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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2008

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

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Children with celiac disease and diabetes, their quality of life and parental stress

Maria Strating

December 2008
**Colofon**

**Vraagnummer:** GV137a

**Titel:** Children with celiac disease and diabetes, their quality of life and parental stress

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Abstract

Abstract: Aims: To assess quality of life in children afflicted with both celiac disease and diabetes and to see whether there are socio demographic and disease specific variables affecting quality of life. To assess the impact of multi-morbidity of their children on the parents and how parental stress is related to the quality of life of their children. Methods: A total of 50 children were invited to complete the Kidscreen-52, the Disabkids-27, the Disabkids diabetes specific module and the CDDUX (celiac disease specific questionnaire). Their parents were invited to fill in the Pediatric Inventory for Parents. A total of 28 (56%) subjects, age 8-18 responded. Results: When compared to healthy children, subjects reported a comparable quality of life. Compared to other chronically ill children, subjects report to deal better with their treatment and feel more independent. Subjects grade their quality of life with a mean of 8.6 (scale 0-10). Young age had a negative and early diagnosis a positive influence on the general quality of life. The variables gender, SES, number of glucose measurements and hypoglycemic attacks were of influence on school performances. Girls, children of middle SES, children with high number of glucose measurements and high number of hypoglycemic attacks performed better at school. Children using an insulin pump and children with high number of glucose measurements report to feel physically unfit. Children using injections report to live with less impairments and have more confidence in the future and live compared to children using an insulin pump. Subjects in good metabolic control (low HBAc1 values) report to be bothered by their treatment. The biggest impact on the parents is caused by issues around communication with the medical staff and feeling misunderstood by family and friends. Furthermore the parents report to have a comparable impact on role performance and on medical care taking as parents of children with cancer. The stress of parents is related to the quality of life of the children. The more stress is reported by the parents the worse the quality of life of their children. Conclusions: Children with diabetes and celiac disease rate their quality of life positively. Young children and children who had to wait a long time before being diagnosed report a lower quality of life. Parents report a big impact on their lives, especially concerning issues around communication. Parental stress and the quality of life of their children are linked.
1. Introduction

A chronic illness has a big impact on the life of a child and the people surrounding the child. Besides the threat of disruption of the normal growth and development, often there are far reaching consequences for psychological and social functioning.

The consequences of chronic illness for a child and its social environment have been investigated in several studies for several diseases. Less known are the consequences when a child suffers from two chronic diseases (1). The quality of life in children with diabetes as well as celiac disease has not been previously assessed. On request of the Dutch Celiac Association, the NCV, in this research this assessment will be made.

1.1. Celiac disease

Celiac disease is an intolerance for gluten. Gluten (glue) is the collective name for the in alcohol solutable proteins of wheat, rye and barley. Triticale (a combination of wheat and rye), kamut and spelt are also known to be harmful. Recently it has been shown that oats are save for both adults and children with celiac disease. The problem with oats is they are often contaminated with gluten during harvest and milling process. In addition, some patients do react with an immune response to oats and clinical follow up when eating oats is advised (2). Gluten intolerance leads to damage of the small intestine mucosal border when genetic predisposed people use gluten containing foods. A gluten free diet leads to recovery. Celiac disease has got a strong association with HLA-genes on chromosome 6. These genes play a role in the regulation of the immune response. The HLA-DQ2-heteromere is found in 95% of the patients: with the other 5% mostly DQ8 is found. Because the HLA-DQ2-heteromere is also found in 30% of the healthy population, it is assumed that other genetic factors and environmental factors are involved in the genesis of celiac disease (3).

Celiac disease is a lot more common in the Netherlands than was previously assumed. Through accumulated knowledge and better diagnostic methods the prevalence of diagnosed celiac disease in our country has increased from 1:5000 to 1:1400, but this is still the top of the iceberg. Screening studies have shown that the real prevalence is 1:200 to 1:300 in the general population. In the Netherlands, for each child with recognized celiac disease there are 7 children with unrecognized celiac disease (4).
Table 1. Some clinical manifestations of celiac disease in children and adolescents (2)

<table>
<thead>
<tr>
<th>System</th>
<th>Manifestation</th>
<th>(Possible) Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrointestinal</td>
<td>Diarrhea</td>
<td>Atrophy of the small bowel mucosa</td>
</tr>
<tr>
<td></td>
<td>Distended abdomen</td>
<td>Malabsorption</td>
</tr>
<tr>
<td></td>
<td>Vomiting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anorexia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Weight loss</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Failure to thrive</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aphthous stomatitis</td>
<td></td>
</tr>
<tr>
<td>Hematology</td>
<td>Anemia</td>
<td>Iron malabsorption</td>
</tr>
<tr>
<td>Skeleton</td>
<td>Rachitis</td>
<td>Calcium/vitamin D malabsorption</td>
</tr>
<tr>
<td></td>
<td>Osteoporosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enamel hypoplasia of the teeth</td>
<td></td>
</tr>
<tr>
<td>Muscular</td>
<td>Atrophy</td>
<td>Malnutrition</td>
</tr>
<tr>
<td>Neurology</td>
<td>Peripheral neuropathy</td>
<td>Thiamine/vitamin B12 deficiency</td>
</tr>
<tr>
<td></td>
<td>Epilepsy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Irritability</td>
<td></td>
</tr>
<tr>
<td>Endocrinology</td>
<td>Short stature</td>
<td>Malnutrition</td>
</tr>
<tr>
<td></td>
<td>Pubertas tarda</td>
<td>Calcium/vitamin D malabsorption</td>
</tr>
<tr>
<td></td>
<td>Secondary hyperparathyroidism</td>
<td></td>
</tr>
<tr>
<td>Dermatology</td>
<td>Dermatitis herpetiformis</td>
<td>Autoimmunity</td>
</tr>
<tr>
<td></td>
<td>Alopecia areata</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Erythema nodosum</td>
<td></td>
</tr>
<tr>
<td>System</td>
<td>Manifestation</td>
<td>(Possible) Cause</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Idiopathic pulmonary hemosiderosis</td>
<td></td>
</tr>
</tbody>
</table>

Growth delay is just one of the possible presenting symptoms. The classical presentation of the thin, moody toddler with chronic fatty diarrhea, bloated belly and flat behind has become relatively rare. The first symptoms do still often occur at a young age, but can also only prevail at a adult age. Besides gastro-intestinal complaints such as belly ache, bad appetite and diarrhea there are also extra-intestinal complaints but many patients have no complaints of the intestine and little other symptoms. One has to consider celiac disease when belly ache, constipation and difficulty treated anemia occur, even if length and weight fall within the norm. The skin presentation of celiac disease, dermatitis herpitisformis, is relatively rare in children (3).

Treatment is a lifelong strict gluten-free diet. Just a trait of gluten can damage the intestine (3).

### 1.2. Diabetes

There are two types of diabetes, type 1 and type two. Type 1 diabetes is also called insulin dependent diabetes. Its origins lie in the islands of Langerhans, who fail to produce insulin. This form of diabetes often begins at a young age. The disease is caused by the own immune-system which destructs the beta-cells which produce insulin. The cause of this deviant behavior of the immune-system is not completely cleared up. Genetic as well as environmental factors play a roll. Diabetes is associated with the HLA-gene and on this gene the DR and DQ loci.

Diagnosis is made when symptoms such as thirst and polyuria, itching and weight loss occur. The blood sugar level is too high and sometimes ketones are found in urine. In severe cases acidification of the blood and eventually coma can occur. This type of diabetes prevails in about 6 out of 1000 people, that is about 0.6% of the Dutch population.

The main pillar of treatment is insulin, which in this case is life saving. People with diabetes mostly have to inject insulin four times a day; mostly this is fast acting insulin before meals and medium acting insulin before going to sleep. Apart from that treatment consists out of physical exercise and a diabetic diet. It is important to eat regularly (a couple amounts of meals at the same hour of the day) appropriate types of food (a balanced diet low in fat, cholesterol and simple sugars).

Type two diabetes used to be called non-insulin-dependent diabetes. Contrary to diabetes type one it is not an auto-immune disease. The body does produce insulin but the glucose can’t enter the cells. Even though the islands of Langerhans produce enough insulin, the body cells are less sensitive to insulin. That’s why the glucose can’t enter the cell (fast enough). This is what is called insulin resistance. There is a strong genetic determination of non insulin dependent diabetes and insulin resistance, but the environmental factors of calorie excess, reduced activity and obesity also make a major contribution (5). Because the liver gets
signaled by the cells that they need glucose, the liver will make extra glucose even though the blood sugar level is already raised. Because of this the blood sugar level will raise even more.

