving from an equatorial vicinity up to the north have a higher risk to become ill with T1D, demonstrating an apparently causal relation with environmental factors. However, the pathogenesis of T1D is complex. Great diversity in incidence is also shown in regions of similar latitude, which indicates the impact of other risk factors (Rosenbauer et al., 1999).

Genetic susceptibility can be regarded as one of them. There is a significant increase in the risk of developing T1D if a relative is also affected (Tillil & Köbberling, 1987). If there is no family history of T1D, the chance of being affected by T1D equals 0.4%. Being an offspring of an affected mother raises the risk of getting T1D by 2 to 4%. If both parents are affected the risk is already up to 30%. A monozygotic twin of an affected person has a life time risk of 50% (Levitsky & Misra, 2010). Patients with genetic susceptibility run a high risk of developing diabetes if exposed to one or more supposing environmental factors such as diet (exposure to cow's milk at an early age), viral infections, immunizations, vitamin D deficiency, perinatal factors such as maternal age, neonatal jaundice and history of preeclampsia. However none of these factors have been thoroughly verified (Levitsky & Misra, 2010).

1.2 Diabetic Therapy

Up to now, there are no therapeutic possibilities to cure diabetes. The only option is a lifelong, intensive treatment. As Serra (2004) mentioned “diabetes in everyday life can be compared to a lifelong juggling with three balls: insulin, nourishment and physical exercise. How to juggle is theoretically fairly easy but in reality the approach is very demanding.”

The aims of treatment are the achievement and maintenance of a normal metabolic condition (normoglycaemia and avoidance of hypoglycemia), growth with adequate weight and the avoidance of successive damage (Bartus & Holder, 2012). The most important aspect of therapy is the regular and consequent application of insulin (via injections or an insulin pump) or sugar in which the dose depends on nourishment and physical exercise (Bartus & Holder, 2012). With a good adaptation to the treatment regimen, patients can achieve a complication-free clinical course which minimizes the chances of late sequelae (Bartus & Holder, 2012). T1D shows different treatment peaks in which special attention to the patients is necessary (Podeswik et al., 2007). The first one takes place in the event of the first manifestation of the disease in which the focus lies within the framework of adaptation to the disease and its treatment demands. The second one takes place at a difficult regulation of diabetes or in the event of a severe failure of the metabolic process which can occur either

because of developmental hormone fluctuations in puberty or a (psycho-) social- related loss of compliance, for example in youth, when the adaptability to the disease does not turn out well because of an attitude characterized by refusal (Podeswik et al., 2007). These and similar crises can make a participation in an aftercare project necessary (Podeswik et al., 2007).

1.3 Illness-management model- the basis of aftercare

Aftercare supports the child and its family by the management of the illness and the integration into the normal life. Management of the illness can be considered as a "continous treatment-accompanied process of emotional and intellectual coping with the demand of the treatment and the associated procedures" (Kusch, Labouvie, Fleischhack & Bodde, 1996).

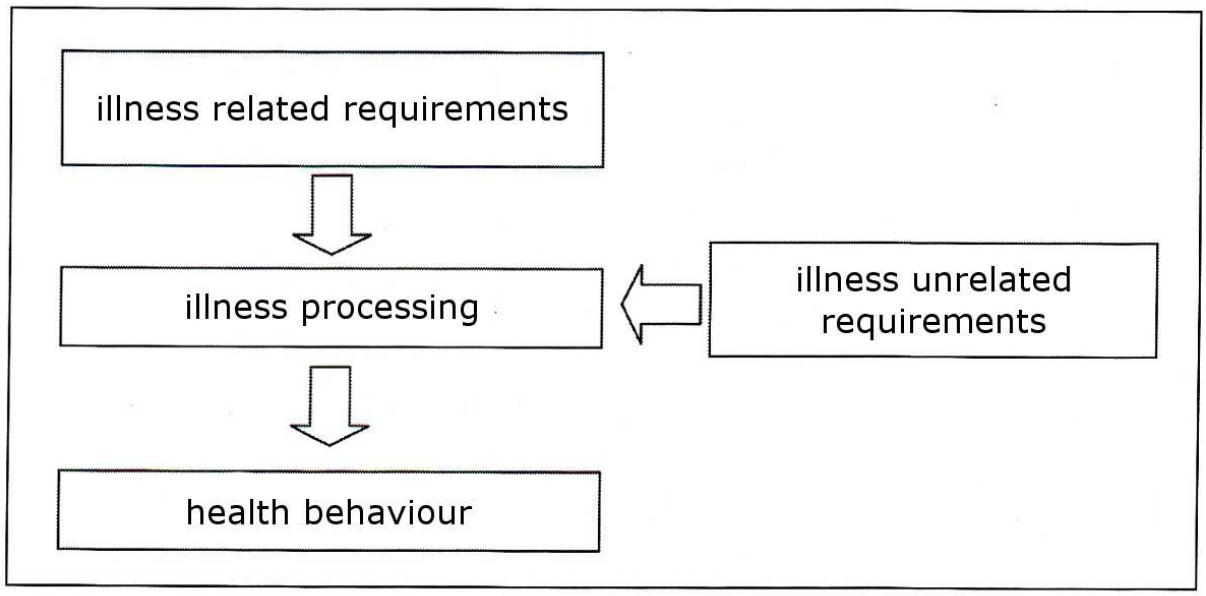

Figure 1 Illness management model (Podeswik et al., 2007)

In the illness management model, the interaction of illness related and unrelated requirements with its emotional and physical strains influence the process of coping with the illness (Podeswik et al., 2007). Illness-coping is not a once gained competency but rather a dynamic process that is experienced anew each time and of which the result has to be revised again and again. New insights influence the points of view of a child and its parents relative to the actual demands and the individual coping competencies must be gained anew and

practised. Professional support in the aftercare can help to develop a progressive competency of one's own illness management and coping.

Health behaviour is the observed result of the intra psychological process of illness coping. A positive health behaviour results in the desired outcome of the entire process of aftercare. All demands and strains, its interaction as well as its ramifications that effect the health of the child can be explained by the illness management model. Therefore, this model can serve as the base for the delivery of aftercare. Altogether, the use of the illness-management model characterizes the entire process of aftercare services (Podeswik et al., 2007).

1.4 Scientific findings about "Aftercare"

A few studies concerning "aftercare" have been conducted in regard to its effectiveness and its economic efficacy. An American study examined an integrated treatment model for children with T1D. Findings showed that "aftercare" which included social welfare, diabetic training and access to an interdisciplinary team resulted in a better HbA1 (long- term blood glucose), an improved quality of life and an ameliorated self-efficacy (Caravalho & Saylor, 2000).

Further "aftercare" projects also proved to be effective. For example one study called PRIMA examined the effect of an "aftercare"-programme on preterm and high-risk babies which showed that the strain within the family could be reduced, the mother-child interaction improved as well as the emotional regulation of the preterm babies. This study also showed that "aftercare" is of high value from the economic point of view because it reduced the number of in-patient and ambulant treatments (Podeswik et al., 2007).

1.5 DiNa

In May 2009, the department of pediatrics of St. Agnes-Hospital Bocholt, Germany, which has a diabetes treatment and training centre with approximately 190 outpatients between 0 to 18 years of age, started an additional project called DiNa which is an abbreviation of "Diabetes Nachsorge" (diabetes aftercare). DiNa is holistic, family friendly and individualisticly orientated adapted to the needs and advises and trains patients in their outpatient department in every single aspect of diabetes. In special cases DiNa even looks after patients

at home. DiNa's assistance is free of any cost for the families of the pediatric patients. The project team consists of the following partners:

The department of paediatrics of the St. Agnes-Hospital

The department of pediatrics of St. Agnes-Hospital Bocholt, Germany, combines physicians, diabetic counselors, a psychologist, pediatric nurses and diet assistants. It offers the classical stationary registration within the context of the patient's first manifestation, his or her adjustment to the new circumstances, outpatient control appointments every three months, the necessary interventions to deal with crises at hand and the necessary schooling on the part of the clinic within an outpatient setting, counseling by specialists, detailed specialist talks and symposia.

The 'Caritas' organisation

The 'Caritas' organisation in conjunction with the dekanate Bocholt is Germany's largest charitative organisation which is concerned with the welfare of people. The 'Caritas' organisation within the context of its model project DiNa brings the “FiZ” (“Family ist Zukunft”) and a children's outpatient care programme of Bocholt's social station into special focus.

FiZ: The FiZ-programme provides information, counselling and specialist assistance as an outpatient cooperation partner for affected families as well as for institutions which are in charge of the children and youth affected by diabetes. The tasks and services provided by the FiZ as a partner of DiNa are the provision of information intended to help families deal with problems (specific and non-specific), the coordination of activities between the clinic and the families, the development of individual plans of assistance for the family based upon the special needs and in keeping with the available resources, the coordination with the corresponding forms of assistance, the accompanying of the family during the measures to be undertaken, the control of the effectiveness of the measures and if necessary changes to the aims and forms of assistance and the provision of information relative to forms of assistance such as nursing allowance and the documentation for handicapped people. Thus, the FiZ is a centralized information service which includes counselling services and serves as case manager in outpatient cases.

Outpatient children's care service: a further important partner of DiNa introduces the Caritas social station with its 'outpatient diabetes-team' which consists of nurses, diabetic assistance and diabetic counsellors. Access to the outpatient's children's care services is gained through the children's diabeticological team in the respective hospital that judges the needs of the young patients either after the first manifestation of symptoms or after the appearance of manifold problems in the course of the diabetic management.

Diabolinos e.V.

“Diabolinos e.V.“ is a supportive association which offers self-help groups. Such groups meet regularly in subject oriented evenings that may include family groupings as well as larger communal groupings. There are also telephone emergency assistance groups that deal either with questions relative to the management of diabetes or other problems. By means of active publicity such a communal organization, the association manages to collect donations which help to maintain projects in the context of diabetes.

This constellation of cooperation partners with DiNa enables a flexible approach to totally different point of views for families. The medical treatment of the young patients with diabetes mellitus remains first priority. The clinic team assist the family from the first manifestation of diabetes onwards and can monitor - within the spectrum of DiNa with its conjunction to various cooperation partners- entirely different living conditions of the families whenever the illness of the child or adolescent presents difficulties for the family over the long-term. An illustration of the DiNa network can be found in figure 2.

DiNa is especially engaged in the event of the first manifestation which is treated stationary. On the one hand, the family is supported by the transition from the clinic into everyday life and on the other hand, the inpatient treatment is reduced to the minimum. In the first phase of the disease, when diabetic management must be implemented into everyday life, families are often worried, frightened, emotional and strained. The daily visit of the nurse reduces the burden on the families and gives the specialist the opportunity to prevent poor adherence to treatment regimens. If after a period of two weeks further support seems to be necessary, the other cooperation partners get in touch with the families. Also in families where diabetes causes trouble, even after a long diabetes duration, the cooperation partners get involved.

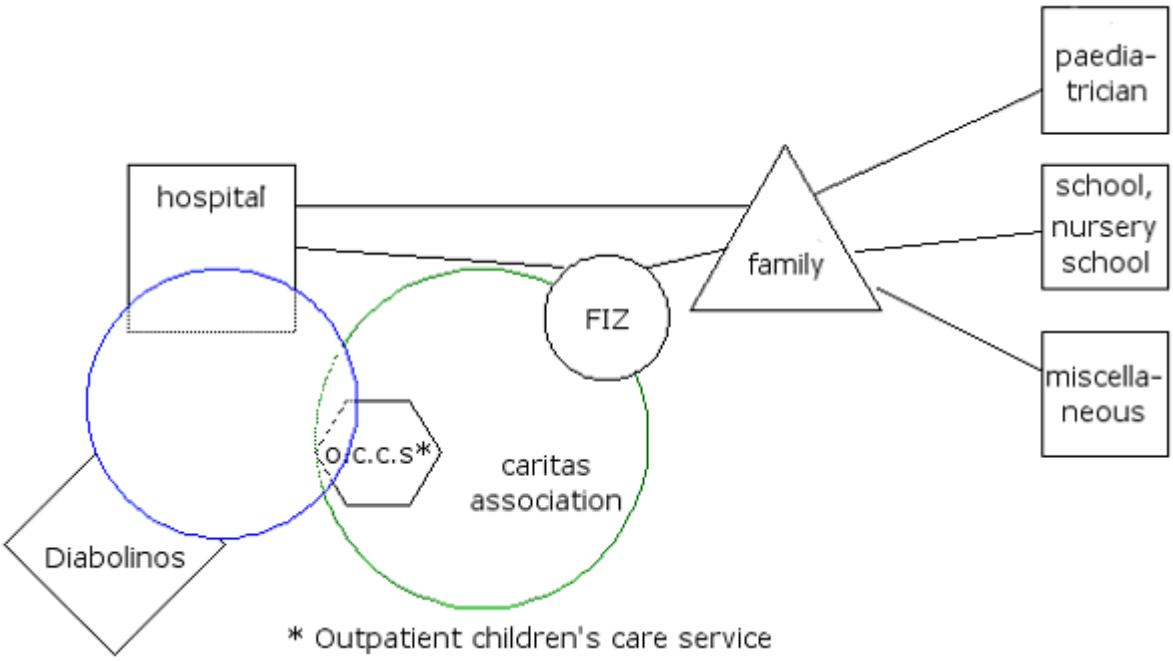

Figure 2 Support of DiNa (Diabetes aftercare) for families with psychosocial problems

The aim of DiNa is to improve the health-related quality of life of the patients which includes strengthening the psychosocial development and social integration of the young patients with T1D in accordance with the international paediatric guidelines of diabetic therapy (Delamater, 2007).