This form of diabetes mostly exists in obese people; 85% of people with diabetes type two has overweight, even though 15% are of normal weight at the time of diagnoses. This type of diabetes often surfailes at an older age, usually above 40 years of age. However, because of our changed life style and eating habits and the fact that we are getting fatter, diabetes type two occurs increasingly at a younger age, even occurring before the age of twenty.

The complaints and symptoms of type two diabetes are the same as those of type one diabetes. The difference is that the complaints will occur more gradually. The prevalence of type two diabetes is 30 to 40 out of 1000 people, that is 3-4% of the Dutch population.

The treatment of type two diabetes is weight reduction, a diabetic diet and exercise. When this falls short, insulin treatment will be started (above mainly from www.diabetes.nl).

Worldwide diabetes has the highest prevalence of chronic illnesses in children. It occurs at many different ages: babies, toddlers and preschool infants. Often it is being diagnosed too late or wrong. Each year diabetes type 1 is increasing with 3% and diabetes type 2 with 5% in children under 6 years of age. Worldwide it is estimated that 70,000 children younger than 15 years get diabetes type 1, that makes 200 children a day. Of the estimated 40,000 children that have diabetes worldwide, more than a quarter live in South East Asia and more than a fifth live in Europe. Until recently diabetes type two was only identified in adults. Nowadays this type is increasing at an alarming rate in children and adolescents. In a period of 20 years diabetes type 2 has doubled in Japan. In North America (dependant of the region) 8 to 45% of children diagnosed with diabetes have the type two version. In Belgium 2600 children younger than 18 have diabetes type 1 and the amount of children with diabetes type two is steadily growing (www.gezondheid.be).

Next to asthma, diabetes type 1 is the most frequently occurring chronic disease in children. According to the general practitioners registration CMR-Nijmegen the prevalence of diabetes in children age 4-14 in the Netherlands is 0.5 each 1000 boys and 1.8 each 1000 girls. These numbers are based on relatively small samples. The difference between boys and girls probably is a coincidence because of these small numbers. There is no difference between boys and girls in incidence in the Netherlands.

Besides this general practitioners registration an estimation can also be made on the basis of research from 1996-1999 in the Netherlands amongst pediatrics, internists and members of the Diabetes Vereniging Nederland. The prevalence in this period was 4.200: 0.28 per 1000 children age 0 -4 , 0.74 per 1000 children age 5-9 and 1.43 per 1000 children age 10-14, resulting in an estimation of 4600 children in the Netherlands.

An inquiry amongst pediatrics throughout the country showed that in 2003/2004 approximately 60 children with diabetes type two were known. Almost all of these children have (severe) overweight and it concerns primarily girls. In spite of the fact that this number is relatively low, it is alarming that this disease, which originally is a disease of the elderly, is nowadays found in children. These 60 diagnosed patients most probably are just the top of the iceberg. This means that beside these patients probably a big group of young people with glucose metabolism disturbances exists and also that the amount of young people with type two diabetes is growing (www.nationaalkompas.nl).
1.3. Celiac disease and diabetes mellitus type 1

Patients with diabetes type 1 more often have celiac disease than the general population. Already in 1969 this association was first reported (6). The diseases have a shared genetic background, they are both located on the HLA-gene. Celiac disease is associated with several auto-immune diseases, it could be that these are caused by celiac disease and screening is advocated as to prevent this (7). Diabetes type two is not an auto-immune disease and therefore is not associated with celiac disease. Nowadays, because of the growing number of children with type two, the possibility of finding diabetes type two in children with celiac disease is there.

Holmes compared 26 reports about the prevalence of celiac disease in diabetes type one patients. The results varied between 0.97 and 16.4, with a mean of 4.5% (8). Rostom finds numbers between 1.5 and 8% doing a meta-analyses at biopsy. These varying numbers can be explained by variations in study design and by differences in the criteria used to diagnose celiac disease (9).

From the about 4600 children with diabetes mellitus type one in the Netherlands, 4.5% approximately has got celiac disease. This is about 207 children. Obviously this is an crude estimation. Compared to 0.5 % of celiac disease in the population, 4.5% of celiac disease in the population with diabetes type one shows that the prevalence is higher in the latter.

Patients with diabetes do not necessarily need to have symptoms of celiac disease. Often they do not go to a doctor with complaints, but suffer a ‘silent’ form of celiac disease. This means they have no clinical symptoms, but will have immunological and histological findings typical for celiac disease (10). Before the screening these patients (and their parents) will not report symptoms (8). Classical symptoms such as diarrhea are absent, but vague symptoms such as bellyache and anemia can exist (11). For this reason celiac disease is not always diagnosed. Another reason for the fact that celiac disease is not being recognized is that existing complaints are thought to be caused by diabetes (12).

1.4. Quality of life

Quality of life as an outcome value is becoming increasingly important. Not only the disease and the treatment are important, but also the impairments for the patient and what can be done about this are very meaning-full. Health is not only the absence of disease but a state of physical, psychological and social well being (WHO, 1948). Most researchers agree that the aspects mentioned by the WHO, the physical, psychological and social aspect, together reflect what is meant by quality of life.

When measuring quality of life we are patient oriented. We look at problems they encounter and when they are known, interventions directed at these precise problems can be made. Better care can be given when assessments are made as to what the patient needs. Communication between patients and doctors can improve when the doctor understands the patient and knows of problems experienced by the patient(13). The social environment can react more adequate when they understand the patient and when they know the problems that exist. In the same way the government, insurance companies etc. can make changes to solve problems once these problems are assessed.
1.4.1 Living with a chronic disease; celiac disease

Quality of life of children with celiac disease is studied by Kolsteren who concludes that children with celiac disease have an adequate level of quality of life compared to the reference group of healthy children. Children with celiac disease aged 8 to 11 were slightly less satisfied with their motor- and social functioning compared with the children of the reference sample but still report rather high scores for these domains. Compared with the reference sample, adolescents with celiac disease were slightly less satisfied with their social, emotional and physical functioning(14). Also Grootenhuis in her research finds little differences in medium scores compared to the norm group. On the other hand children with celiac disease score worse on some domains (15). According to Mearin not finding differences compared with reference groups is due to different questionnaires being used. Using another questionnaire might result in different findings (2). Nijholt finds in her research also a high mean score in the Dutch context of this score (the score she finds on general quality of life – range 0-10, is 8.2). Additionally this score lies above the golden standard of Cummins. Nevertheless these children would judge their quality of life to be higher if they did not have celiac disease. This implies that celiac disease is indeed influencing their lives (16).

Living with celiac disease requires a big adjustment concerning food consumption. A lot of food cannot be eaten anymore and one will be constantly busy checking the ingredients of products. Sometimes products change or the way they are being produced and this means a patient stays busy checking them. A trace of gluten can cause complaints. A breadcrumb in the marmalade of a celiac patient might be too much. A private butter tub, jar of marmalade, always clean cutlery, it are all necessary adjustments (www.coeliakie.info).

The problems most commonly mentioned by the respondents in Saukonens research were the limited supply of gluten free products at school, in restaurants, and so forth, and the complexity of making dietary arrangements for such things as camping and travelling (17). Obtaining gluten free products may be a problem when the local supermarket has little gluten free products in its assortment (18).

Going out for dinner and social contacts become difficult because patients cannot eat what is presented to them and might have to explain themselves. For the same reason travelling is also experienced as being troublesome (19). Having to explain why they cannot eat certain things can be experienced as tiresome and as if not fitting the norm, resulting in the wish to be similar to others. In the case of children, many of these problems will be encountered by their parents, when they do the shopping and prepare the food and make the holiday plans. What is the impact on the parents and how is this related to the quality of life in the children?

1.4.2 Life with a chronic illness; diabetes

Children with diabetes experience a lower quality of life compared to children in a healthy reference group but compared to other chronically ill children they do better (20). Also Ausili finds a decreased quality of life compared to a healthy reference group (21). Adolescents are described as reporting their own health as being similar to that of healthy peers, but the presence of diabetes related symptoms and anxiety is correlated with lower physical and psycho-social functioning (22).

To have diabetes has a big impact on the life of a child and its social environment. Often they must get three to four injections a day and a couple of times a day the blood sugar levels should be checked. On top of that care should be taken as to what’s being eaten and the eating
pattern should be regular. Adjustments to this pattern have to be made in case of physical exercise, sports or with stress. All of this asks for major adjustment and discipline, as well of the child as of the parents/caretakers.

Further the disease has an influence on the development of the child, school performance and social activities, like going out (www.kinderdiabetes.nl).

1.4.3. Life with multiple chronic diseases

Having multiple chronic diseases is associated with poor outcome. Patients have decreased quality of life, psychological distress, longer hospital stays, a higher cost of care and higher mortality (1). Children with multiple chronic conditions have more mental and physical problems. With the number of chronic conditions increasing, the prevalence of developmental delay, learning disabilities and emotional and behavioral problems increases. Similarly, medical consumption (hospital, doctors) increase with the number of multiple conditions reported. The more conditions, the greater the deterioration in health status, measured in amount of days in bed, absence of school and decreasing activities (23).

To have multiple diseases does not change the problems experienced but the severity of them. Physical and social restrictions increase and psychological co-morbidity is another extra burden (23). Multiple chronic disease has a negative influence on quality of life, not only on how people in general feel about their quality of life, but also on psychological stress (24). More researchers reporting decreased quality of life with multi morbidity are Asai and Hauser (25;26).

Having diabetes and celiac disease together requires an additional adjustment. Except for the regularity and the controls of blood sugars, the patients get even more limited in what they can eat.

It is not easy to be diagnosed with celiac disease when already diagnosed with diabetes. It is not easy to not eat a trace of gluten a whole life long, especially taking in account the diabetes. A lot of foodstuffs with carbohydrates that are advised to diabetes patients contain gluten, think of bread, crackers or pasta. When a diabetes patient with diabetes only gets a hypo, dextrose and after that carbohydrates needs to be taken. In the case of a patient who is also afflicted with celiac disease this has got to be gluten free: a matter of being well prepared. The patient should always carry something; a pair of rice crackers, gluten free crackers or something similar so that the hypoglycemic attack can be taken care of (www.coeliakie.info).

Gluten free diet can raise the psychological stress in children with diabetes. Children and adolescents with celiac disease report they have less friends, they feel uncomfortable with themselves because they are different and they are jealous of the independence of their friends. These findings have been shown more often in the psychological profiles of children with diabetes. For this reason it is possible that having both diseases reinforces the psychological stress already experienced (27).

On the whole, we can expect a decreased quality of life on all domains for the children with diabetes and celiac disease.
1.5. The factors that influence quality of life.

The present research will look at illness-related and social demographic factors and how these factors can explain differences between children in the different aspects of quality of life. These aspects are as mentioned above, social, psychological and physical functioning. Because of the restricted available time it is not possible to involve intermediate factors because these are complex concepts for which more questionnaires are necessary, which will be too much to present to the children. Beside looking at the different aspects of quality of life, also a general grade will be given for the general quality of life, as a subjective judgment of the patient. Furthermore it is chosen to look at the impact which the diseases of the child have on the parents and how this affects the quality of life of the children.

1.5.1. Social demographic factors.

1.5.1.1. Gender differences.

Research done by Kolsteren makes clear that among children with celiac disease girls report a reduced quality of life compared to boys. The adolescent girls reported more physical complaints than the adolescent boys with CD (14). In Gaue’s research girls scored lower than boys on assessment of mental health, self-esteem, and family cohesion. Girls also reported a greater impact of diabetes, more worries and less satisfaction with life than boys (22).

From several researches among diabetes patients it becomes clear that female patients experience worse quality of life than men (28;29). This corresponds with results of other patient groups, but also in the healthy population men frequently report a higher quality of life (12).

Due to these findings the expectation is that girls will report a lower quality of life than boys on all aspects of quality of life.

1.5.1.2. Age differences

The younger the patient the better quality of life is being assessed/evaluated. Being younger produced better physical and psychological aspects of quality of life (21). In a research done by Graue comes forward that age is important for the quality of life. Higher age in adolescents was associated with lower scores for, mental health, self esteem, behavior and general health. Older adolescents were more worried, perceived a greater impact of diabetes on daily life and lower diabetes-related life satisfaction (29). Based on these findings a lower quality of life on all domains is expected with increasing age.

1.5.1.3. SES (Socio Economic Status)

The level of education is a good indicator for the socio-economic status of a person/family. The level of education of parents is related indirectly to the child (30). In the three models which Smith, Brooks-Gunn and Jackson describe it is being assumed that more economic resources will improve the well-being of the children directly or indirectly. The expectation
on the basis of this literature and other researches (31;32) is that children from families with high SES (parents with higher level of education) assess their quality of life higher than children with low SES (parents with low level of education).

1.5.1.4. Family composition

To what extent does the family composition have an impact on quality of life? It is expected that a one parent family, because the parent already has a heavy workload, has more difficulties with the extra load it brings of having a child with multiple chronic disease and that this will reduce the quality of life. With less care physical functioning might be decreasing, thus having an impact on social and psychological functioning of the child. Therefore an overall decrease in quality of life is expected.

1.5.2 Illness-specific; celiac disease

1.5.2.1. Age and early diagnosis

An early diagnosis of celiac disease is beneficial for the quality of the life of the children because they do not have to walk around with unrecognized complaints and because they can get used to the diet and the illness at a younger age (33;34) and because they stick better to the diet at a younger age (35). The latter might be because of children are still developing taste and habits and integrate the taste and use of gluten free products easier into their lifestyle. Young people might be more flexible and because they have got so much to learn and are not yet fixed in certain patterns, they can integrate the illness and the behavior it brings with and consider it as normal, whereas an older person has to change his/her ways and then feel and experience the disease as having to be deviant from the way they were used to (the ‘normal’ way). A younger age of diagnosis and a quick diagnosis is expected to increase quality of life, especially on psychological and social functioning.

1.5.2.2. Compliance

Compliance here means to what extent the patient sticks to the diet. In celiac disease the diet is the pillar of treatment, and if well followed the physical complaints disappear as the intestine repairs itself. The relation between physical complaints and quality of life is clear: the quality of life improves if one has less physical complaints. When the diet is well followed and the complaints diminish one would expect the same relationship between compliance and quality of life. However, reality is more complicated. It might be that following the diet and the resulting social restrictions might decrease quality of live even though the health situation has improved.

If the patients sticks to the diet the physical complaints reduce and a growth improvement will follow (18;36-39). Having less complaints gives a larger well-being (40) (41;42). The expectation that compliance to the diet would increase quality of life is supported by the results of several researches (25;26). Nevertheless there are also researches which find no link between compliance and quality of life (41-43) or even show a negative link. As it is, women keep themselves to the diet better but report a worse quality of life than men. An explanation for this could be the increased social restrictions when following the diet. Men might be less strict following the diet and therefore are not faced with social restrictions. Also mentally one might not feel too good about the strict diet. So it can be that on the physical aspect of quality
of live an improvement is found, whereas on the psychological and mainly the social aspect a
deterioration is found. All in all it is unclear whether the demands of the diet or the
consequences on the physical level or the consequences on the social level have a greater
influence on quality of life.

1.5.3. Illness-specific diabetes

1.5.3.1. Age of diagnosis

The earlier the diabetes is discovered, the better the results on the physical and mental fields
of quality of life (21). The expectation is that quality of life will be reported to be better by
younger patients, because at a younger age, being ill and how to deal with that are more easily
learned and integrated into future lives as compared with becoming ill at older age.

1.5.3.2. Number of glucose controls a day

Ausili finds a link between number of glucose controls a day and quality of life: the more
controls a day the better the quality of life (21). This might have to do with having control
over one’s life and feeling better because of this. The higher the number of glucose controls a
day, the better will be the metabolic control, for adjustments can be made according to the
observed blood sugar values. So better metabolic control gives better quality of live, because
one is in control and because better metabolic control will give less complications and less
complications result in better quality of life. In this way, according to Ausili, a high number of
controls a day will prove favorable for the physical and psychological aspects of quality of
life, and this is to be expected in our research.

1.5.3.3. Metabolic control

Research shows that a well controlled metabolism is associated with increased quality of life
(21). Rosello adds to this that adequate metabolic control is associated with less complications
(44). Less complications give a better quality of life because complications will decrease
physical functioning and will enhance fear.

The largest study with adolescents with diabetes shows that good metabolic control gives an
improved quality of life whereas bad metabolic control has been associated with fear
(anxiety), depression, low self-image and fear concerning diabetes (45). This is in accordance
with the results of Guttmann-Bauer, who also finds that adolescents with diabetes type 1
report a better quality of life when they are in better metabolic control (46). Yet another big
study with diabetes type 1 adolescents shows that lower HbA1c was associated with lower
impact, fewer worries, greater satisfaction and better health perception (47). However, these
results are conflicting. Some studies found that HbAc1 values (measure for metabolic control)
were not associated with quality of life (48;49).

1.5.3.4. Hypoglycemia

When the blood sugar becomes too low, for example when the patient has not eaten enough or
when too much insulin is injected, hypoglycemia occurs. Phenomena appear such as
transpiration, trembling, headache, blurred vision, palpitations and hunger feeling. After these
unpleasant symptoms, deterioration in cognitive-motor functions, accidents, unconsciousness,
seizures and even death might be the consequence. Patients with more hypoglycemia experience a lower quality of life (50).