1.6 Health- related quality of life

From a medical point of view, diabetes therapy aims at avoiding long-term life-threatening consequences of the disease. From a psychosocial point of view the important outcome variable is the patients´ well-being and quality of life.

HRQOL assessment of children has only recently come into focus (Peterson, Schmidt, Bullinger & DISABKIDS Group, 2006). Unlike HRQOL in adults with T1D, the measurement of health-related quality of life in paediatric patients has been neglected for a long time. In recent years, however, it has gained more consideration in health research and health promotion (Ravens-Sieberer, Gosch & Abel, 2001a).

“HRQOL is defined as the physical, emotional and social aspects of an individual’s disease and/or its treatment” (Peterson et al., 2006, p. 51). Health-related quality of life is thus a multidimensional construct. Most questionnaires of health-related quality of life

measure the impact of specific diseases and its treatments. According to Polonsky (1996) consensus in assessing HRQOL is reached in regard to three core domains of quality of life, namely physical, psychological and social functioning. These main items can be subdivided into further dimensions and facets.

Spezia Faulkner (2003) found that adolescents with diabetes judge their quality of life significantly lower than their healthy peers. Other studies are more controversial in regard to the quality of life of children and adolescents with T1D. On the one hand, self-reported quality of life of children and adolescents with T1D is similar in comparison to non-affected children as revealed in several studies (Laffel, Connell, Vangsness, Goebel-Fabbri, Mansflield & Anderson 2003; Hoey, Aanstoot, Chiarelli, Daneman & Danne, 2001; Mc Millan, Honeyford, Datta, Madge & Bradley 2004; Bartus et al., 2001). On the other hand, affected children and adolescents complain about feelings of restriction. These findings are confirmed by Mc Millan et al. (2004) who states that 70% of the affected children and adolescents regard their quality of life as satisfactory but nevertheless 60% of the questioned patients think diabetes to be a restrictive factor. This apparent paradox can be explained by a study of Wagner, Abbott and Lett (2004) which points out that diabetes is not the predominant factor in assessing the quality of life. Family, friendship and school are rated as more important.

Quality of life of adolescent patients with T1D is especially influenced by metabolic control and the attitude of the family towards the illness. Thus, poor disease control and family conflicts correspond with a low quality of life (Hoey et al., 2001). However, Valenzuela et al. (2006) stated that family parameters are more important than clinical parameters such as the specific treatment.

The acquisition of data on the HRQOL in children and adolescents can help to identify subgroups or individuals who have a higher risk of problematic psychological implications (Ravens-Sieberer et al., 2001a). Especially studies are needed which focus on the health-related quality of life of paediatric patients and which describe factors influencing the health-related quality of life (Ravens-Sieberer, Ellert & Erhart, 2007). “Because the adherence to self-management that ultimately leads to good glycaemic control requires good self-preparation to integrate the experience of the chronic disease, it is essential to explore the HRQOL of children and adolescents with T1DM“ (Kalyva, Malakonaki, Eiser & Mamoulakis, 2011, p. 37). Furthermore, research concerning the issue of health-related quality of life in diabetic

patients has been mostly carried out in Australia, North America and UK and there is a lack of research conducted elsewhere (Kalyva et al., 2011).

Although quality of life is considered to be an important outcome variable in paediatric research, little is known about the relationship between HRQOL and other significant constructs (Peterson et al., 2006). This is the reason for the growing interest in identifying factors that shape the paediatric patients' health-related quality of life either in a positive or negative way (Peterson et al., 2006). In one of the few studies concerning this issue, Ravens-Sieberer, Redegeld and Bullinger (2001b) found that 37% of the variance in HRQOL in a paediatric obesity group was explained by coping strategies, lack of emotional support and poor global health. Peterson et al. (2006) pointed out a positive correlation between positive coping and health-related quality of life. In regard to T1D an early onset and a long duration of the disease (Yu, Kail, Hagen & Wolters, 2000) along with poor metabolic control (Debono & Cachia, 2007) can be linked to poorer health-related quality of life. In regard to gender, girls have demonstrated lower HRQOL, have more worries about diabetes, are less satisfied and have a poorer conception of their own health in comparison with boys (Eiser & Morse, 2001).

1.6.1 Psychological distress

Apart from the three components of the therapy including insulin injections, diet and physical activity, the treatment of diabetics demands a regular control of the blood glucose level which requires discipline of the patients' daily routine. To achieve the aims of the regimen, the patients have to spend a lot of time, effort and energy which has a great psychological impact on the patients (ADA, 2009). Apart from the major changes in lifestyle, the possibility of developing life-threatening complications such as cardiovascular disease, retinopathy, nephropathy and neuropathy can cause a lot of psychological distress (Landell-Graham, Yount & Rudnicki, 2003). In children, the responsibility of the diabetic management is to a great extent guarded by parents. The young patients are often unable to care for their diabetes on their own. Nevertheless, managing the disease can be overwhelming for children (Debono & Cachia, 2007). When children reach adolescence and are entering puberty, they are struggling for their autonomy which is associated with rapid biological changes (Jacobson, Hauser & Wolfsdorf, 1987). Especially an attitude characterized by refusal can lead to poorer adherence

to medications and worse metabolic control which results in a poor quality of life (Chih et al., 2009). Thus, life adjustment problems are common in this age group.

Several studies reveal that children and adolescents with T1D have a higher risk to develop psychological disorders (Jacobson et al., 1997; Kovacs, Goldston, Obrosky & Bonar, 1997; Northam, Matthews, Anderson, Cameron & Werther, 2004). In comparison to healthy children and adolescents, the prevalence of internalized as well as externalized disorders are two to three times higher in children and adolescents with T1D (Grey et al., 2002). Depressive symptoms are shown especially in paediatric patients who do not have as much familiar affection. A bad regulation of metabolic functioning also triggers mood disorders (Hood et al., 2006). Clinical as well as sub clinical eating disorders are much more common as revealed in the overall prevalence of 10 to 15 percent in affected adolescents (Grylli, Hafferl-Gattermayer, Schober & Karwautz, 2004). Especially females are prone to defiant eating behaviour and abnormal attitudes towards eating (Maharaj, Rodin, Olmsted, Connolly & Daneman, 2003). There is no difference in the occurrence of anorexia as such, but the incidence of bulimia and “binge eating disorder“ are higher in comparison to their healthy peers (Jones, Lawson, Daneman, Olmsted & Rodin, 2000). A further issue in female patients is that they manipulate their weight by reducing the amount of insulin intake, a phenomenon called “insulin-purging“, which frequency is even higher than eating disorders by 12 to 40 percent (Wiedebusch, Muthny & Ziegler, 2008).

1.6.2 Social relationships

Diabetes can impair the social relationships of patients. When children reach puberty they often feel pushed to manage their disease with more discipline. This can lead to feelings of being alone, unsupported and being different from healthy peers (Debono et al., 2007). This idea is supported by a study of Jacobson et al. (2004). They followed adolescents with T1D and a control group and found out that those with diabetes had fewer friendships, more difficulties in intimate love relationships and less sense of trust compared to the control group of the same age.

1.6.3 Physical functioning

Short-term complications of T1D can affect physical health in children and adolescents. Diabetic patients suffer from frequent infections and recurrent hypoglycaemic episodes, often linked to several side effects, which can be a burden (Debono et al., 2007). This is verified by Davis, Morrissey, Wittrup-Jensen, Kennedy-Martin en Currie (2005) who emphasized the great impact of hypoglycaemia on the productivity, well-being and quality of life of affected patients.

1.7 Self-efficacy

According to Ott, Greening, Palardy, Holderby and DeBell (2000) especially self-efficacy seems to have a positive impact on the metabolic control of T1D. Furthermore Grey, Boland, Davidson, Yu, Sullivan-Bolyai and Tamborlane (1998) and Rose, Fliege en Hildebrandt (2002) indicated that diabetes-related self-efficacy has an impact on the quality of lives of adolescents.

Self-efficacy is a key concept from Bandura's social-cognitive theory and is defined as the “conviction that one can successfully execute the behaviour required to produce outcomes“ (Bandura, 1977). Self-efficacy is predominantly influenced by direct personal mastery experience. Furthermore, it is also affected by social experience and physical state (Bandura, 1982). The level of self-efficacy determines the amount of effort one spends to a specific behaviour and has an impact on the perseverance in a given task in regard to any difficulties or failure. Bandura (1986, 1997) claimed that self-efficacy ideas are situation and behaviour specific. They are based on the expectations of outcomes from a target behavior in advance and it can also predict the amount of distress and depression experienced in coping with obstacles (Bandura, 1977). In general, it has a good predictive value for health behaviour (Holden, Moncher & Schinke, 1990). In a chronic disease increased self-efficacy improves adherence to advised treatment regimens.

Self-efficacy correlates positively with quality of life (Rose et al., 2002; Grey et al., 1998). Patients with T1D need to perform in regard to daily insulin injections, self-monitoring of blood glucose, regular exercise and also an adjusted diet. All these aspects of self-management have an apparently high relation to self-efficacy (Glasgow, Fisher & Anderson, 1999). Especially adolescents with T1D are at risk for poor metabolic control and life

adjustment problems which might lead to poorer quality of life. Chih, Jan, Shu and Lue (2010) propose to focus on the identifying factors for a better diabetes control at this age in order to avoid long-term complications. They also state that adolescents with diabetes are prone to avoidance when given increasing responsibility for the management of their chronic illness. Therefore, the factor of self-efficacy is worthy of investigation.

1.8 Stress and stress coping

Stress can be caused by perceived and experienced distress as a result of certain events or "stressors" and can lead to worse metabolic control, more psychological distress in general, and poorer treatment adherence (Farrell, Hains, Davies, Smith & Parton, 2004). Stress may have an impact on the affected youth in a direct and an indirect way. In a direct way, metabolic control is affected by means of physiological changes such as an increase in hepatic glycogen production and insulin resistance (Mortensen et al., 1998). Indirectly, stress can interfere with the treatment adherence (Helgeson, Escobar, Siminerio & Becker, 2010). However, the relationship between stress and glycaemic control is inconsistent across studies (Berlin, Rabideau & Hains, 2012). Stress can cause contradictory effects in individuals (Kramer, Ledolter, Manos & Bayless, 2000). Some profit from "stressors" by a better management of diabetes such as a more frequent blood glucose control (Blonde & Carter, 2005). Others engage in behaviours which result in suboptimal management and metabolic control. Thus, the context of stress plays an important role (Berlin et al., 2006). Based on Wallander and Varni's (1998) stress and coping model, the impact of stress depends on the stress processing of the individuals which includes the stress perception and coping as well as the sources or ecological context of stress such as family environment, social support, school environment and peers. Berlin et al. (2012) found that family stress rather than interpersonal/peer stress appears to be a major stress domain associated with suboptimal metabolic control.

According to Moore (1975), there are three types of stress factors in childhood and youth, namely life crises (illness, move and/or death of a parent), developmental problems (puberty, school entries) and everyday tensions and problems. The latter represents the most important aspect in stressful life by children and youth. In addition to everyday stressors, longitudinal studies have revealed that adolescents with T1D were significantly burdened by illness-specific stressors such as blood glucose self-control, metabolic instability, staying in

hospitals, injections, keeping a strict diet and long-term complications (Seiffge-Krenke, 2001). Thus, coping with the necessity of self-management can be a very demanding task. In scientific research dealing with the transactional stress model, there is a differentiation between problem-orientated coping and emotion-regulating coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). Problem-orientated strategies relate to the direct confrontation with problems and therefore result in attempts of an active problem-solving. Emotion-regulating strategies, on the other hand, are intended to ease stress-causing events by means of negative emotional reactions (Folkman et al., 1986). It is assumed that a problem-orientated approach is the better solution in a controllable situation whereas otherwise indirect coping would be the better approach (Folkman et al., 1986).

The coping styles often used by children are cognitive restructuring, wishful thinking and to a smaller extent distraction, social support, problem solving and emotional regulation where social support and problem-solving, followed by cognitive restructuring have proved to be the most effective coping styles (Rathner & Zangerle, 1996). Coping styles are differently used by adolescents. Adolescents frequently use resignation, wishful thinking and problem-solving, followed by cognitive restructuring. In this context, social support and problem solving can be regarded as the most positive strategies (Rathner & Zangerle, 1996).

The experiences of advanced demands without the means of adequate coping can lead to symptoms of stress. The experience of stress can be expressed in psychological as well as physical symptoms (Weber, 2003). While subjective well-being is a very important factor for the health condition, it is very important to link specific coping styles with quality of life which has not been studied extensively so far (Grylli, Wagner, Hafferl-Gattermayer, Schober & Karwautz, 2005).

1.9 Communication between affected child and its parents

The quality of parental interaction has a large impact on the management of diabetes care in youth and can be associated with treatment adherence and metabolic control (Jaser & Grey, 2010; Hood, Butler, Anderson & Laffel, 2007). Especially, negativity, nagging and criticism is associated with poor adherence and glycaemic control (Duke et al., 2008) and seems to be a good predictor of psychological well-being. A study of Wiebe (2007) for example showed that a parenting style which is coined by guilt and negative criticism is related to more depression

in adolescents with T1D as well as a lower self-efficacy for handling diabetes. Greening, Stoppelbein & Reeves (2006) made the hypothesis that positive parental interaction increased the youth's treatment adherence by means of better self-efficacy. This view was supported by a study of Ott, Greening, Palardy, Holderby & DeBell (2000) who found that self-efficacy proved to be a mediator between critical parental behaviors and adherence in adolescents with T1D. It becomes problematic when parents and their children cannot distinguish between typical age-related problems and diabetes-related conflicts (Wiedemann, 2009). This is for example the case when parents state: “If you bring a too high blood sugar level home, you can forget the party at the weekend.” Or when the youth threaten: “If you prevent me from chatting in the internet, I stop measuring my blood sugar level.” Such a mixing of different problem areas makes it difficult to find constructive solutions (Wiedemann, 2009). A collective teamwork of youth and their parents in the process of diabetic management has resulted in the best approach to a good metabolic control (Wiedemann, 2009). It presumes that parents have the role of an advisor who accompany and support their children and who are willing to grant their teenage-children elements of individual responsibility (Wiedemann, 2009). This teamwork approach has the effect that family conflicts can be reduced which has a positive effect on the quality of life of all members of the families. However, the studies focused mainly on older adolescents. Thus, literature reveals a salient gap considering parental interaction in younger children or preadolescents with T1D because younger children depend more on their parents than older adolescents (Anderson, Auslander, Jung, Miller & Santiago, 1990). Whereas in an age of preadolescence, the patients start to attempt to take up more responsibility for the diabetic care (La Greca, Follansbee & Skyler, 1990). All these findings underline the need to examine the quality of the communication between parents and their affected child (Duke et al., 2008) and to explore its direct or indirect influence on the quality of life. As the parental interaction has an impact on the metabolic control (Jaser & Grey, 2010) and the quality of life of patients with T1D is especially influenced by metabolic control (Hoey et al., 2001), a mediation effect of metabolic control between the parental interaction and the quality of life is worth investigation.

1.10 Quality of life of parents of a chronically ill child

Not only for the affected child but also for the whole family, a chronic disease means suffering a lot of strain (Petermann, 2002). Family life is affected by the illness specific requirements and special needs of a chronically ill child (Troester, 2005).

The parental quality of life is regarded as a result of the physical and psychological state, the social situation in combination with the parent's ability to function in life (Goldbeck and Storck, 2002). The confrontation with having a chronically ill child can go along with worries about the welfare and the future of their affected child. The care of the affected child requires personal as well as time demanding resources which can lead to the feeling of being overstrained (Goldbeck & Storck, 2002). Parents of a chronically ill child more often report restrictions on the emotional stability and their general well-being than parents of healthy children (Goldbeck & Storck, 2002). Goldbeck and Storck (2002) sum up the psychological risks, parents of chronically ill children are confronted with. These risks include and increased vulnerability for depression, psychosocial deviations and a higher prevalence of clinical and sub clinical disorders. Children with diabetes mellitus whose parents are helpless and little cooperative more frequently have a bad metabolic control (Petermann, Noeker & Bode, 1987) which in turn is associated with a poorer quality of life (Guttman-Bauman, Flaherty, Strugger & Mc Evoy, 1998).

1.11 Adherence

Despite the availability of effective diabetes regimens, adolescents with type 1 diabetes show poorer adherence to treatment therapies in comparison to other paediatric patients (Borus & Laffel, 2010). A better adherence to diabetes management has a positive influence on metabolic control and in turn, lower hemoglobin A1c (HbA1c) levels are associated with a better quality of life (Eren, Erdi, & Sahin, 2008). Furthermore, the complexity of the treatment requires constant control of blood glucose and the patients face the burden of enduring insulin devices at the body. Despite of the progress in technology that improved insulin delivery with pens or pumps, adherence to diabetes therapies seems to be problematic for all patients, but proved to be most difficult for adolescents (Morris, Boyle and McMahon, 2009). This age group face numerous obstacles to adherence, including developmental behaviours,

interaction in family and perceived social pressures which adds up to the relative insulin resistance brought on by developmental physiology (Borus & Laffel, 2010).

1.12 Intellectual ability

Self-management practices can be related to certain intellectual abilities. Especially planning and problem solving competencies are associated with ameliorated self-management behaviours (Primozic, Tavcar., Dernovsek & Oblak, 2012). Findings of Sinclaire, Girling and Baye (2000) showed that diabetes patients with lower cognitive abilities were less engaged with diabetes management behaviours, required significantly more help in life and were more likely to have stayed at the hospital in the year before.

1.13 Research questions

In recent years, researchers have been concerned with different factors in relation to diabetes mellitus in order to explore determinants of lower health conditions in adolescents who show an increased risk of developing late sequelae (Gonder-Frederick, Cox and Ritterband, 2002). Especially studies are needed which focus on the health-related quality of life of paediatric patients and which describe factors influencing the construct of health-related quality of life (Ravens-Sieberer, Ellert & Erhart, 2007). The identification of relevant risk factors should contribute to the development of risk management strategies in order to ameliorate the quality of life, to strengthen the metabolic control and to reduce complications (Diabetes Control and Complications Trial Research Group, 1994).

So in order to explore factors that relate to the paediatric patients' quality of life either in a direct or indirect way, the objective of this study was to investigate the correlates of the health-related quality of life (HRQOL) of paediatric patients with T1D. The quality of life is a construct that cannot be easily measured, though (Giannakopoulos et al., 2009). Thus, the level of congruence between the patients' self-reports and the parents' proxy-reports on the patients' quality of life was examined in order to better judge the suitability of both sources of information. Additionally, this study investigated changes in HRQOL and self-efficacy over a period of two years (2011 vs 2013) by paediatric patients who have participated in the DiNa project.

2 Method

2.1 Sample and procedure

In the waiting room of the outpatients' department of the pediatric ward of St. Agnes-Hospital, a questionnaire consisting of three different scales was administered to 94 patients and one questionnaire consisting of two different scales was administered to their accompanying parent(s) between April and July 2013. Furthermore the diabetes team consisting of a doctor, a psychologist and a diabetic nurse was asked to fill in a questionnaire during their team counselling. The patients and their parent(s) were asked consecutively if they were willing to participate in a study about HRQOL in children and adolescents with T1D (2011). Parental permission was ensured. Before handing out the questionnaires, informed consent was obtained. The participation was completely voluntary. The only inclusion criterion was an age between 8 and 16 years. It took each patient about 40 minutes to fill out the questionnaire. Parents needed about 20 minutes to fill out their questionnaire.

The questionnaires of the patients included basic demographics consisting of sex, age, number of siblings and type of school. The questionnaire of the parents included demographic data about their professional- and marital status. Furthermore questions about financial problems, occurrence of medical/psychological diseases in the family and a question about their child's performance in school were asked.

In 2011, one questionnaire consisting of two different scales was administered to 59 patients between March and May 2011. Based on the patient number, 23 patients could be identified who filled in the Kid Kindl® and the PSESD in 2011 as well as in 2013.

2.2 Measures

2.2.1 Health-related quality of life

Health-related quality of life was assessed with the Kid Kindl®- Diabetes- module and the Kindl®- parent version. The Kid Kindl®- Diabetes- module consists of 36 items which can be divided into the three main constructs of physical (items 1-12, e.g. “During last week, I could not do any sports”), psychological (items 13-23) and social functioning (items 25-37).

Psychological functioning can be further divided into *psychological well-being* (item 13-17, e.g. “During last week, measuring blood glucose levels was annoying me”) and *self-esteem* (items 18-23, e.g. “During last week, I was ashamed of my diabetes”). Social functioning is subdivided into the categories *family* (items 24-28, e.g. “During last week, my parents controlled me too much”), *friends* (items 29-33, e.g. “During last week, I was excluded because of my diabetes) and *school* (items 34-36, e.g. “During last week, I had difficulties to concentrate because of my blood glucose level”). The parents proxy-reported the quality of life of their children. This version consists of 24 items, which are assigned to the same dimensions, that is to say: physical functioning (e.g.“During last week, my child felt sick”), psychological well-being (e.g. “During last week, my child laughed a lot and had a lot of fun”), self-esteem (e.g. “During last week, my child was proud”), family (e.g.”During last week, my child felt at ease at home”), friends (e.g. “During last week, my child did something together with a friend”) and school (e.g.”During last week, my child managed to do his/her homework on his/her own”).

Answers could be given by means of a five-point Likert-scale ranging from *never* (score 1) to *always* (score 5). A higher score is associated with a higher HRQOL score. The total score was calculated by the sum score divided by the number of items. The same procedure was applied to each sub scale. The psychometric properties reveal a high reliability (Cronbach’s $\alpha \geq .70$) in the majority of the tested samples (Ravens-Sieberer, 1998). In regard to convergent validity, the total score of the Kid Kindl® had a high correlation with the sub scale *general well-being* of the Child Health Questionnaire and the sub scales *vitality* and *psychological well-being* of the SF-36 ($r > .60$) (Bullinger & Kirchberger, 1998). Moreover, the questionnaire had a high acceptance by children and adolescents (Ravens-Sieberer, 1998).

2.2.2 Self-efficacy

The PSESD “Paediatric self-efficacy scale Diabetes” was specially developed to measure self-efficacy in regard to diabetic management in children and adolescents with T1D (Winter, 2011). The items imply typical problematic situations the pediatric patients can be confronted with. Examples of items are: “I can cope with too high and too low levels of blood glucose, even if I don’t expect them“. “Whatever happens with my blood glucose level, I’m sure how to handle it.” An exploratory factor analysis identified one clear factor which was interpreted as a representation of diabetic management in regard to problematic situations. The

questionnaire consists of ten items but it was recommended in an earlier study to exclude the first three items. Thus, this study used the other seven items which are answered on a four-point scale: 1) “does not correspond“, 2) “hardly corresponds“, 3) “mostly corresponds“ and score 4 means “totally corresponds“. Higher scores indicate a higher level of self-efficacy whereby the average score was calculated. Considering the internal consistency, a Cronbach’s alpha of .86 was found which is an indication of a very high internal consistency of the questionnaire of the PSESD (Winter, 2011).

2.2.3 Stress and stress coping

The SSKJ3-8 (Fragebogen zur Erhebung von Stress und Stressbewältigung im Kindes- und Jugendalter) was used to measure stress and stress coping for children and adolescents in class 3 up to class 8 (Lohaus, Eschenbeck, Kohlmann & Klein-Heßling, 2006). The questionnaire consists of three different scales. The first scale deals with stress vulnerability (6 items) which focuses on the potential stress of everyday problems. The young patients rated the extent to which a variety of situations are stressful using a 4 point scale ranging from 'no stress at all' to 'very much stress' which is underlined by smiley’s with the particular facial expressions. One example is: “Imagine, you would like to tell your parents something important but your parents have no time and don't listen to you. How much stress do you have if something like that happens to you?”

The second scale assesses strategies to overcome stress. Two particular situations are covered of two sets of thirty items each (2 * 30). In the first situation, the youth is asked to imagine to have an argument with a very good friend. In the second one, the young patients are asked to imagine to have a lot of homework which they cannot manage on their own. These two situations consist of five sub scales which cover six items each: a) seeking social support (e.g.: “If something like that happens to me, I will tell someone from my family what has happened”), b) problem-solving (e.g.: 'If something like that happens to me, then I will get ready to solve the problem.”, c) avoidant coping (e.g.: “If something like that happens to me, I will pretend it doesn't strike me.”), d) palliative emotion regulation (e.g.: If something like that happens to me, I will have a rest” and e) anger- related emotion regulation (e.g.: ' 'If something like that happens to me, I will get angry and bang the door behind me”). Answers could be given on a five-point Likert-scale ranging from 'never' to 'always'.

The third scale measures stress symptoms experienced in the last week (18 items) such as headache, restlessness, stomach ache, sleeplessness, dizziness, tremble and heartbeat which is assessed on a three point scale covering 'never', 'once' and 'several times'. A difference is made between physical (e.g. “In the last week, how often did you have a headache”) and the psychological symptoms whereby the psychological symptoms sub scale consists of the dimensions 'anger' (e.g.: “In the last week, how often were you annoyed?”), 'sadness' (e.g.: “In the last week, how often were you sad?”) and 'fear' (e.g.: In the last week, how often did you feel restless?”). In relation to the internal consistency the SSKJ3-8 achieved values between .66 and .89 whereas the values of the retest-reliability lie between .56 and .82. On the whole, the reliability values reach the extent that justifies the use of the questionnaire in practice (Lohaus, Eschenbeck, Kohlmann, & Klein-Heßling, 2006). Extended studies relative to the construct validity (Inter correlations of the scales of the questionnaire and factorial validity) and the criterion validity prove that the instrument is applicable to give users a differentiated impression of stress events of children and youth (Lohaus et al., 2006).

2.2.4 Quality of the communication between the paediatric patients and their parents

The diabetes team filled in questions about the quality of the communication between the young patients and their parents. The development of these questions was based on aspects of the teamwork model of Wiedemann (2009) who states that in order to reduce the number of conflicts between parents and their affected children with diabetes, some rules have to be followed. These questions were derived from the following aspects: 1) parents should not interrupt their children, 2) diabetes problems should not be mixed up with age-related problems, 3) Parents should not use generalizations (“You always...”/ “you never...”) and 4) Parents should not give orders without explaining their intentions. The diabetes team could give answers on a five-point scale ranging from “never happens” to “always happens”.