A hypoglycemic attack causes disruption in cognitive and motor functioning and has a significant negative impact on psychosocial function and quality of life. During hypoglycemia hormonal changes and neuroglycopenia occur. This causes physical symptoms like unconsciousness and seizures, cognitive impairment and negative changes in affect and social behavior. Mood can change into feelings of tension and anger and negative interpersonal behavior, such as argumentiveness can occur. Patients as well as their family may develop significant fear of hypoglycemia (51). Taken together the expectation is that high frequency of hypoglycemic incidents in the past decreases quality of life on all domains.

1.5.3.5. Nature of treatment: the insulin pump

According to Ludvigsson there is a common opinion that the pump is superior to multiple daily injections. The pump offers the most physiological insulin substitution. Ludvigsson states that for children and adolescents there is a lack of randomized controlled studies comparing the pump to modern multiple daily injections. In some studies the pump seems to give a slight decrease of HbA1c, a slightly better quality of life, perhaps less hypoglycemia. However, serious hypoglycemia, sometimes fatal, occurs, DKA seems to increase, weight gain and local infections at injection sites may occur (52).

Dirlewanger finds improvement of the quality of life because the pump gives the children more flexibility and because less hypo's occur with it (53). In a review article, carried out by Barnard (54), three pediatric/adolescent studies are included. All of these report an improved quality of life and greater satisfaction amongst the children as well as their parents. Benefits were most often related to improved lifestyle rather than to glycogenic control. These same results were found in the study performed by Opipari-Arrigan (55). Because of these results, the expectation is that using an insulin pump will result in an increased quality of life, mostly in the social domain, because of the improved lifestyle, but also on all the other domains, because hypoglycemia occurs less which will give an improvement on all domains.

1.5.4. Intermediate factors: psychosocial factors

There are several psychosocial factors which possibly influence the quality of life. Examples are coping, adaptation capacity, health/disease cognitions, parental care and involvement, parental control, family functioning, social support, social network and life course (29;56-59). As reported before these variables will not be involved in this study.

1.6. Impact on the parents.

Except for the impact on the children themselves there will be an impact on the parents (19;58). The parents have to take care that the children stick to the diet, measure their glucose and make sure they get their medication. It is their duty to do the shopping, selecting gluten-free products and preparing the food. They will have to give a lot of additional care and will experience social restrictions traveling or going out for dinner. This besides all the worries and distress a parent will experience when his/her child has a disease. Providing medical care and helping children with medical procedures are reported to be stress-full but more robustly related to the overall state anxiety was the disruption of the normal role as a caretaker.
Having less time for other children, having financial trouble and having little time for their own needs were found to be more stress-full than the medical care giving (60). Higher levels of stress in parents of children with chronic illnesses, in contrast to parents of healthy children, are a well documented finding (60). It is well known that childhood behavior and parental stress are linked (61). Consistent with past research Lewin finds positive correlations between parental stress ratings and child internalizing and externalizing behaviors. Additionally, parent stress ratings were positively related to child reported depression, loneliness and social anxiety. One possible explanation is that children who experience high levels of behavioral problems cause their parents to experience higher levels of stress. High levels of stress may also exacerbate anxiety, depression and behavior disorders in children through inconsistent parenting. Another consideration is that both parents and children may be negatively impacted by the child medical condition, causing stress in parents and depression, anxiety or loneliness in children. Finally, children might be more predisposed to experiencing stress themselves, owing either to hereditary or environmental factors (62). So, the expectation is that the parents will have higher levels of stress compared to parents of healthy children and that these high stress levels of the parents will have a negative impact on all aspects of quality of life of the children. The stress may cause the parents to be less able to stick to the diet and this may worsen metabolic control, which is supposed to have consequences for the quality of life of the children. The better the parents feel, the better the children feel. Research of Hoare shows that more than one third of the variance in quality of life between children could be attributed to the impact on the family (58).

1.7. the research model.
1.8 Research questions:

The following questions have been formulated:

1. What is the quality of life of children with celiac disease and diabetes?
2. Which social demographic and illness related variables can explain differences between children?
3. What is the impact of the disorders of the child on the parents?
4. What is the impact of the parental stress on the general quality of life of the children?
2. Methods and procedure

2.1 Literature search and procedure

Relevant information has been collected by means of Pubmed with the Mesh-terms celiac disease AND diabetes (414 results), celiac disease AND diabetes AND quality of life (27 results), celiac disease AND quality of life (27 results), diabetes AND quality of life (732 results), co morbidity AND quality of life AND chronic disease (138 results) with at times an introduced limit children 0-18 of age or review. A further means of acquiring information was by looking into references made in relevant articles and by looking into related articles. An additional search was performed in Picarta using the terms parental stress.

2.2 Respondents and procedure

The target group of this research is children with the age of 8-18 years old who have been diagnosed with diabetes and celiac disease and their parents/caregivers. In between the members registered at the NCV (Nederlandse Coeliakie Vereniging), northern department, where 40 children who had both diseases. All of them were approached. Being members of the northern department of the NCV, they came from the northern provinces of Holland, being Friesland, Groningen, Drenthe and Overijsel. Apart from these children a call was placed on the NCV website asking people fitting the description to contact the NCV and a similar add was placed in the magazine published by the NCV. These calls would reach all of Holland. To all of the people on the list as well as the people that responded to the placed adds a questionnaire was sent accompanied by a letter. After two weeks a reminder was sent. The letter with the questionnaires as well as the reminder were sent by the NCV so that anonymity would be granted, the questionnaires were asked to be sent back in a post-paid envelop to the researcher, thereby again granting anonymity; the researcher did not know any names nor addresses and the NCV would not know who responded.

2.3 The questionnaires.

The questionnaires to be filled in by the children are all quality of life questionnaires. They were all made using focus groups, discussing the problems encountered and using this information in formulating questions to be asked. This is called a bottom up approach. The parents were asked to fill in the Pediatric Inventory for Parents, a questionnaire measuring stress in parents with ill children.

The following questionnaires have been selected for the children:

Kidscreen-52 (63)
Disabkids chronic generic long version (57) (64)
Disabkids chronic specific for diabetes (57) (65)
CDDUX, specific for celiac disease (66)

Next to these standardized questionnaires personal questions were asked, in where factors/variables possibly responsible for differences in between subjects were asked for.

2.3.1. Kidscreen-52

The kidscreen-52 measures 10 components of health related quality of life. These 10 components can be associated with the physical, mental and social domain of quality of life as follows; Physical aspect: physical activities and health, psychological aspect: feelings, mood, feelings about yourself and social aspect: spare time, family, house and neighborhood, friend, school and friends, yourself and others at school, financial resources.

Table 2.1. Kidscreen-52, construction

<table>
<thead>
<tr>
<th>Domain</th>
<th>Component</th>
<th>Amount of items</th>
<th>Number of component</th>
<th>Possible raw score(min/max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Physical Well-being</td>
<td>5</td>
<td>1</td>
<td>5/25</td>
</tr>
<tr>
<td>Mental</td>
<td>Psychological Well-being</td>
<td>6</td>
<td>2</td>
<td>6/30</td>
</tr>
<tr>
<td></td>
<td>Mood &amp; Emotions</td>
<td>7</td>
<td>3</td>
<td>7/35</td>
</tr>
<tr>
<td></td>
<td>Self- Perception</td>
<td>5</td>
<td>4</td>
<td>5/25</td>
</tr>
<tr>
<td>Social</td>
<td>Autonomy</td>
<td>5</td>
<td>5</td>
<td>5/25</td>
</tr>
<tr>
<td></td>
<td>Parent Relation &amp; Home Life</td>
<td>6</td>
<td>6</td>
<td>6/30</td>
</tr>
<tr>
<td></td>
<td>Financial Resources</td>
<td>3</td>
<td>7</td>
<td>3/15</td>
</tr>
<tr>
<td></td>
<td>School Environment</td>
<td>6</td>
<td>9</td>
<td>6/30</td>
</tr>
<tr>
<td></td>
<td>Social Acceptance (Bullying)</td>
<td>3</td>
<td>10</td>
<td>3/15</td>
</tr>
<tr>
<td></td>
<td>Social Support &amp; Peers</td>
<td>6</td>
<td>8</td>
<td>3/15</td>
</tr>
</tbody>
</table>

The items have been scored on a 5 point Likert-scale, where a higher score means a better quality of life. The following items were phrased in a negative way and had to be recoded: item 1 from the component physical activities and health, item 1-7 from the component mood, item 3, 4 and 5 from the component about yourself and item 1-3 from the component yourself and others at school.

The total score, being a Rasch Person parameter because all assumptions made by the Rasch-model are being met by all items, will be transformed into z-scores and from z-score into T-score by multiplying with 10 and adding 50 (67).