2.2.5 Quality of life of parents

This study used the ULQIE (Ulm quality of life inventory for parents of chronically ill children), originally known as the “Ulmer Lebensqualitaet-Inventar für Eltern chronisch kranker Kinder” in order to measure the quality of life of the parents. The instrument was developed by Goldbeck & Storck in 2002 and consists out of 29 items. The questionnaire measures various

aspects of the quality of life of parents under the consideration of a chronical illness of the child including physical and daily functioning, satisfaction with the situation in the family, emotional distress, self-development and well-being. The instrument has satisfactory psychometric properties and internal consistency (Goldbeck and Storck, 2002). UlQIE proved to be a successful instrument for parents of children with diabetes mellitus (Goldbeck, 2006).

2.2.6 Adherence

How carefully and consequently the young patients have documented blood glucose levels was determined by the diabetes team employing the German school mark system going from one (excellent) to six (complete failure). This measure serves as surrogate for the determination of the patients' adherence.

2.2.7 Intellectual ability

The diabetes team of the St. Agnes-Hospital in Bocholt, Germany, also evaluated -employing the German school mark system- how well the school attendance ability of a child would be (whether it is attentive and learns fast, whether it is concentrated), how adjustment of doses of insulin are calculated and how well it is done according to their age.

2.3 Medical data

2.3.1 Metabolic Control

Metabolic control of the patients was measured using hemoglobin A1c which was obtained during the routine clinic visit. HbA1c reflects the average level of blood glucose during a 2-3 month period (Bartus & Holder, 2012). It is commonly used as a measure of long-term blood glucose management and the standard to index whether diabetes treatment goals are being achieved (higher levels indicate poorer control) (Tran and Wiebe, 2011). Levels of < 7% are associated with a reduction in the incidence of the complications associated with diabetes, such as nephropathy, retinopathy, neuropathy, heart disease and stroke (Berlin et al., 2006).

2.3.2 Hypoglycaemias

The number of hypoglycaemias over the last three months was also filled in by the diabetes team. Hypoglycaemia is defined as a too low blood sugar level below the level of 50mg/dl. This is a result of either too much insulin, too little nourishment, intensive physical activity or by the consumption of alcohol. Symptoms of this condition are restlessness, extreme appetite, a lightly reduced working of the brain, increase in aggression to the point of getting cramps or falling into a state of shock depending on the degree of under sugaring (Bartus & Holder, 2012).

2.3.3 Ketoacidoses

The number of ketoacidoses over the last three months was also taken up by the diabetes team of the St. Agnes-Hospital in Bocholt, Germany.

A ketoacidosis is characterized by a continous increase of the blood sugar because glucose cannot reach the muscle- and fat cells because of a lack of insulin (Bartus & Holder, 2012). Apart from that, the liver produces glucose on the increase. Due to the lack of insulin in the cells, fat is broken down resulting in a production of keton bodies which lead into the appearance of lactic acid in blood. The ketoacidosis is defined clinically by non-specific symptoms such as vomiting, polyuria, thirst and weakness. In the further clinical course, symptoms such as turbidity until the lack of consciousness, the *Kußmaul-Kien* respiration and exsiccation can occur (Bartus & Holder, 2012).

2.4 Statistical analysis

Data were analysed using the Statistical Package for Social Scientists (SPSS), version 14.0. In order to get a clear overview of the population, tables of frequencies of the demographic data were drawn up in the first place. Means and standard deviations were calculated for the total score and the scores of the six different sub scales of the Kindl® questionnaires. In order to compare the score results between girls and boys and between age groups (8-12 vs 13-16), means and standard deviations were calculated for those groups, too. In order to provide an indication of the reliability of the questionnaires, Cronbach`s alpha was calculated, too. For Cronbach`s alpha, Nunnally`s advised criterion .70 was taken as a reference point. Mann-

Whitney tests were used to examine differences in age groups (8-12 years versus 13-16) and gender.

In order to investigate the relations between the scales of the Kid Kindl® questionnaire and the other questionnaires, univariate analyses were run. Spearman`s correlation coefficients were calculated between the scales of the Kid Kindl® and the scores of the PSESD, the SSKJ3-8, the Kindl®-parent version, the medical data, the treatment adherence, the intellectual ability, the quality of the communication between the paediatric children and their parents, the ULQIE and the parent's self-rated health condition as well as financial and school problems. This study used Cohen's (1988) conventions to interpret effect size. A correlation coefficient of .10 was considered a weak association, a correlation coefficient of .30 was thought to represent a moderate relation and a correlation coefficient of .50 or larger was interpreted as a strong correlation. In multivariate analyses, multiple regression analyses were used in order to further investigate the relation between different aspects of health-related quality of life and the other significant constructs in depth. During these analyses, several assumptions of the model were checked. To assess the assumption of no multicollinearity, the correlation matrices were scanned. Values of $R > .9$ indicate that there is collinearity in the data (Field, 2009). By means of the collinearity diagnostics of variance inflation factor (VIF), data were checked for subtle forms of multicollinearity. VIF values greater than 5 or 10 or 'tolerance' values (1/VIF) below 0.2 or 0.1 are indications of concern for multicollinearity (Field, 2009). In order to avoid autocorrelation in residual term, the Durbin-Watson test was used, which tests for serial correlation between errors. A value close to 2 means that the residuals are uncorrelated (Field, 2009). In order to look for cases which might influence the regression model, the standardized residuals and values of Cook's distance were checked. More than 1% of cases of standardized residuals with absolute values above or beneath +- 2 and Cook's distance values exceeding the value 1 indicate cases which might influence the model (Field, 2009).

Finally, the normality of residuals was tested by means of a histogram and a normal probability plot which plots the cumulative probability of a variable against the cumulative probability of a distribution.

Mediation analyses using the causal steps approach of Baron & Kenny (1986) were used in order to test whether quality of the communication between the paediatric patients and their parent exert influences on the HRQOL through metabolic control as intervening variable.

Wilcoxon signed-rank tests for dependent samples were done in order to examine whether signifcant changes of the health-related quality of life and self-efficacy over a period of two years could be found by the paediatric children who participated in the DiNa project.

3 Results

3.1 Demograhic data

Table 1 shows an overview of the demographic data of the paediatric patients. In total, 94 paediatric patients participated in the study. Girls were slightly over represented (58.5%) in contrast to boys (41.5%). All ages were represented in the sample in which the twelve year olds form the best represented age group by 19.1%. Almost half of the sample had one sibling (48.9%) and almost a third of the sample had two siblings (28.7%). All school types were represented in the study. However, the *Grundschule* (22.3%), the *Realschule* (28.7%) and the *Gymnasium* (29.8%) were most attended. Apart from three children who came from Russia, Lebanon and Romania, all patients were German in the sample. The demographic data between female and male patients did not demonstrate any significant differences in regard to age ($p = .08$) or number of siblings ($p = .19$) by Mann-Whitney U test. In regard to educational level, there was a significant difference ($p = 0.006$). More girls (37.5%) than boys (17.9%) attended the Gymnasium, the highest school type, whereas more boys (15.4%) than girls (5.5%) attended the *Hauptschule*, the lowest school type.

Table 1 Demographic data of the patients

variable	n	(%)
Gender		
Girls	55	(58.5%)
Boys	39	(41.5%)
Age		
8	7	(7.4%)
9	8	(8.5%)
10	8	(8.5%)
11	11	(11.7%)
12	18	(19.1%)
13	8	(8.5%)
14	10	(10.6%)
15	11	(11.7%)
16	13	(13.8%)
Mean age = 12,36(SD=2,48)		
Siblings		
0	6	(6.4%)
1	46	(48.9%)
2	27	(28.7%)
3	10	(10.6%)
4	3	(3.2%)
5	0	(0%)
6	1	(1.1%)
Missing	1	
School		
Grundschule	21	(22.3%)
Hauptschule	9	(9.5%)
Realschule	27	(28.7%)
Gesamtschule	5	(5,3%)
Gymnasium	28	(29.8%)
Sonderschule	3	(3,2%)
Missing	1	

Table 2 shows the demographic data of the parents of the paediatric patients. 70.5 % of the parents were married and 12 parents did not live with the biological partner of the affected child any more. 5% stated to have financial problems. However, 17 parents refused to answer this item. 20.1% declared to have an additional medical or psychological affected member within the family. Also at this point, 17 parents neglected this item.

Table 2 Demographic data of the parents of the paediatric patients

variable	n	(%)
Family status		
Married	67	(70.5%)
Divorced	3	(3.2%)
Single parent	4	(4,2%)
Living with a partner	5	(5,3%)
missing 16		
Financial problems		
None	69	(72.6%)
Low wages	8	(8,4%)
Income support	1	(1,1%)
Missing	17	
Further medical, psychological illnesses within the family		
None	57	(60.6%)
Yes	20	(20.1%)
Missing	17	

3.2 Health-related quality of life

3.2.1 Self-reported health-related quality of life

Table 3 shows the means, standard deviations and Cronbach`s alpha`s for the total score and the score of the six sub scales of the Kid Kindl® questionnaire. Means and standard deviations are also compared between girls and boys and between age groups (age 8-12 versus 13-16). Cronbach`s alpha of the total score of the Kid Kindl® was found to be .71 which is an indication for an acceptable reliability of the scale. As Nunnally`s (1978) advised criterion of an alpha of 0.7 is taken as a reference point, it become apparent that several sub scales are insufficiently consistent such as physical functioning (α = 0.57), psychological well-being (α = 0.65), the sub scale friends (α = 0.61) and school (α = 0.49). The other sub scales, however, do reach this criterion.

Table 3 Descriptive statistics of the Kid Kindl® scores

	Items	Total		Girls		Boys		Age 8-12		Age 13-16		
Kid Kindl® scales		M	SD	M	SD	M	SD	M	SD	M	SD	α
KidKindl®Total[1]	36	3.01	0.37	3.01	0.22	3.02	0.45	3.03	0.17	2.98	0.43	0.71
Physical functioning[2]	12	4.11	0.55	4.09	0.57	4.14	0.53	4.12	0.48	4.09	0.55	0.57
Psychological well-being[3]	5	3.84	0.69	3.73	0.65	4.00	0.72	3.94	0.62	3.74	0.69	0.65
Self-esteem[3]	6	4.19	0.69	4.15	0.60	4.24	0.83	4.29	0.64	4.04	0.74	0.70
Family[4]	5	3.93	0.91	3.96	0.86	3.87	0.99	4.03	0.75	3.72	1.06	0.86
Friends[5]	5	3.98	0.65	4.00	0.61	3.96	0.72	4.03	0.46	3.88	0.71	0.61
School[6]	3	4.23	0.70	4.22	0.68	4.23	0.73	4.04	0.75	4.04	0.75	0.49

Note [1]: 20 missing Note [2]: 10 missing Note[3]: 5 missing Note [4:] 3 missing Note [5]: 2 missing Note [6]: 1 missing

As the maximum score of the scales amounts to the value of 5, the descriptive statistics show that the highest sample scores were achieved with the *school* sub scale (M = 4.23), followed by the *self-esteem* (M = 4.19) and *physical functioning* (M = 4.11). The total score, however, revealed the lowest score (M = 3.08). The scores on the Kid Kindl® scales did not differ significantly by gender (Total U = 622.50, z = -2.40, p = .81, r = -.03). By age group, younger patients (8-12) had significant higher scores on the dimension *school* (U= 754.00, z = -2.36, p = .02, r = -.25).

3.2.2 Parents' proxy reports on the quality of life of their children

Table 4 shows the means, standard deviations and Cronbach's alpha's for the seven scales of the Kindl® parent-version. A differentiation was also made between gender and age groups. The total scale of the Kindl® parent version has an alpha of .86 which is an indication for good internal reliability. The coefficient of internal consistency of the sub scale *psychological well-being*, *family* and *school* do not reach Nunnally's (1978) advised criterion of .70. However, the other three sub scales reach this criterion.

The scores of the quality of life did not differ by gender by Mann- Whitney U test. By age groups, parents of younger patients rated the quality of life significantly higher on the *overall quality of life* (U = 412.50, z = -2,67, p = .01, r = -.31), *physical functioning* (U = 567.50, z = -2.46, p = .01, r = -.27), *family* (U = 563.50, z = -2.53, p = .01, r = -.28) and *school* (U = 644.50, z = -2.13, p = .03, r = -.23).

Table 4 Descriptive statistics of the Kindl®-parent version scores

	Items	Total		Girls		Boys		Age 8-12		Age 13-16		
Kindl®-parent version scales		M	SD	M	SD	M	SD	M	SD	M	SD	α
Kindl®Total [1]	24	4.01	0.40	3.96	0.38	4.05	0.43	4.13	0.38	3.86	0.38	0.86
Physical functioning [2]	4	4.03	0.67	3.96	0.68	4.13	0.64	4.20	0.61	3.82	0.69	0.74
Psychological well-being [2]	4	4.17	0.52	4.14	0.55	4.22	0.48	4.26	0.49	4.05	0.54	0.64
Self-esteem[3]	4	3.81	0.64	3.83	0.69	3.77	0.56	3.92	0.57	3.66	0.69	0.80
Family[4]	4	3.99	0.60	4.04	0.57	3.92	0.64	4.12	0.55	3.80	0.63	0.68
Friends[4]	4	4.02	0.56	3.94	0.59	4.13	0.49	4.11	0.55	3.89	0.55	0.72
School[5]	4	3.95	0.64	3.91	0.58	4.00	0.71	4.04	0.68	3.82	0.55	0.55

Note [1]: 21 missing Note [2]: 12 missing Note[3:] 15 missing Note[4]: 11missing note[5]:9 missing

3.3 Univariate analysis

3.3.1 Relation health-related quality of life and diabetes-related self-efficacy

Table 5 Spearman's correlation coefficients between the Kid Kindl® scales and the PSESD

	Self-efficacy[1]
Kid Kindl® scales	
Kid Kindl® Total	.11
Physical functioning	.27*
Psychological well-being	.32**
Self-esteem	.33**
Family	.24*
Friends	.13
School	.18

*: p < .05
**: p < .01 (2-tailed)

Note [1]: Measured by the PSESD ,an instrument that measures self-efficacy in regard to diabetic management by pediatric patients

Table 5 shows an overview of the correlations between the scores on the Kid Kindl® scales and the scores on the PSESD by means of the non-parametric statistic of Spearman`s correlation coefficients. There was no significant relationship between the overall health-related quality of life and diabetes-related self-efficacy $r_s = .11$, $p > .05$. Several sub scales of the Kid Kindl® questionnaire, however, were significantly related to diabetes-related self-efficacy. A better psychological well-being revealed a moderate relationship to a higher diabetes-related self-efficacy $r_s = .32$, $p < .01$. The same effect size was found between a higher self-esteem and a higher diabetes-related self-efficacy, $r_s = .33$, $p < .01$. A better physical functioning, $r_s = .27$, $p < .05$, and a better family well-being, $r_s = .24$, $p < .05$, were also significantly related to a higher diabetes-related self-efficacy, representing weak associations.

3.3.2 Relation health-related quality of life and stress vulnerability

Table 6 Spearman's correlation coefficients between the Kid Kindl® scales and the first scale of the SSKJ3-8

	Stress vulnerability[1]
Kid Kindl® scales	
Kid Kindl® Total	-.00
Physical functioning	-.11
Psychological well-being	-.19
Self-esteem	-.10
Family	-.13
Friends	-.32**
School	.01

*: p < .05
**: p < .01 (2-tailed)

Note [1]: measured by the first scale of the SSKJ 3-8

Table 6 shows that only the social dimension *friends* was significantly negatively related to stress vulnerability (r_s = -.32, p < .01), representing a moderate relationship. Worth mentioning is that the overall HRQOL and the *quality at school* show absolutely no relationship with stress vulnerability at all.

3.3.3 Relation health-related quality of life and stress coping

Table 7 Spearman's correlation coefficients between the Kid Kindl® scales and the five different coping styles measured by the SSKJ3-8

	S.Social support[1]	Problem-solving	Avoidant coping	Palliative e.reg.[2]	Anger-rel.e.reg.[3]
Kid Kindl® scales					
Kid Kindl® Total	.03	.30*	-.41**	-.03	-.26*
Physical functioning	.11	.33**	-.41**	-.09	-.41**
Psychological well-being	.09	.26*	-.32**	-.04	-.28*
Self-esteem	.31**	.36**	-.29*	.04	-.35**
Family	.19	.20	-.26*	.00	-.40**
Friends	.19	.27*	-.23	.01	-.43**
School	.18	.23*	-.17	-.03	-.20

*: p < .05
**: p < .01 (2-tailed)

Note [1]: Seeking social support Note [2]: Pallliative emotion regulation Note[3:] :Anger-related emotion regulation

Table 7 shows an overview of the correlations between the scores on the Kid Kindl® scale and the scores on the stress coping scale. Overall health-related quality of life was negatively related to an avoidant coping style, $r_s = -.41$, $p < 0.01$, and to an anger-related coping style, $r_s = -.26$, $p < .05$, and positively related to a problem-solving coping style, $r_s = .30$, $p < 0.05$. Similar patterns could be predominantly found between the six different aspects of the HRQOL and the different coping styles.

Worth mentioning is that only a higher self-esteem represented a moderate relationship with seeking social support as a coping strategy, $r_s = .31$, $p < .01$.

3.3.4 Relation health-related quality of life and stress symptoms

Table 8 Spearman's correlation coefficients between the Kid Kindl® scales and stress symptoms measured by the SSKJ3-8 (third scale)

	Stress symptoms	Physical symptoms	Psychol. symptoms	Anger	Sadness	Fear
Kid Kindl® scales						
Kid Kindl® Total	-.32**	-.14	-.33**	-.23*	-.31**	-.25*
Physical functioning	-.46**	-.23*	-.46**	-.26*	-.43**	-.42**
Psychological well-being	-.43**	-.32**	-.39**	-.31**	-.41**	-.32**
Self-esteem	-.43**	-.40**	-.35**	-.22*	-.36**	-.34**
Family	-.42**	-.29**	-.41**	-.30**	-.30**	-.47**
Friends	-.34**	-.28*	-.32**	-.37**	-.16	-.27*
School	-.25*	-.25*	-.21	-.10	-.26*	-.17

*: $p < .05$
**: $p < .01$ (2-tailed)

As can be expected, a higher well-being on the different sub scales of the HRQOL is associated with less physical and psychological complaints. Worth mentioning is that only *physical symptoms* did not correlate significantly with the overall HRQOL ($r_s = -.14$, $p > .05$). It is also noticeable that except from a weak association with the psychological sub scale *sadness,* the *quality in school* bears no significant relationship with the psychological symptoms of the patients. However, it became apparent that a worse *quality with friends* is especially associated with a feeling of *anger* and a worse *quality in family* is especially related with a feeling of *fear*.

3.3.5 Relation health-related quality of life and the parent' assessment of health-related quality of life

Table 9 Spearman's correlation coefficients between the Kid Kindl®scales and the scales of the Kindl®- parent version

	Kindl®-parent version						
	Total	Physical funct.	Psy. Well-being	Self-esteem	Family	Friends	School
Kid Kindl® scales							
Kid Kindl® Total	.23	.16	.10	.20	.08	.09	.39**
Physical functioning	.36**	.22	.16	.35**	.22	.10	.39**
Psychological well-being	.32**	.31**	.17	.28*	.17	.16	.39**
Self-esteem	.39**	.36**	.25*	.27*	.19	.18	.31**
Family	.33**	.24*	.29**	.29*	.36**	.18	.22*
Friends	.09	.15	.18	.00	.24*	.28*	.13
School	.34**	.32**	.15	.30**	.17	.23*	.31**

*: $p < .05$
**: $p < .01$ (2-tailed)

As can be seen in table 9, the overall self-reported HRQOL of the pediatric patients does not correlate with the quality of life assessed by the parents ($r_s = .23$, $p > .05$) . There was also neither a significant relationship between the sub scales *physical functioning* ($r_s = .22$, $p > .05$) nor between the sub scales *psychological well-being* ($r_s = .16$, $p > .05$) of the Kid Kindl® and the Kindl®-parent version. For the other four specific sub scales of the Kid Kindl®, however, significant moderate relationships could be revealed with the same measured dimension of the Kindl® parent version. Worth mentioning is that almost all the different aspects of the Kid Kindl® scales , except the dimension *friends*, correlate moderately strong to the overall quality of life and the dimension *schoo*l of the parents' proxy reports.

3.3.6 Relation health-related quality of life and metabolic control

Table 10 Spearman's correlation coefficients between the Kid Kindl® scales and the values of the metabolic control

	HbA1c[1]	Hypo`s[2]	Ketoacidosis[3]
Kid Kindl® scales			
Kid Kindl® Total	-.12	.04	-.25
Physical functioning	-.10	.13	-.05
Psychological well-being	-.17	.21	-.06
Self-esteem	-.31**	.33**	-.29*
Family	-.25*	.33**	-.29*
Friends	-.22*	.14	-.32*
School	-.36**	.31**	-.25

*: p < .05
**: p < .01 (2-tailed)

Note [1]: HbA1c reflects the average level of blood glucose during a 2-3month period (higher levels indicate poorer control)
Note [2]: number of hypoglycaemias in the last three month = blood sugar level below the level of 50mg/dl
Note[3]: number of ketoacidoses in the last three months: Continous increase of the blood sugar level

Results indicated that psychological and social aspects of the HRQOL revealed significant relationships with metabolic control. Especially a higher *self-esteem* (r_s = -.31, p < .01) and a better felt *quality at school* (r_s = -.36, p < .01) related moderately strong to a medical better value of HbA1c. Also the social dimensions f*amily* (r_s = -.25, p < .05) and *friends* (r_s = -.22, p < .05) showed a significant but weak relationship with the main value of metabolic control. Unusual seems the significant positive relationships between *self-esteem* (r_s = .33, p < .01) , the *quality in family* (r_s = .33, p < .01) and the *quality at school* (r_s = .31, p < .01) with the number of hypoglycaemias during the last three months which might be a side effect in the attempts to reach a low HbA1c which will be discussed later on. *Self-esteem* (r_s = -.29, p < .05), and the dimensions *family* (r_s = -.29, p < .05) and *friends* (r_s = -.32, p < .05) also bear a significant negative relationship with the number of incidents of ketoacidoses during the last three months, representing weak to moderate associations.

3.3.7 Relation health-related quality of life and treatment adherence, intellectual ability and communication between parents and child

Table 11 Spearman's correlation coefficients between the Kid Kindl® scales and the marks of the adherence, Intellectual ability and communication questionnaires

	Adherence[1]	Intellectual ability[2]	Communication[3]
Kid Kindl® scales			
Kid Kindl® Total	-.10	-.05	-.26*
Physical functioning	-.14	-.11	-.26*
Psychological well-being	-.20	-.25*	-.34**
Self-esteem	-.34**	-.28	-.32**
Family	-.26*	-.18	-.25*
Friends	-.18	-.15	-.27**
School	-.19	-.20	-.29**

*: $p < .05$
**: $p < .01$ (2-tailed)

Note [1]: German school marks (1 = excellent to 6 = unsatisfactory for how well patients documented blood glucose levels (surrogate for treatment adherence) rated by diabetes team of St. Agnes-Hospital
Note [2]: German school marks for intellectual ability rated by diabetes team of St. Agnes-Hospital
Note[3]: Quality of the communication between the pediatric patients and their parents (a lower score indicates a better quality of the communication)

Table 11 shows that once again the psychological and the social aspects of the HRQOL were noticeable in revealing associations with the treatment adherence and the quality of the communication. Especially a higher self-esteem is related to a better mark for the patients' treatment adherence ($r_s = -.34$, $p < .01$) and also a better *family functioning* is associated with a better blood glucose monitoring ($r_s = -.26$, $p < .05$). The psychological aspects, *psychological well-being* and *self-esteem*, and the social aspects, the *quality at school* and the *quality with friends,* were especially related to a better communication between the paediatric patients and their parents. Worth mentioning is that all aspects of the HRQOL beared significant meaningful relationships with the quality of the communication. Only *psychological well-being,* however, showed a significant but weak relationship with a better mark for intellectual ability ($r_s = -.25$, $p < .05$) rated by the diabetes team.

3.3.8 Relation between metabolic control, treatment adherence, intellectual ability and communication

Table 12 Spearman's correlation coefficients between the values of metabolic control and the marks of adherence, intellectual ability and communication

	Adherence[1]	Intellectual ability[2]	Communication[3]
Metabolic control			
HbA1c[4]	.62**	.63**	.44**

*: p < .05
**: p < .01 (2-tailed)

Note [1]: German school marks (1 = excellent to 6 = unsatisfactory for how well patients documented blood glucose levels (surrogate for treatment adherence) rated by diabetes team of St. Agnes-Hospital
Note [2]: German school marks for intellectual ability rated by diabetes team of St. Agnes-Hospital
Note[3]: Quality of the communication between the pediatric patients and their parents (a lower score indicates a better quality of the communication)
Note[4]: HbA1c reflects the average level of blood glucose during a 2-3month period (higher levels indicate poorer control)

Table 12 shows strong significant relationships between metabolic control and the marks gained for treatment adherence (rs = .62, p < .01) and intellectual ability (rs = .63, p < .01). The quality of the communication between the paediatric patients and their parents shows a moderate relationship with metabolic control (rs = .44, p < .01).

3.3.9 Relation health-related quality of life and parents` quality of life

Table 13 Spearman's correlation coefficients between the Kid Kindl® scales and the UlQIE and the parent's health condition

	Quality of life parents[1]	Parent`s health condition[2]
Kid Kindl® Scales		
Kid Kindl® Total	.26	.13
Physical functioning	.39**	.34**
Psychological well-being	.29*	.26*
Self-esteem	.49**	.31**
Family	.34**	.22
Friends	.21	.15
School	.10	.05

*: p < .05
**: p < .01 (2-tailed)

Note [1]: ULQIE measures the quality of life of parents under the consideration of a chronically ill child
Note [2]: parent's rated mark for their present health condition (a higher mark indicates a better health condition)

Results demonstrated that various aspects of the HRQOL were significantly positively associated with various aspects of the quality of life of parents under the consideration of a chronically ill child (see table 13). Especially, a higher self-esteem reflects a higher well-being of the parents (r_s = .49, p < .01). A better *physical functioning* (r_s = .34, p < .01) and *self-esteem* (r_s = .31, p < .01) were also moderatly related to how parents assessed their present health condition.

Health-related quality of life and financial problems

Table 14 Spearman's correlation coefficients between the Kid Kindl® scales and financial problems

	Financial problems[1]
Kid Kindl® Scales	
Kid Kindl® Total	-.03
Physical functioning	-.17
Psychological well-being	-.35**
Self-esteem	-.15
Family	-.17
Friends	-.14
School	-.27*

*: p < .05
**: p < .01 (2-tailed)

Note [1]: Parents could put a cross in the ''no'' box (score 1)or ''yes'' box (score 2) for financial problems

Table 14 shows that financial problems in the paediatric patients' families were also associated with psychological and social aspects of the HRQOL, especially with a worse *psychological well-being* (r_s = -.35, p < .01) and a worse *quality at school* (r_s = -.27, p < .05).