Table 2.2. Description of the components of the Kidscreen-52

<table>
<thead>
<tr>
<th>Domain</th>
<th>Component</th>
<th>High score when. ..</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Physical Well-being</td>
<td>Physically fit, healthy and energetic</td>
</tr>
<tr>
<td>Mental</td>
<td>Psychological Well-</td>
<td>Joyful, sees life as being positive, content with life, happy,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Self- Perception</strong></td>
<td>Being cheerful</td>
<td></td>
</tr>
<tr>
<td><strong>Mood &amp; Emotions</strong></td>
<td>Good feeling and good mood</td>
<td></td>
</tr>
<tr>
<td><strong>Social Autonomy</strong></td>
<td>Free to make decisions, independent, autonomy</td>
<td></td>
</tr>
<tr>
<td><strong>Parent Relation &amp; Home Life</strong></td>
<td>Feeling save, supported and loved, being understood, experiencing parents as honest and open</td>
<td></td>
</tr>
<tr>
<td><strong>Social Support &amp; Peers</strong></td>
<td>Accepted, supported and taken up in the group, mutual trust</td>
<td></td>
</tr>
<tr>
<td><strong>School Environment</strong></td>
<td>Likes it at school, good performances, likes going to school</td>
<td></td>
</tr>
<tr>
<td><strong>Social Acceptance (Bullying)</strong></td>
<td>Is not being bullied, is being respected and accepted</td>
<td></td>
</tr>
<tr>
<td><strong>Financial resources</strong></td>
<td>Is content with financial situation</td>
<td></td>
</tr>
</tbody>
</table>

A comparison will be made with a reference norm made for the Kidscreen-52. This reference norm is derived from data from an international study among 22,269 children. Around the mean there is a margin from the mean plus / minus half a standard deviation (50+/0.5*10). Scores that fall in this margin (45-55) are considered to be a mean score on quality of life, above this margin (above 55) to be above and below this margin (below 55) to be below the mean quality of life. The Kidscreen-52 research is normalized to 38% of children in the mean, and 31% below and 31% above this mean margin.

### 2.3.2. Disabkids, chronic generic long version

The Disabkids chronic generic module consists of 37 Likert-scaled items assigned to six dimensions: Independence, Emotion, Social inclusion, Social exclusion, Limitations and Treatment. The subscales of these six dimensions of the DCGM-37 can be combined to produce a general score for health related quality of life (HRQoL), denoted as the DCGM-37 total score. The six sub-scales are additionally associated with three domains, denoted as mental, social and physical domains. These HRQoL domains have evolved from the mental, social and physical domains of HRQoL, as conventionalized by the WHO.

<table>
<thead>
<tr>
<th>Mental</th>
<th>Independence</th>
<th>Confidence about future, living without impairments caused by condition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Emotion</td>
<td>Emotional worries, concerns, anger, problems because of the condition</td>
</tr>
<tr>
<td>Social</td>
<td>Social inclusion</td>
<td>Understanding of others, positive social relationships</td>
</tr>
<tr>
<td></td>
<td>Social Exclusion</td>
<td>Stigma, feeling left out</td>
</tr>
<tr>
<td>Physical</td>
<td>Limitation</td>
<td>Functional limitations, perceived health status, difficulties sleeping</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td>Perceived impact of taking medication, receiving injections, taking insulin, applying cortisone, etc.</td>
</tr>
</tbody>
</table>
The items are being scored on a 5 point Likert-scale, where a higher score means a better quality of life. The following items were phrased in a negative way and had to be recoded: 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 32, 33, 34, 35, 36, 37.

Table 2.4. Disabkids chronic generic measure

<table>
<thead>
<tr>
<th>Domain</th>
<th>Component</th>
<th>Number of items</th>
<th>Items</th>
<th>Possible range of raw scores (min/max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental</td>
<td>Independence</td>
<td>6</td>
<td>1, 2, 3, 4, 5, 6</td>
<td>6/30</td>
</tr>
<tr>
<td></td>
<td>Emotion</td>
<td>7</td>
<td>13, 14, 15, 16, 17, 18, 19</td>
<td>7/35</td>
</tr>
<tr>
<td>Social</td>
<td>Social inclusion</td>
<td>6</td>
<td>26, 27, 28, 29, 30, 31</td>
<td>6/30</td>
</tr>
<tr>
<td></td>
<td>Social exclusion</td>
<td>6</td>
<td>20, 21, 22, 23, 24, 25</td>
<td>6/30</td>
</tr>
<tr>
<td>Physical</td>
<td>Physical limitation</td>
<td>6</td>
<td>7, 8, 9, 10, 11, 12</td>
<td>6/30</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td>6</td>
<td>32, 33, 34, 35, 36, 37</td>
<td>6/30</td>
</tr>
</tbody>
</table>

For each dimension scores are calculated if all items or all items minus one have been answered. Transformed scores (with a range of 1-100) are calculated with the formula 100*(mean-1)/4 and these scores will be compared with the scores of the reference group.

2.3.3. DISABKIDS, chronic specific, diabetes
The diabetes Module has two scales, an Impact and a Treatment scale. The impact scale describes emotional reactions of needing to control everyday life, and to restrict one’s diet. The Treatment scale refers to carrying equipment and planning treatment.

Table 2.5. Disabkids, chronic specific diabetes, construction.

<table>
<thead>
<tr>
<th></th>
<th>Amount of items</th>
<th>Items of dimension</th>
<th>Possible raw score (min/max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact</td>
<td>6</td>
<td>1+2+3+4+5+6</td>
<td>24(6,30)</td>
</tr>
<tr>
<td>Treatment</td>
<td>4</td>
<td>7+8+9+10</td>
<td>16(4,20)</td>
</tr>
</tbody>
</table>

The items are scored on a 5 point Likert-scale, where a higher score means a better quality of life. All 10 items have to be recoded.

2.3.4. CDDUX, chronic specific, celiac disease
The CDDUX has three subscales: communication, diet and having celiac disease.

Table 2.6. CDDUX construction

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Number of items</th>
<th>Items</th>
<th>Possible range of raw score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>3</td>
<td>3, 6, 7</td>
<td>3/15</td>
</tr>
<tr>
<td>Diet</td>
<td>6</td>
<td>4, 8, 9, 10, 11, 12</td>
<td>6/30</td>
</tr>
<tr>
<td>Having celiac disease</td>
<td>3</td>
<td>1, 2, 5</td>
<td>3/15</td>
</tr>
</tbody>
</table>

Items are scored on a 5 point Likert scale, anchored by 1 _ very good, 2 _ good, 3 _ no opinion, 4 _ bad and 5 _ very bad. A low score indicates a high quality of life.
2.3.5. Personal questions

The last part of the questionnaire consists of personal questions. These questions concern socio demographic circumstances and disease specific characteristics of the respondents. The socio demographic circumstances asked for are gender, age, socio-economic situation and family composition. To establish the socio economic status the education level of the father is used. The level of education can be low (basisonderwijs,vbo), middle (mavo,havo,mbo) or high (hbo,wo). The celiac disease specific factors of relevance for this research are age of diagnosis, the amount of time the children had complaints before being diagnosed and whether or not the diet is adhered to (compliance to the diet). The diabetes specific factors are age of diagnosis, amount of hypoglycemic attacks, number of glucose measurement, nature of treatment and HbAc1- value.

2.3.6. The general quality of life

The general quality of life was assessed by asking the respondents to give a mark ranging from 1 to 10, where a 1 is very negative and a 10 a very positive judgment of the quality of life. Besides it was asked how the general quality of life would be perceived without one of the diseases (celiac disease and diabetes).

2.4. The Pediatric Inventory for Parents

The PIP was designed as a general measure of parental stress associated with childhood disease, not limited to a specific illness (68). The measure consists of 42 items divided into four theoretically derived subscales: communication with the family /medical professionals (e.g., talking with the nurse), emotional functioning (e.g., feeling helpless), medical care (e.g., bringing my child to clinic), and role functioning (e.g., missing important events, unable to attend work). These subscales were developed on the basis of a consensus rating for each item by a team of psychologists. Items are scored on two five point Likert scales: the frequency domain(e.g., how often has the event occurred?) and the difficulty domain (e.g., how difficult was this event for you?) anchored by 1_not at all and 5_extremely. Frequency and Difficulty domain scores are generated for each subscale and for the total measure as the sum of relevant items. The range for both domain scores is 42-210 (60). The higher the score the higher the stress level.

Table 2.7. PIP item construction

<table>
<thead>
<tr>
<th>Sub scale</th>
<th>Number of items</th>
<th>Items</th>
<th>Possible range of scores(min/max)</th>
<th>Possible range of scores(min/max)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Frequency domain</td>
<td>Difficulty domain</td>
</tr>
<tr>
<td>Communication</td>
<td>9</td>
<td>2, 7, 12, 17, 22, 27, 32, 37, 40</td>
<td>9/45</td>
<td>9/45</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>15</td>
<td>1, 4, 6, 9, 11, 14, 16, 19, 21, 24, 26, 29, 31, 34, 36</td>
<td>15/75</td>
<td>15/75</td>
</tr>
<tr>
<td>Medical care</td>
<td>8</td>
<td>3, 8, 13, 18, 23, 28, 33, 38</td>
<td>8/40</td>
<td>8/40</td>
</tr>
<tr>
<td>Role functioning</td>
<td>10</td>
<td>5, 10, 15, 20, 25, 30, 35, 39, 41, 42</td>
<td>10/50</td>
<td>10/50</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>+ Total score</td>
<td>+ Total score</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Frequency domain</td>
<td>Difficulty domain</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>42/210</td>
<td>42/210</td>
</tr>
</tbody>
</table>

### 2.5. Response

In total 50 questionnaires were sent. In total, 28 questionnaires were returned (children and parents questionnaires), which is a response rate of 56%.

### 2.6. Data analysis.

Use has been made of the Statistical Package for the Social Sciences (SPSS15). To see if there are significant differences between the group of children from this research and the scores of the questionnaires from other researches a one sample t-test is used. Differences between groups have been made with the Mann Whitney U for the variables gender and nature of treatment and the other variables using correlation, Spearman’s rho.
3. Results

First a description will be given of the general and the disease specific characteristics of the respondents. After that the results of the different quality of life questionnaires will be presented. Then the results of the socio economic and disease specific variables that might be on influence on the quality of life will be shown. The last paragraph will give the results of the pediatric inventory for parents questionnaire and will describe the relationship between parental stress and the quality of life of the children.

3.1 Description of general characteristics

Twenty eight children and their parents responded. This is 13 % of the estimated 207 children in Holland with celiac disease and diabetes. The following table (table 3.1) gives a description of the general characteristics of the group that responded.

<table>
<thead>
<tr>
<th>characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girls</td>
<td>20</td>
<td>71,4</td>
</tr>
<tr>
<td>Boys</td>
<td>8</td>
<td>28,6</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8-12</td>
<td>12</td>
<td>42,9</td>
</tr>
<tr>
<td>13-18</td>
<td>16</td>
<td>57,1</td>
</tr>
<tr>
<td>Family composition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two parent family</td>
<td>23</td>
<td>82,1</td>
</tr>
<tr>
<td>One parent family</td>
<td>3</td>
<td>10,7</td>
</tr>
<tr>
<td>Co-parents</td>
<td>2</td>
<td>7,1</td>
</tr>
<tr>
<td>Number of children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>3,8</td>
</tr>
<tr>
<td>2</td>
<td>17</td>
<td>65,4</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>23,1</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>7,7</td>
</tr>
<tr>
<td>Co-morbidity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>11,1</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>88,9</td>
</tr>
</tbody>
</table>
The higher % of girls corresponds with the literature (2:3:1) (69).
The age of the respondents varies between 8 and 18. The following bar chart shows the distribution (fig 1).

![Distribution of age](image)

Fig 1. Distribution of age

The mean age is 13,2 years (SD 3,1).

The level of education of the parents, which is a reflection of the socio economic status of the children is divided into three groups. None of the mothers nor the fathers are in the lower education level. From the mothers 55,6 % are in the middle range and the other 44,4% have a high level of education. From the fathers 44,4 % are in the middle range and 55,6% have a high level of education. All fathers are employed and so is 78,6 % of the mothers. The fathers work between 10 and 60 hours with 84,6% working between 36 and 40 hours a week. The mothers work between 6 and 32 hours a week, with 71,4% working 20 hours and less.

On the open question asked in the Disabkids about co-morbidity (“do you have other diseases apart from diabetes”) all the children responded: celiac disease. In the personal questions there was one question which asked about specific celiac disease related co-morbidities, with an outcome of 3 children having thyroid associated disease. It remains unclear if any non-specific co-morbidities exist.
3.2. Description of disease specific characteristics of the respondents

3.2.1. Celiac disease

3.2.1.1. Age of diagnosis

About 11% of the children was diagnosed before the age of three. The diagnosis celiac disease was made for 29% of the children at age 3 – 6 and 37% was diagnosed between the age of 6-9. The remaining 22% was diagnosed at an age between 9 and 12 years old.

3.2.1.2. Amount of time with complaints before diagnosis (early/late diagnosis)

In this group of children 21% never had any complaints before being diagnosed with celiac disease, 37% of the children had complaints up to half a year and 21% had complaints up to two years. Between 4 and 6 years of complaints before being diagnosed is a reality for eleven percent of the children. The longest time between complaints and diagnosis is 8 years, accounting for 10% of children in this group.

3.2.1.3. Compliance.

All children except for one reported they always stick to their diet. Of the 96,4% of children that stick to the diet 73,1% feels physically better since they are on the diet and 26,9% feel the same. When the children do accidentally eat gluten 32% has no complaints, whereas 10,7% gets a belly ache, bloated belly and nausea, 3,6% gets diarrhea or other problems with the defecation, and 53,6% has a variety of complaints.

3.2.2. Diabetes specific

3.2.2.1. Age of diagnosis

All children were diagnosed before the age of 11. At a very early age, before the age of two, 10% was diagnosed. 29% was diagnosed between 2 and 4 years of age. A percentage of 18 was diagnosed with diabetes between 4 and 6 years of age, 25% between 6 and 8 and 18% between 8 and 11 years of age.

3.2.2.2. Number of glucose measurements a day

The majority of children measure their glucose 3 (21%), 4 (25%) or 5 (32%) times a day. Only a few measure less than that (3,6% measures one time a day and 3,6% measure 2 times a day), and a few measure more (7,1% measure 6 times a day and 7,1% measure 7 times a day).
3.2.2.3. Metabolic control

18% of the children do not know their HbA1c-value. A non-diabetic HbA1c-value would be 3.5-5.5%. When afflicted with diabetes 6.5% would be an acceptable value. The values in this group vary between 6.5 and 9.5. Just one of the children has a HbAc1 value of 6.5. HbAc1 values between 6.5 and 7 are reported by 17.4% of the children. The biggest percentage of children has a HbAc1 value of 7, namely 26.1% and another 26.1% have values in between 7 up to 8. Values in the range higher than 8 up to 9 is 17.4% and HbAc1 values higher than 9 are reported by 8.7% of the children.

3.2.2.4. Hypoglycemic attacks

There is a percentage of 35.7% of children that has got between 10-20 hypoglycemic attacks a month. Out of this 10.7% say they have 20 attacks a month. The rest has 6 or less attacks a month, with 14.3% not having any at all (table 3.2.).

<table>
<thead>
<tr>
<th>Number of attacks in the last month</th>
<th>Number of children</th>
<th>% of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>1</td>
<td>3</td>
<td>10.7</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>7.1</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>7.1</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>3.6</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>3.6</td>
</tr>
<tr>
<td>10</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>3.6</td>
</tr>
<tr>
<td>15</td>
<td>2</td>
<td>7.1</td>
</tr>
<tr>
<td>20</td>
<td>3</td>
<td>10.7</td>
</tr>
</tbody>
</table>

3.2.2.5. Nature of treatment

All of the children except one use insulin. The treatment with insulin is done either by injections (48%) or by an insulin-pump (52%).

3.3. Quality of life.

In this research the quality of life is measured by the Kidscreen and the Disabkids. The difference between these questionnaires is that the Kidscreen is a more general measure, giving the opportunity of comparison with healthy children. The Disabkids is made for children with a chronic condition so only comparisons can be made between groups of children with chronic conditions. Next to these some more specific measures were used, the Disabkids diabetes specific module and the CDDUX. The Disabkids diabetes specific module has been developed to measure quality of life of children with diabetes and the CDDUX measures quality of life of children with celiac disease. Finally the respondents were asked to rate their quality of life (0-10) and the results of this will be given in the last paragraph of this section.
3.3.1. Quality of life as measured by the Kidscreen and the Disabkids

3.3.1.1. Physical domain of the Kidscreen

On the total score of the physical domain of the Kidscreen (which is the same as the scale “Physical Well-being”) no significant difference is found between the children from this research and the children from the Kidscreen study sample. Compared to this sample out of the healthy population, which was calculated after a research with 17000 children done by the Kidscreen group, the children with celiac disease and diabetes have a slightly higher proportion of children that score below the norm (Fig.2). The norm set by the Kidscreen group is 31% and in this research 32.1% of the children score below the norm. This difference is very small and not significant (t-test, NS). The proportion of children that are in the acceptable range (scores between 45 and 55) is 39.3% for the children with celiac disease and diabetes compared to a proportion of 38% of healthy children in this range. Then for the children that are doing physically well (a score > 55) the children with celiac disease and diabetes have a proportion of 28.6% children doing well, compared to the healthy children who’s norm has been set at 31%. Even though these differences are not significant (t-test, NS), it may show a small trend in where it seems that the group of children with celiac disease and diabetes are doing slightly worse on the physical aspect of quality of life as defined by the Kidscreen group as feeling slightly less physically fit, healthy and energetic.