3.3.10 Health-related quality of life and school problems

Table 15 Spearman's correlation coefficients between the Kid Kindl® scales and school problems

	School problems[1]
Kid Kindl® Scales	
Kid Kindl® Total	-.26*
Physical functioning	-.17
Psychological well-being	-.23*
Self-esteem	.04
Family	-.03
Friends	-.23*
School	-.08

*: p < .05
**: p < .01 (2-tailed)

Note [1]: School problems in regard to performance rating: a higher mark on this item indicates more school problems

Results showed that the *overall health-related quality of life* (r_s = -.26, p < .05) and the psychological and social dimensions, *psychological well-being* (r_s = -.23, p < .05) and *friends* (r_s = -.23, p < .05), were significantly negatively related to school problems in regard to performance rating. However, these results represent weak associations. Worth mentioning is that the dimension *school* is not significantly associated with school problems at all (r_s = -.08, p > .05).

3.4 Multivariate analyses

Based on the significant results of the univariate analysis, multiple regression analyses were done to further investigate the relation between the different aspects of health-related quality of life and the different predictors. The different scales of the Kid Kindl® were each defined as dependent variable. The *backward* method was used in which the computer begins placing all predictors in the model and then calculates the contribution of each one. If predictors do not make significant contribution to how well the model predicts the dependent variable, they are removed from the model and the contribution of the remaining predictors are reassessed. Before proceeding with the analyses, several assumptions were checked. Testing the assumption of no multicollinearity, correlations of above 0.80 or .90 could be detected between stress symptoms, psychological symptoms and the sub scales 'anger', 'sadness' and 'fear'. Based on the strongest significant correlation between the specific aspect of HRQOL and the above mentioned sub scales of stress symptoms found in the univariate analysis, only one of these scales was each put into the model as a predictor. Checking the normality of residuals, only the histogram of the model with the dimension *school* as dependent variable showed a skewed distribution which was a sign of non-normality of the residuals. The other assumptions seemed to have been met.

3.4.1 Multiple Regression Analysis: Kid Kindl® Total as dependent variable

Table 16 Multiple Regression Model: Kid Kindl® Total as dependent variable

	B	SE B	β
Constant	3.55	0.11	
Avoidant coping	-0.01	0.00	-.42**

Stress symptoms	-0.01	0.00	-.33 **

Note: R^2 = .36; *: p < .05; **: p < .01

Having run the *backward* method, the remaining predictors which are making a statistically significant contribution to how well the model predicts the overall HRQOL were an *avoidant coping* style (t(47) = -3.44, p < 0.01) and *stress symptoms* (t(47) = -2.69, p = .01). Table 16 gives the b-values, their standard errors and the standardized betas with their significance. The negative coefficients of the b-values of the predictors represent a negative relationship with the outcome variable. The value of the standardized beta of the predictor *avoidant coping* indicates that as the score on this scale increases by one standard deviation (7.32), the score on the overall HRQOL decreases by 0.42 standard deviations. The standard deviation for the overall HRQOL is 0.19 and so this constitutes a change of -0.08 (-0.42 * 0.19). If the score on the sub scale *stress symptoms* increases by one standard deviation (7.71), the score on the overall HRQOL decreases by 0.33 standard deviations. This constitutes a change of -0.06. These interpretations are true if the score on the other sub scale is each held constant.
Together, these scores on the sub scales *avoidant coping* and *stress symptoms* of the SSKJ3-8 account for 36% of the variance in overall HRQOL (F (2, 47) = 13.35; p < .01).

3.4.2 Multiple Regression Analysis: Physical functioning as dependent variable

Table 17 Multiple Regression Analysis: Physical functioning as dependent variable

	B	SE B	β
Constant	4.85	0.59	
Avoidant coping	-0.03	0.01	-.38**
Stress symptoms	-0.04	0.01	-.40**
Communication [1]	-0.04	0.02	.21
Quality of life of parents[2]	0.01	0.00	.22
Physical symptoms	0.06	0.03	-.29*

Note: R^2 = .62; *: p < .05; **: p < .01

Note [1]: Quality of the communication between the pediatric patients and their parents
Note [2]: Quality of life of the parents under the consideration of a chronically ill child measured with the ULQIE

As *physical functioning* was put into the model as dependent variable, the remaining predictors were also an *avoidant coping* style (t(37) = -3.30, p < .01) and *stress symptoms* (t(37) = -3.39, p < .01). Additionally, the rating for the *quality of the communication between*

the paediatric patients and their parents (t(37) = -1.91, p= .06), *quality of life of the parents* (t(37) = 1.91, p= .06) and *physical symptoms* (t(37) = 2.10 p < .05) remained in the model. However, only the first two predictors (**p < .01) and *physical symptoms* (**p < .05) were making a significant contribution to the model. The b-values of *avoidant coping, stress symptoms*, *quality of communication* and *physical symptoms* indicate a negative relationship with *physical functioning*. It has to be taken into consideration that a lower score on *communication* can be linked to a higher quality. Together, all remaining predictors account for 62 % of the variance in *physical functioning* (F (5, 37) = 11.95, p = .00).

3.4.3 Multiple Regression Analysis: Psychological well-being as dependent variable

Table 18 Multiple regression model: Psychological well-being as dependent variable

	B	SE B	β
Constant	3.63	0,9	
Avoidant coping	-0.04	0.11	-.40**
Stress symptoms	-0.02	0.01	-0.25
Kindl® Total[1]	0.46	0.18	.31*

Note: R^2=.47; *: p <.05; **: p<.01

Note [1]: Overall quality of life measured with the Kindl®-parent version

In psychological well-being, the backward method remained again *avoidant coping* (t(39) = -3.15, p < .01), and *stress symptoms* (t(39) = -1.92, p = .06) and the overall HRQOL assessed by the parents (t(39) = 2.51, p = .02) in the model, which account for 47 % of the variance (F(3, 39) = 11.35, p < .01). Worth mentioning is that especially *avoidant coping* (**p < .01) made a significant contribution to the model. The b-values of *avoidant coping* and *stress symptoms* indicate a negative relationship with the outcome variable, whereas the b-value of the overall HRQOL assessed by the parents represent a positive relationship with *psychological well-being*. The value of the standardized beta of the predictor *avoidant coping* for instance indicates that as the score on this scale increases by one standard deviation (7.48), the score on *psychological well-being* decreases by 0.40 standard deviations. The standard deviation for psychological well-being is 0.65 and so this causes a change of – 0.26 (-0.40 * 0.65) if the other predictors are held constant.

3.4.4 Multiple Regression Analysis: Self-esteem as dependent variable

Table 19 Multiple Regression Model: Self-esteem as dependent variable

	B	SE B	β
Constant	3.76	0.59	
Quality of life of parents[1]	0.02	0.00	.44**
Stress symptoms	-0.02	0.01	-.30*
Avoidant coping	-0.02	0.01	-.21

Note: R^2 = .50; *: p < .05; **: p < .01

Note [1]: Quality of life of parents under the consideration of a chronically ill child measured with the ULQIE

Table 19 shows the b-values, their standard errors and the standardized betas with their significance of the multiple regression analysis with *self-esteem* as dependent variable. *Quality of life of the parents* (t(40) = 3.73 p = < .01), *stress symptoms* (t(40) = -2.39 p = .02) and *avoidant coping* (t(40) = -1.76 p= .09) remained in the model and account for 50% of the variance in self-esteem (F(3, 40)= 13.12, p < .01). The b-value of the quality of life of the parents which is measured by the ULQIE is strongly significantly different from 0 (**p < .01). Stress symptoms also made a significant contribution to the model (*p < .05). Only the b-value of the scores on the ULQIE was indicating a positive relationship with self-esteem.

3.4.5 Multiple Regression Analysis: Family as dependent variable

Table 20 Multiple Regression Model: Family as dependent variable

	B	SE B	β
Constant	4.6	1.21	
Communication[1]	-0.08	0.04	-.25*
Family[2]	0.66	0.18	.44**
School[3]	-0.37	0.19	-.24
Fear	-0.15	0.05	-.39**

Note: R^2 = .45; *: p < .05; **: p < .01

Note [1]: Quality of the communication between the pediatric patients and their parents
Note [2]: Family quality measured with the Kindl®-parent version
Note[3]: Quality at school measured with the Kindl®-parent version

In the multiple regression model with *family* as dependent variable, four predictors remained in the model. These predictors are the quality of the communication between the patients and their parents (t(41) = -2.03, p < .05), the sub scales *family* (t(41) = 3.69, p < .01) and *school* (t(41) = -1.91, p = .06) of the Kindl®-parent version and the sub scale *fear* out of the SSKJ3-8

(t(41) = -3.23, p < .01). How the parents assessed the *quality of family* functioning is the strongest significant predictor of how the pediatric patients judged their *quality of family functioning*. Fear also had a strong significant contribution to the model and beared a negative relationship with the outcome variable. Together, the four predictors account for 45% of the variance in the quality of family functioning (F(4, 41) = 8.42, p < .01).

3.4.6 Multiple Regression Analysis: Friends as dependent variable

Table 21 Multiple Regression Model: Friends as dependent variable

	B	SE B	β
Constant	4.83	0.15	
Anger-rel.e.reg.[1]	-0.01	0.00	-.23
School problems	-0.1	0.05	-.26*
Communication[2]	-0.02	0.01	-.21
Stress symptoms	-0.01	0.00	-.22

Note: R^2 = .35; *: p < .05; **: p < .01

Note [1]: anger-related emotion regulation (coping strategy) measured by the second scale of the SSKJ 3-8
Note [2]: quality of the communication between the pediatric patients and their parents

In the multiple regression model with *friends* as dependent variable, the coping style *anger-related emotion regulation* (t(48) = -1.77, p = .08), *school problems* (t() = -2.13, p < .05), *communication* (t(48) = -1.76, p = .09) and *stress symptoms* (t(48) = -1.74, p = .09) survived the removal criterion. However, only the b-value of *school problems* was significant and represented a negative relationship with the outcome variable. Together, all remaining predictors account for 35% of the variance in the quality with friends (F (4, 48) = 6.56, p < .01).

3.4.7 Multiple Regression Analysis: School as dependent variable

Table 22 Multiple Regression Model: School as dependent variable

	B	SE B	β
Constant	5.00	0.74	
Physical symptoms[1]	-0.06	0.02	–.30**
School[2]	0.21	0.1	.25*
HbA1c	–.11	0.06	–.20

Note: R^2 = .23; *: p < .05; **: p < .01

Note [1]: measured with the third scale of the SSKJ 3-8 Note [2]: Quality at school measured with the Kindl® - parent version

Table 22 gives the b-values, their standard errors and the standardized betas with their significance of the multiple regression model with *school* as dependent variable. After using the backward method with all significant correlates out of the univariate analyses, *physical symptoms* (t(50) = -2.65, p= .01), the aspect *school* of the parents' proxy reports (t(50) = 2.04, p < .05) and the HbA1c level (t() = -1.23, p = .22) remained in the model and account for 23 % of the variance in the outcome variable (F(3, 50) = 4.61, p < 01). *Physical symptoms* was the strongest predictor of the model, followed by how parents rated the *school quality* of their children. The b-value of the HbA1c level represents a negative but non-significant relationship with the aspect *school* of the HRQOL.

3.5 Mediation Analyses

Results from univariate analyses showed that the quality of the communication between the paediatric patients and their parents beared significant relationships to every single aspect of the HRQOL (see table 11). Results also showed a significant relation between metabolic control and the quality of the communication.

In order to further investigate the relation between the quality of the communication between the paediatric patients and the HRQOL and in order to investigate in how far this relationship might be mediated by the metabolic control of the patients, mediation analyses were conducted. This method is described by Baron & Kenny (1986). Using their causal steps approach for detecting mediation, four conditions for a mediator effect are tested on the basis of four different regression analyses. First of all, the first simple regression analysis must show that the independent variable (X) significantly predicts the dependent variable (Y) (pad C, total effect). Secondly, the second regression analysis must demonstrate that the independent variable (X) is a significant predictor of the mediator (M) (pad A). Thirdly, conducting a third simple regression analysis, the mediator has to significantly predict the outcome variable (Y) (pad B). Fourthly, a multiple regression model with the independent variable (X) and the mediator (M) as predictors has to show that the mediator (M) is still making a significant contribution to how well the dependent variable is predicted. If X is no longer significant when M is controlled, the finding supports full mediation. If X is still significant the finding supports partial mediation.

As all aspects of the HRQOL (Kid Kindl® scales) were tested as independent variables, only the dimensions *family* and *school* fulfilled all four conditions for a mediation analysis:

The following mediation relationships were worked out:

1) Communication (independent variable) – HbA1c (mediator) – family (dependent variable);

2) Communication (independent variable) – HbA1c (mediator) – school (dependent variable).

Results of the mediation analyses can be found in tables 24 and 25 in the appendix. Results show that the *quality of the communication* affects the *family quality* by means of the metabolic control. The quality of the communication also affects the *school quality* through the metabolic control. As the communication was no longer significant when HbA1c was controlled, these findings support full mediations. Graphically, the mediations are depicted in figures 3 and 4.