![Fig 2 Percentage of children with total scores of <45, 45-55 or >55 on the Physical domain Kidscreen](image)

3.3.1.2 Physical domain of the Disabkids

Compared to other chronically ill children of the Disabkids reference group the children of this research seem to have slightly more physical limitations (t-test, NS), but on the component treatment, which is considered to be a part of the physical aspect of quality of life as defined by the Disabkids group, the children of this research (table3.3.) score 80 versus a
score of 72 from the children of the Disabkids field study sample (t-test, t=3.0, p=0.006). So even though they might be slightly less fit and healthy and energetic compared to healthy children and have slightly more functional limitations, perceived health status and difficulties sleeping compared to chronically ill children, the perceived impact of taking medication, receiving injections, taking insulin etc. is significantly lower compared to chronically ill children.

Table 3.3. Mean (SD) scores from the Disabkids physical components

<table>
<thead>
<tr>
<th>Physical aspect</th>
<th>Celiac disease and diabetes (n=28)</th>
<th>Chronic ill children from Disabkids field study sample (n=1128)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical limitation</td>
<td>72,2 (13,9)</td>
<td>73,9 (18,2)</td>
</tr>
<tr>
<td>Treatment</td>
<td>80,3 (13,8)</td>
<td>72,3 (22,7)*</td>
</tr>
<tr>
<td>T-test</td>
<td>* p&lt;0.01</td>
<td></td>
</tr>
</tbody>
</table>

3.3.1.3 Psychological aspect of the Kidscreen.

On the total score of the psychological domain of the Kidscreen no significant difference is found between the children from this research and the children from the Kidscreen study sample. The children with celiac disease and diabetes have a proportion of 40,7% children in the middle range with scores between 45 and 55 (Kidscreen norm: 38%, see fig 3). The percentages of children that have scores higher than 55 and lower than 45 are both 29,6% . Compared to the healthy group of children who have both 31% of children with scores below 45 and scores above 55, the children with celiac disease and diabetes have a smaller proportion of children above or below the norm score (t-test, NS). On the subscales “Psychological Well-being”, “Mood & Emotions” and “Self- Perception” no significant difference is found between the two groups of children (t-test, NS).

Fig.3 percentage of children with total scores of <45, 45-55 or >55 on the Psychological domain of the Kidscreen
3.3.1.4. Psychological domain of the Disabkids

The children from this research score higher on both the components ‘Independence’ and ‘Emotion’ of the psychological aspect of quality of life compared to the chronically ill children of the Disabkids. The subscale ‘Independence’ is of significant difference, showing that the children with diabetes and celiac disease have more confidence about the future, and report to live with less impairments caused by their condition compared to other chronically ill children (t-test, t=2.7, p=0.011). The differences in the subscale ‘Emotion’; emotional worries, concerns, anger and problems because of the condition, between the group of children with celiac disease and diabetes and the chronically ill children from the Disabkids field study are not significant (t-test, NS).

Table 3.4. Mean (SD) score of the Disabkids psychological domain components

<table>
<thead>
<tr>
<th>Psychological aspect</th>
<th>Celiac disease and diabetes (n=28)</th>
<th>Chronic ill children from Disabkids field study sample (n=1128)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence</td>
<td>84.5 (12.7)</td>
<td>76.9 (18.3)*</td>
</tr>
<tr>
<td>Emotion</td>
<td>79.5 (12.7)</td>
<td>76.7 (20.6)</td>
</tr>
</tbody>
</table>

T-test *p<0.05

3.3.1.5. The social aspect of the Kidscreen

On the total score of the social aspect of the Kidscreen 40.7% of children with celiac disease and diabetes compared to 38% of healthy children have scores that fall in the acceptable range of more than 45 and less than 55 (fig 3)(t-test, NS). The proportion that have low scores (below 45) is smaller with 29.6% of children with celiac disease and diabetes compared to 31% of the healthy sample (t-test, NS). The proportion with a score above 55 is also lower with again 29.6% of children with celiac disease and diabetes compared to 31% of children in the healthy sample (t-test, NS). This means that 40.7% of the children with diabetes and celiac disease have a normal score on the social issues concerning relationships with family and friends, amount of time and money to spent and on how they are doing at school. No significant differences were found on the subscales of the social domain of the Kidscreen between the children from this research and the children of the Kidscreen study sample (t-test, NS).
3.3.1.6. The social aspect of the Disabkids.

No significant differences (t-test, NS) are found on the scores of the Disabkids between the children of this research and the children from the Disabkids field study (table 3.5).

Table 3.5. Disabkids chronic generic module-37, mean (SD)

<table>
<thead>
<tr>
<th></th>
<th>Celiac disease and diabetes (n=28)</th>
<th>Chronic ill children from Disabkids field study sample (n=1128)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social inclusion</td>
<td>76.7 (12.2)</td>
<td>75.3 (17.8)</td>
</tr>
<tr>
<td>Social exclusion</td>
<td>85.0 (13.4)</td>
<td>85.2 (15.6)</td>
</tr>
</tbody>
</table>

3.3.2. Celiac disease related quality of life

The total score of the CDDUX is not significantly different between the children of this research and the children with celiac disease from the research of the CDDUX group. On issues concerning communication and diet celiac disease the children afflicted with celiac disease as well as diabetes do not differ from the children with celiac disease only (table3.6.). There is a significant difference found on the subscale having CD (t-test, t=−2.192, p=0.038). Children with celiac disease only are having more problems with the fact they have celiac disease than the children with both celiac disease and diabetes.
Table 3.6. Mean (SD) scores CDDUX

<table>
<thead>
<tr>
<th></th>
<th>Children with celiac disease and diabetes (n=28)</th>
<th>Children with celiac disease (n=527)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>8,0 (2,8)</td>
<td>8,6 (2,4)</td>
</tr>
<tr>
<td>Diet</td>
<td>21,8 (5,3)</td>
<td>22,2 (4,3)</td>
</tr>
<tr>
<td>Having CD</td>
<td>10,6 (1,9)</td>
<td>11,5 (2,2)*</td>
</tr>
<tr>
<td>Total</td>
<td>40,4 (8,7)</td>
<td>42,2 (7,1)</td>
</tr>
</tbody>
</table>

T-test *p<0.05

3.3.3. Diabetes related quality of life

On the diabetes specific quality of life measure, the children with diabetes and celiac disease do not differ from the children with diabetes out of the Disabkids study sample (table 3.7).

Having celiac disease next to diabetes does not seem to have a bigger impact on the children (t-test, NS). Also the consequences of treatment are considered the same whether afflicted with diabetes alone or afflicted with both diabetes and celiac disease (t-test, NS).

Table 3.7 Mean (SD) Disabkids specific diabetes module

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Children with diabetes and celiac disease (n=27)</th>
<th>Children with diabetes. Disabkids field study sample (n=205)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact</td>
<td>62,3 (17,2)</td>
<td>62,7 (22,2)</td>
</tr>
<tr>
<td>Treatment</td>
<td>58,3 (17,3)</td>
<td>58,9 (23,4)</td>
</tr>
</tbody>
</table>

3.3.4. General quality of life.

The children in this research rate their quality of life with high grades. For this group the average rating was 8,6 (SD=1,3). The range was between 5 and 10, with just 7,4% of the children with a grade of 5 or 6. The highest grade, a 10 is given by no less than 29,6%.

Another 29,6% did evaluate the quality of their lives with a 9 (Table 3.8). Nijholt found a slightly lower score of 8,2 in her study into children with celiac disease. In this research from Nijholt 22,7% of the children score below 7, compared to 7,4% from the children in this research (16).

Table 3.8. General quality of life scores (n=28)

<table>
<thead>
<tr>
<th>Rating</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>1</td>
<td>3,7</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>3,7</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
<td>7,4</td>
</tr>
<tr>
<td>8</td>
<td>6</td>
<td>22,2</td>
</tr>
<tr>
<td>8,5</td>
<td>1</td>
<td>3,7</td>
</tr>
<tr>
<td>9</td>
<td>8</td>
<td>29,6</td>
</tr>
<tr>
<td>10</td>
<td>8</td>
<td>29,6</td>
</tr>
</tbody>
</table>

When asked how satisfied they would be with their lives if they had no celiac disease nor diabetes, the ratings are even higher. Here the ratings given are between 9 and 10, with 15,4% of children giving the grade 9 or 9,5 and no less than 84,6% of children rating the quality of their lives with a 10 if they would not have celiac disease and diabetes.
3.4. The factors that influence quality of life.