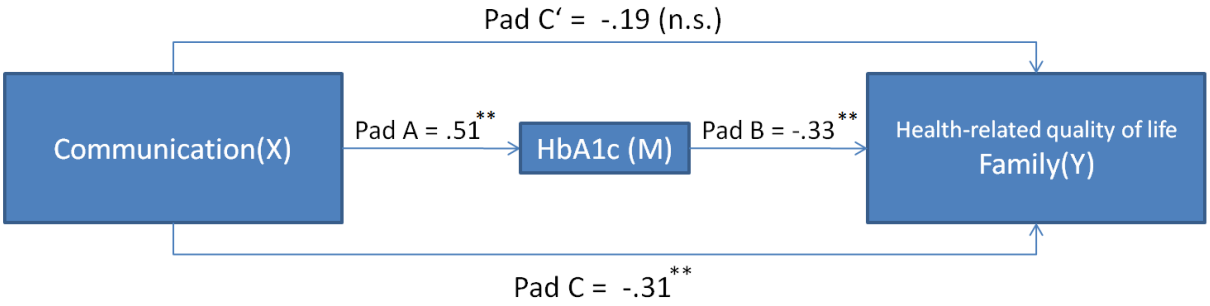

Figure 3 Illustration of the mediation design: Communication(X) affects Family(Y) indirectly through M

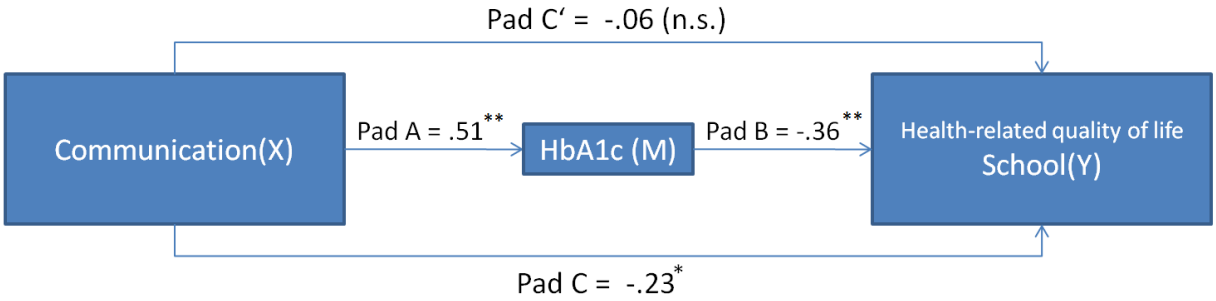

Figure 4 Illustration of the mediation design: Communication(X) affects School(Y) indirectly through M

3.6 The level of congruence between the patients' self reports and the parents' proxy reports on the quality of life

Table 23 Comparison of the descriptive statistics of the Kid Kindl® scores of the paediatric patients with the scores of the parents and the test statistic, the significance and the effect size of the Wilcoxon signed-rank test (2 related samples)

	Patients [1]		Parents[2]		z	p	r
Kindl® scales	M	SD	M	SD			
Kindl®Total	3.08	0.37	4.01	0.40	-6.73	.00**	-.87
Physical functioning	4.11	0.55	4.03	0.67	-0.79	.43	-.09
Psychological well-being	3.84	0.69	4.17	0.52	-2.91	.00**	-.33
Self-esteem	4.19	0.69	3.81	0.64	-5.59	.00**	-.65
Family	3.93	0.91	3.99	0.60	-1.07	.29	-.12
Friends	3.98	0.65	4.02	0.56	-2.02	.04*	-.22
School	4.23	0.70	3.95	0.64	-4.29	.00**	-.47

Note [1]: Patients filled out the Kid Kindl® Diabetes module Note [2]: Parents filled out the Kindl®- parent version

Table 23 shows next to each other the means and standard deviations of the Kid Kindl® scores of the paediatric patients and the Kindl®-parent version scores of the parents. Next to it, the z-score, its corresponding significance and its effect size were illustrated. Results showed that several scores of the two groups were significantly different. Parents strongly overestimated the overall quality of life of their children (Mdn = 4.00 (parents), Mdn = 3.00 (patients), $z = -6.73$, $p < .01$, $r = -.87$. Also the assessments on the dimensions *psychological well-being* (Mdn = 4.25 (parents), Mdn = 3.80 (patients)), $z = -2.91$, $p < .01$, $r = -.33$, and *friends* (Mdn = 4.00 (parents), 4.20 (patients)), $z = -2.02$, $p < .05$, $r = -.22$, were systematically overestimated. However, *self-esteem* was strongly underestimated of the parents (Mdn = 4.00 (parents), Mdn = 4.33 (patients), $z = -5.59$, $p < .01$, $r = -.65$. Also on the dimension *school,* paediatric children rated their quality of life higher (Mdn = 4.33) than parents did (Mdn = 4.00), $z = -4.29$, $p < .01$, $r = -.47$. Results showed similar patterns after running the parametric test, the t-test for related sample, in order to control the found results.

3.7 Change of health-related quality of life and self-efficacy over a period of two years

Table 26 Comparison of the descriptive statistics of the Kid Kindl® scores of the paediatric patients (n=23) in 2011 and 2013 and the test statistic, the significance and the effect size of the Wilcoxon signed-rank test

Kid Kindl ®scales	2011		2013		z	p	r
	M	SD	M	SD			
Kid Kindl ®Total	3.07	0.18	3.00	0.13	-1.47	.14	-.31
Physical functioning	4.04	0.49	4.13	0.42	-0.76	.45	-.16
Psychological well-being	3.62	0.87	3.96	0.50	-1.96	.05*	-.41
Self-esteem	4.18	0.67	4.33	0.47	-1.36	.18	-.28
Family	3.70	1.15	4.19	0.68	-2.34	.02*	-.49
Friends	4.55	0.67	4.17	0.17	-2.83	.01**	-.59
School	4.04	0.81	4.28	0.64	-1.73	.08	-.36

Table 26 shows the means and standard deviations, the z-score, its significance and its effect size by the Wilcoxon signed-rank test of the 23 participants who rated their HRQOL by means of the Kid Kindl® in 2011 as well as in 2013. Results showed that the overall health-related quality of life did not reveal any significant change in the period of two years. However, psychological well-being was significantly rated higher in 2013 (Mdn = 4.00) than in 2011 (Mdn = 3.60), $z = -1.96$, $p < .05$, $r = -.41$. Family functioning was also significantly higher assessed in 2013 (Mdn = 4.40) than in 2011 (Mdn = 3.80)), $z = -2.34$, $p < .05$, $r = -.49$. Only the dimension *friends* had significant higher scores in 2011 (Mdn = 4.80) than in 2013 (Mdn = 4.20), $z = -2.83$, $p < .01$, $r = -.59$.

Table 27 Comparison of the descriptive statistics of the PSESD (instrument to measure self-efficacy in regard to diabetic management) scores of the paediatric patients (n=23) in 2011 and 2013 and the test statistic, the significance and the effect size of the Wilcoxon signed-rank test (2 related samples)

	2011		2013		z	p	r
	M	SD	M	SD			
self-efficacy	23.45	4.38	26.27	2.12	-3.35	.00	-.70

Table 27 shows the means and standard deviations, the z-score, its significance and its effect size by the Wilcoxon signed-rank test (2 related samples) of the 23 participants who rated their diabetes-related self-efficacy by means of the PSESD in 2011 as well as in 2013. Results showed that in 2013, diabetes-related self-efficacy was significantly higher (Mdn = 27.00) than in 2011 (24.50), $z = -3.35$, $p < .01$, $r = -.70$.

4 Conclusion & Discussion

The main goal of this study was to investigate the correlates of the health-related quality of life of paediatric patients with T1D. This study made interesting findings concerning the result that particularly the psychological and social aspects- in contrast to the physical aspect- of the HRQOL were frequently associated with the factors investigated in this study. Especially metabolic control, treatment adherence, the quality of the communication between the paediatric patients and their parents, financial problems in family and school problems in regard to performance ratings were especially and simultaneously associated with psychological and social aspects of the HRQOL which underlines the importance of giving psychosocial support to the paediatric patients. DiNa with its special concern for the psychosocial development seems thus to be a very useful project in strengthening the HRQOL of the patients. In addition, *avoidant coping* proved to be a salient factor in predicting the overall HRQOL, *physical functioning* and the *psychological well-being* which is an indication that the promotion of positive coping abilities can serve as an important therapeutic measure which can prevent psycho- pathological side effects of diabetes mellitus.

This study also showed that the level of congruence between the paediatric patients' self-reports and parents' proxy reports on the child's HRQOL was low and assessments varied between different aspects. Parents overestimated the overall HRQOL, *psychological well-being* and the *quality with friends*. However, *self-esteem* and the *quality at school* were significantly underestimated. These results indicate that proxy assessments should be considered carefully as the only measure for HRQOL of paediatric children. Parents responded in a more consistent manner, though, which suggest that paediatric patients' HRQOL should be measured via both sources of information whenever resources allow this procedure. As *psychological well-being* and the *quality in family* of the HRQOL and self-efficacy were significantly higher rated in 2013 than in 2011 by paediatric patients who have participated in the DiNa project, results might be interpreted as a success of DiNa in achieving its goals.

In regard to the relationship between the several aspects of the HRQOL and self-efficacy, this study discloses several significant relationships which is consistent with the studies of Grey et al. (1998) and Rose et al. (2002) who already pointed out positive relationships between these constructs. Especially the dimensions of *psychological well-being*, *self-esteem* showed significant positive correlations. As Branden (1969) defined self-esteem

as “the experience of being competent to cope with the basic challenges of life and being worthy of happiness”, it is not surprising that this construct beared a positive relationship to diabetes-related self-efficacy gained through personal mastery experience in the daily routine of handling T1D.

In regard to the relation between the dimensions of the health-related quality of life and stress vulnerability, only the social dimension *friends* showed a strong negative correlation with stress vulnerability. As Karr & Johnson (1991) mainly distinguished four areas of stress for children and youth namely school, friends, parents and siblings, only the aspect *friends* seemed to have a positive influence on the stress vulnerability in the present study. This relation mirrors the importance of social integration which is a focus of the project DiNa of the St. Agnes-Hospital, Bocholt, Germany, and which should continue to engage attention in future. In forthcoming research it would be interesting to investigate the role of social integration in regard to health-related quality of life in depth.

Coping was operationalized by five dimensions in the present study whereby *seeking social support*, *problem-solving* and *palliative emotion regulation* (Hanson, 2001) can be roughly classified as favourable active coping strategies and *avoidant coping* and *anger-related emotion regulation* can be considered as unfavourable coping strategies (Hanson, 2001). In this study, especially *problem-solving* correlated positively with almost all dimensions of the HRQOL which is consistent with results from literature whereby positive coping strategies were frequently associated with a higher self-esteem and lower emotional strain (Winkler Metzke & Steinhausen, 2002). *Seeking social support* was associated with a higher *self-esteem* which is not surprising in the face of the results that psychological and social aspects of the HRQOL were frequently simultaneously associated with correlates in this study. This relationship also underlines the prominent value of having a social background which can serve as a buffer in stress situations. The unfavourable coping strategies *avoidant coping* and *anger-related emotion regulation* often negatively correlated to the dimensions of the HRQOL (see table 7). Running multiple regression analyses, it was noticeable that especially *avoidant coping* made significant contributions in predicting the *overall health-related quality of life, physical functioning* and *psychological well-being*. This is in line with a study of Winkler-Metzke & Steinhausen (2002) who found that unfavourable coping strategies, especially *avoidant coping*, were related to internalized problems (Winkler Metzke & Steinhausen, 2002). In literature, avoidant coping is considered a health hazard because of its only short-

term effect of relieving stress (Kaluza, 2004) which is on the same line with the found results in the present study. However, Lohaus et al. (2006) states that the Kid Kindl® scales do not relate to *avoidant coping* which is contradictory to the result in the present study that disclosed *avoidant coping* to be one of the strongest factors in predicting the HRQOL. *Palliative emotion regulation* which is related to the short- or long-term regulation and control of the physiological or psychological stress situation, for example relaxation and distraction, seems to have no impact on the HRQOL in this study. It might be a neutral coping strategy which does not do any harm nor good to the HRQOL which is in line with findings of Lohaus et al. (2006) who states that the Kid Kindl® scales do not relate at all with *palliative emotion regulation*.

These results confirm the fact that positive coping abilities can serve as buffer for the negative effects of the chronic disease. Therefore, the promotion of coping abilities can serve as an important therapeutic measure which can prevent psycho- pathological side effects of diabetes mellitus. Furthermore, such a promotion of coping abilities seems important because the way how children and youth cope with stress situations determines the way how adults deal with them (Seiffke-Krenke & Nieder, 2001) and also because chronically ill patients tend to apply more *avoidant coping* in comparison to healthy people (Kaluza, 2004). Grey & Berry (2004) have already proved that a training of coping abilities has a positive effect on the metabolic control of diabetic patients which confirms that a promotion of coping abilities can be regarded as a promising therapeutic measure for diabetes mellitus in future. To further investigate this aspect would be an interesting issue in forthcoming research.

Considering the relation between the HRQOL and stress symptoms, a higher well-being of the dimensions of the HRQOL were generally shown when physical and psychological complaints were found to be low. This is an expected result which was already published by Lohaus et al. (2006). Furthermore, results from multiple regression analyses disclosed that the scales of stress symptoms made significant contributions in predicting the health-related quality of life.

This study also found that a higher HRQOL was associated with a lower HbA1c level and thus a better metabolic control which is consistent with the studies of Eren et al. (2008) and Hoey et al. (2007). In the present study, especially a higher *self-esteem* and a higher HRQOL on the social dimensions of the HRQOL were positively correlated with a better blood glucose level. The same aspects were also associated with fewer incidents of ketoacidoses which is in line with the above found correlations. Considering the results of the HRQOL in relation to

hypoglycaemias results appear to be contradictory on first sight. A higher HRQOL was associated with more incidents of hypoglycaemias. This phenomenon might be a side effect of trying to keep the HbA1c level as low as possible. A strict controlled blood glucose appears to be like a tightrope walk which bears the danger of easily slipping into a hypoglycaemia which might explain the positive relation between the HRQOL and the number of incidents of hypoglycaemias. One study of Davis, Keating, Byrne, Russell & Jones (1998) for example showed that increased emphasis on strict blood glucose control of young patients with diabetes mellitus may be expected to cause an increase in the incidents of severe hypoglycaemias. They concluded that attempts to ameliorate glycaemic control must be accompanied by efforts to minimise the effects of hypoglycaemias.

The *treatment adherence* and the *intellectual ability* of the paediatric patients as well as the *quality of the communication between the paediatric patients and their parents* were assessed by the diabetes team of the St. Agnes-Hospital, Bocholt, Germany. This was done in order to receive objective impressions for these constructs whereby the diabetes team has a professional distance to their patients and their families but still enough knowledge to assess the above mentioned constructs because they have attended most of the patients and their families for a long period of time. Results showed that a higher HRQOL were associated with better marks for the *treatment adherence, intellectual ability* and the *quality of the communication between the paediatric patients and their parents*. It was noticeable that again the psychological and social dimensions of the HRQOL were especially associated with these constructs. The *quality of the communication between the patients and their parents* was even significantly related to every single aspect of the HRQOL. As metabolic control also significantly correlated to the *quality of the communication,* the question came up whether metabolic control mediates the relationship between the quality of the communication and the HRQOL which will be discussed in the further course of the discussion. It was striking that metabolic control also strongly significantly related to the assessment of the treatment adherence and intellectual ability of the patients by the diabetes team. These extremely high results might be explained by the “halo effect”, a cognitive bias which explains our tendency to assume that people who have one good trait are likely to have others (Gleitman, Reisberg & Gross, 2007). So in regard to the found results in this study, it might be that the diabetes team rated patients who had good HbA1c values as more adherent to treatment regimens and as more intellectual capable than patients who had bad metabolic values. As the diabetes

team also collected the clinical measures, it would be a suggestion for improvement for forthcoming research to collect data from multiple sources in order to avoid a so called "single source bias" (Campbell & Fiske, 1959).

As we consider the correlation coefficients between the dimensions of the HRQOL of the patients and the parent's total quality of life under consideration of a chronically ill child, it becomes apparent that the higher the patients scored, the higher was the overall quality of life of the parents. The same applied for the relation between the dimensions of the HRQOL and the parent's own rated present health status. This finding is in line with a study of Warschburger (2000) who showed that the quality of life of the parents related to the mental state of their children. Especially *self-esteem* was significantly predicted by the quality of life of the parents after running a multiple regression analysis. The physical component of the HRQOL, though, was also significantly related to the parent's quality of life. This relationship may likely to be reciprocal. A higher strain of the parents could possibly cause a worse rating of the emotional state of their children (Hagen & Schwarz, 2009) or – on the contrary – the parents could be especially sensitized for the physical as well as psychological symptoms of their children (Noeker & Petermann, 2003). These results underline the need to also strengthen the quality of life of the parents. Lowes, Lyne & Gregory (2004) could prove for example that not only the patients' but also the parents' quality of life benefit from getting health literacy which conveys a feeling of control and competency. Hilliard, Monaghan, Cogen and Streisand (2010) suggest parent-focused interventions to increase support and education about child development, parenting, and stress management, which may be valuable for reducing risk for stress by parents of children with T1D. This also confirms the approach of the DiNa project which considers the whole family and not only the patient.

As we consider the relation between the dimensions of the HRQOL and familiar financial problems of the paediatric patient, results show that again the psychological an social aspects reveal an expected negative relationship. Especially a lower *psychological well-being* was significantly related with financial problems of the family. Restricted financial resources might limit the possibilities in life which might explain a suffering of the *psychological well-being*. In literature, a lower family SES was related to poorer self-care behaviours and metabolic control (Adler et al., 1994). School problems in regard to performance ratings were also found to be significantly related to psychological and social aspects of the HRQOL, especially to a lower *psychological well-being* and a lower *quality with friends*. Running a multiple regression

analysis with *quality with friends* as dependent variable, school problems turned out to have the strongest significant contribution in predicting the outcome variable. Worth mentioning is that school problems in regard to performance ratings were not significantly related to the *quality at school*. It seems that the *quality with friends* seems more important in regard to school problems which also underlines the need to be socially integrated in life. The present study found several factors that related to the HRQOL of the paediatric patients with T1D. Considerable caution must be taken when interpreting these results because some measures utilized in the study were exploratory and were not validated estimates of the represented constructs. Furthermore correlation coefficients have to be interpreted carefully because they give no indication of the direction of causality which means they give no clue which variable causes the other to change.

Regarding the scores on the HRQOL, several sub scales of the Kid Kindl® were insufficiently consistent which decreases the reliability of the present study. This is in contrast to an analysis of the data of the questionnaire in which most sub scales achieved values around alphas of .70. For the total scale even and alpha value of .80 was attained (Ravens-Sieberer & Bullinger, 2000). A gender effect did neither play a role by the assessments of the patients nor by the parents which stands in contrast to a study of Eiser & Morse (2011) who reported that girls had a lower quality of life than boys. In regard to the differentiated age groups, a significant difference by the assessments of the patients was only found for the dimension of the *quality at school* in which younger children scored systematically higher. By the parents' proxy reports, younger patients were thought to have a higher quality of the *overall quality of life*, of *physical functioning*, of the *family quality* and of the *quality at school*. These results match the study of Wagner, Müller-Godeffroy, von Sengbusch, Häger & Thyen (2005) who reported that an increase of age is associated with a worse rating of the quality of life. This phenomenon might be due to the fact that adolescents start to understand that they will be confronted with a chronic disease throughout their life. Fears of late sequelae can arise which can cause a reduction in the quality of life (Grey et al., 2002).

Significant relationships between the dimensions of the HRQOL and the *quality of the communication between the paediatric children and their parents* triggered the interest to investigate how or by what means a hypothesized effect exists. Because of the significant correlation of metabolic control with the *quality of the communication*, explorative mediation analyses were run in order to examine whether metabolic control serves as intervening

variable between these two constructs. Results showed that the *quality of the communication* indeed exerts influences through metabolic control in this sample on two dimensions of the health-related quality of life, namely on the dimensions *family* and *school*. These results were based on the four-step approach of Baron & Kenny which is the general approach many researchers use. However, a potential problem is that this approach tends to miss some true mediation effects, the so called type II errors (MacKinnon, Fairchild & Fritz, 2007). Furthermore, due to this exploratory character of the study, results should be picked up and further investigated in depth. It would be quite interesting to be able to explain by what means causal effects on the quality of life by children and youth with T1D occur. However, this is very difficult considering the fact that experimental studies of the quality of life are almost impossible to conduct due to ethical restrictions.

Discussing the question whether the patients themselves or their parents should fill out questionnaires in order to get an impression of the quality of life, it became apparent that it mattered a lot who assessed the quality of life in this study. Contradictory to the results in literature that parents frequently underestimate the quality of life of their children, parents overestimated the *overall health-related quality of life*, the *psychological well-being* as well as the *quality with friends* in the present study. Only the ratings on *self-esteem* and the *quality at school* seemed to be in line with results in literature. How can the complex construct of quality of life best be measured by paediatric patients at the age of 8 to 16? The results of this study suggest that parent's proxy reports should be carefully interpreted if it is the only source of information for the paediatric patients' quality of life. Koot & Wallander (2001) stated that the quality of life is mainly subjective in nature and that the patient himself should be the first source of information in regard to his quality of life. However, considering the Cronbach's alpha values for item responses, results showed that the parents' proxy-reports were responded in a more consistent manner than the patients' self-reports. This finding might be due to the fact that the patients might have difficulties in understanding or recalling aspects asked in the questionnaire. Thus for smaller samples, proxy-reports on the paediatric patients' quality of life seem to be preferable. Thus, this study does not identify any entirely superior version of measuring the quality of life of paediatric patients. It seems that the qualtiy of life can best be measured via both sources of information in order to gain a good complemented impression of the patients' quality of life.

Considering the change of the *health-related quality of life* over a period of two years of the paediatric patients who have participated in the DiNa project, results showed that four dimensions of the health-related quality of life did not show any significant difference. This finding could be explained by the "set-point model" which claims that everyone has a basic level (set-point) of quality of life that rarely changes in the course of time (Lucas, 2007). The set-point is only challenged if a severe circumstance occurs which can result in a reduced level of quality of life (Lucas, 2007). However, three dimensions do show a significant difference. *Psychological well-being* and the *quality in family* were significantly higher rated in 2013 than in 2011. The DiNa project who intends to strengthen the paediatric patients as well as the family as a whole might play a role within these positive findings. However, the *quality with friends* was significantly higher rated in 2011 than in 2013. One speculation is that the quality with friends might suffer when children and youth with an increased age have to spend more time on school.

Considering the change of *self-efficacy* over a period of two years, results showed that the patients' self-efficacy was significantly higher in 2013 than in 2011. This might be attributed to the concern of the DiNa project on which all participants of the present study have participated and which is geared towards strengthening the self-efficacy of the patients in order to promote their psychosocial development. An increase of age might also play a role in having developed a higher self-efficacy. However, due to this longitudinal design in descriptive research, results should be interpreted carefully. Another problem which is typical for longitudinal studies was attrition. There were only 23 participants who accurately self-reported their health-related quality of life and self-efficacy in 2011 as well as in 2013 which might have biased the results because the participants' motivation to decently complete the questionnaire could probably be correlated with certain traits that affected this study. However, some adolescents just became too old to fulfil the inclusion criteria.

Some limitations of this study have to be stated. First of all, this study was mainly based on a cross-sectional design which means that causal inferences have to be ruled out. Experimental studies have to be conducted in order to reach firm causal conclusions about the correlates of the HRQOL of the paediatric patients with T1D. Secondly, the sample used was relatively small and only recruited from one regional medical centre in West Germany. Moreover, the demographic sample showed only three participants with foreign nationalities which might not be representative for the German population.

The objective of this study was to investigate the correlates of the HRQOL of paediatric patients with T1D. This study showed that particularly the psychological and social aspects -in contrast to the physical aspect- of the HRQOL were frequently associated with the factors investigated in this study. Especially metabolic control, treatment adherence, the quality of the communication between the patients and their parents, financial problems in family and school problems with regard to performance ratings were simultaneously related to the psychological and social dimensions of the HRQOL. These results mirror the importance of psychosocial support, which might buffer the negative side effects of diabetes mellitus. DiNa with its resolve to strengthen the health-related quality of life which includes promoting the psychosocial development of the patients seems thus to be a useful project in achieving its goals. As the dimensions, *psychological well-being* and the *quality in family,* of the health-related quality of life as well as the self-efficacy of the paediatric patients who have participated in the DiNa project were more highly rated in 2013 than in 2011, these results tend to confirm that the DiNa project is useful in counting success in their endeavours. In future, it would be advisable to collect data before the patients begin participating in the DiNa project which is usually after the first manifestation and to carry out further surveys in regular intervals. As the study did not identify any entirely superior version of measuring the HRQOL, it is recommended to collect data from self reports and proxy reports if time and money resources allow this procedure.

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Appendix

Results of the mediation analyses

Table 24 Mediation analysis of the model: Communication (X) - HbA1c (M): Family (Y)

	Pad A				Pad B				Pad C				Pad C'			
	B	SE B	β		B	SE B	β		B	SE B	β		B	SE B	β	
C[1]	6.26	0.32		C[1]	5.85	0.60		C[1]	4.60	0.24		C[1]	5.70	0.60		
X[2]	0.22	0.04	.51**	M[3]	-0.24	0.07	-.33**	X[2]	-0.09	0.03	-.31**	X[2]	-0.06	0.03	-.19 n.s.	
												M[3]	-0.17	0.09	-.23*	

Pad A = effect X → M Pad B = effect M → Y Pad C = effect X → Y Pad C' = effect X.M → Y

*p < .05, **p < .01, (n.s.) = not significant (2 - tailed)

Note [1]: C = Constant Note [2]: X = Communication Note [3]: M = HbA1c

Table 25 Mediation analysis of the model: Communication (X) - HbA1c (M): School (Y)

	Pad A				Pad B				Pad C				Pad C'			
	B	SE B	β		B	SE B	β		B	SE B	β		B	SE B	β	
C[1]	6.26	0.32		C[1]	5.87	0.45		C[1]	4.62	0.19		C[1]	5.84	0.46		
X[2]	0.22	0.04	.51**	M[3]	-0.21	0.06	-.36**	X[2]	-0.09	0.09	-.23**	X[2]	-0.01	0.03	-.06 n.s.	
												M[3]	-0.19	0.07	-.33**	

Pad A = effect X → M Pad B = effect M → Y Pad C = effect X → Y Pad C' = effect X.M → Y

*p < .05, **p < .01, (n.s.) = not significant (2 - tailed)

Note [1]: C = Constant Note [2]: X = Communication Note [3]: M = HbA1c