To answer the question which variables would be of influence on the quality of life of the children with celiac disease and diabetes, a statistical analysis is made and the results of this will be presented in the next paragraphs. First the socio economic factors gender, age and socio economic situation will be presented, followed by the celiac disease specific factors and the diabetes specific factors that might be of influence on quality of life. Of these factors the relationship with the total scores will be first presented, then of the subscales (the components) and then of some individual items, that might be illustrative in case no relationship with the total scores or subscales are found. Only significant relationships will be mentioned.

3.4.1. Gender.

3.4.1.1. Physical domain

On some items significant differences were found between boys and girls (table 3.9).

Table 3.9 Questions of the Physical domain on which a significant difference was found between boys and girls

<table>
<thead>
<tr>
<th>Can you run well?</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totally</td>
<td>75 %</td>
<td>25 %</td>
</tr>
<tr>
<td>Does it bother you to take medication?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>12.5 %</td>
<td>75 %</td>
</tr>
<tr>
<td>Does it bother you to have the things you need for diabetes on you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>12.5 %</td>
<td>0 %</td>
</tr>
<tr>
<td>Almost never</td>
<td>0 %</td>
<td>55 %</td>
</tr>
</tbody>
</table>

Mann Whitney U, Z between -2.1 and 2.6, p<0.05

3.4.1.3. Social aspect

Girls have a significantly better score on the component “School Environment” (table 3.10). The higher score on the component “School Environment” means that girls like it at school, have good performances and like going to school more than boys do (Mann Whitney U, Z=-2.7 p=0.006).

Table 3.10 Mean (SD) of the components of the social domain of the Kidscreen for boys and girls

<table>
<thead>
<tr>
<th>Components of the social domain</th>
<th>Boys (n=7)</th>
<th>Girls (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>21.7 (1.9)</td>
<td>20.8 (3.7)</td>
</tr>
<tr>
<td>Parent Relation &amp; Home Life</td>
<td>25.0 (3.3)</td>
<td>27.0 (2.5)</td>
</tr>
<tr>
<td>Financial resources</td>
<td>13.9 (1.1)</td>
<td>13.1 (2.7)</td>
</tr>
<tr>
<td>School Environment</td>
<td>21.4 (3.7)</td>
<td>25.7 (3.0)**</td>
</tr>
<tr>
<td>Social Acceptance (Bullying)</td>
<td>14.0 (1.3)</td>
<td>13.7 (1.8)</td>
</tr>
<tr>
<td>Social Support &amp; Peers</td>
<td>23.8 (4.7)</td>
<td>24.9 (3.3)</td>
</tr>
</tbody>
</table>

Mann Whitney U test *p<0.05 **p<0.01
Boys and girls do not differ significantly on the total score of the component “Parent Relation & Home Life” of the Kidscreen, but there is one question on which they differ significantly; “do your parents have enough time for you?” The girls are significantly more positive about this and report their parents to have enough time for them whereas the boys have lower scores on this question (Mann Whitney U, Z=-2.5 p=0.022).

On the total “Inclusion” score no differences were found between boys and girls meaning they both have equal understanding of others and positive social relationships. On the question “how easy do you find it to talk about your disease” part of the component “Inclusion” of the Disabkids, girls score significantly higher (Mann Whitney U, Z=-2.2, p=0.03).

3.4.2. Age differences.

A significant correlation is found between the total score of the Disabkids and age (Spearman’s rho, r=0.462, p=0.013). This means that taken all the domains together, the younger children report an overall lower quality of life compared to the older children.

Table 3.13. Spearman’s rho for age with the total score of the Disabkids (n=28)

<table>
<thead>
<tr>
<th>Age</th>
<th>Total score generic 0.46*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spearman’s rho</td>
<td>* p&lt;0.05</td>
</tr>
</tbody>
</table>

3.4.2.1. Physical domain

A significant correlation was found between the subscale “Physical limitation” of the Disabkids and age (physical limitations, table 3.13). The younger children report to have more functional limitations, more difficulties sleeping and perceive their health status to be less than the older children (Spearman’s rho r=0.473 p=0.011).

Table 3.13. Spearman’s rho for age with the physical subscales of the Disabkids (n=28)

<table>
<thead>
<tr>
<th>Age</th>
<th>Physical limitation 0.47*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>-0.58</td>
</tr>
<tr>
<td>Spearman’s rho</td>
<td>*p&lt;0.05 **p&lt;0.01</td>
</tr>
</tbody>
</table>

3.4.2.2. Psychological domain

A significant relationship was found between age and the component “Emotion” of the Disabkids (Spearman’s rho, r=0.543 p=0.003). The older children have less emotional worries, concerns, anger and less problems because of their condition (emotion, table 3.13).

Table 3.13. Spearman’s rho for age with the psychological subscales of the Disabkids (n=28)

<table>
<thead>
<tr>
<th>Age</th>
<th>Independence 0.35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion</td>
<td>0.54**</td>
</tr>
<tr>
<td>Spearman’s rho</td>
<td>*p&lt;0.05 **p&lt;0.01</td>
</tr>
</tbody>
</table>

The children also differ on specific items (table 3.14.)
Table 3.14 Items on the psychological domain on which a significant relationship was found with age

<table>
<thead>
<tr>
<th>Item</th>
<th>8 years old</th>
<th>11 years old</th>
<th>15 years old</th>
<th>18 years old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you been in a good mood?*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>33%</td>
<td>50%</td>
<td>75%</td>
<td>100%</td>
</tr>
<tr>
<td>Have you been feeling jolly?*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>33%</td>
<td>75%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Have you been unhappy because of your disease?*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>33%</td>
<td>25%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Never</td>
<td>33%</td>
<td>50%</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>Were you able to do things without your parents?*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Always</td>
<td>0%</td>
<td>50%</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>Do you find it inconvenient your life has to be planned?***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>67%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Never</td>
<td>0%</td>
<td>0%</td>
<td>25%</td>
<td>100%</td>
</tr>
<tr>
<td>Do others have something against you?*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>33%</td>
<td>25%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Never</td>
<td>33%</td>
<td>75%</td>
<td>75%</td>
<td>100%</td>
</tr>
<tr>
<td>Do you worry about your appearance?*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Almost never</td>
<td>0%</td>
<td>50%</td>
<td>50%</td>
<td>100%</td>
</tr>
<tr>
<td>Never</td>
<td>100%</td>
<td>50%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Spearman’s rho, r between 0.4 and 0.5 *p<0.05 **p<0.01

3.4.2.3. Social domain

On the subscale “Inclusion” of the Disabkids a significant relationship with age was found (Spearman’s rho, r=0.478, p=0.010). The older children have a better understanding of others and have more positive social relationships (Inclusion, table 3.15.).

Table 3.15. Spearman’s rho for age with the subscales of the Disabkids (n=28)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclusion</td>
<td>0.28</td>
</tr>
<tr>
<td>Inclusion</td>
<td>0.48*</td>
</tr>
</tbody>
</table>

Spearman’s rho *p<0.05 **p<0.01

Also on some specific items differences were found (table 3.16). The older children report to have enough money to spend (Spearman’s rho 0.424 p=0.025). The younger children are more content with the teachers (Spearman’s rho -0.451, p=0.016) and get along better with their teachers than do the older children (Spearman’s rho -0.453, p=0.016). The younger
children do report to be bullied by others more than the older children (Spearman’s rho, \( r = 0.385, p=0.043 \)).

Table 3.16. Questions of the social domain on which a relationship was found with age

<table>
<thead>
<tr>
<th>Question</th>
<th>8 years old</th>
<th>11 years old</th>
<th>15 years old</th>
<th>18 years old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have enough money to spent?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rather often</td>
<td>67%</td>
<td>25%</td>
<td>25%</td>
<td>100%</td>
</tr>
<tr>
<td>Never</td>
<td>33%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Are you content with your teachers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mediocre</td>
<td>0%</td>
<td>25%</td>
<td>75%</td>
<td>100%</td>
</tr>
<tr>
<td>Totally</td>
<td>100%</td>
<td>25%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Do you get along with your teachers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>0%</td>
<td>0%</td>
<td>25%</td>
<td>100%</td>
</tr>
<tr>
<td>Always</td>
<td>100%</td>
<td>25%</td>
<td>25%</td>
<td>0%</td>
</tr>
<tr>
<td>Are you being bullied by your peers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>67%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Never</td>
<td>33%</td>
<td>75%</td>
<td>75%</td>
<td>100%</td>
</tr>
</tbody>
</table>

3.4.3. Socio-Economic Status (SES).

3.4.3.3. Social domain

The total score of the social domain is significantly different (Mann Whitney U, \( Z = -2.3, p=0.017 \)), showing that the children from middle socio economic situation are doing better concerning the social issues of quality of life (table 3.17).

Table 3.17  Mean (SD) of the social domain of the Kidscreen with SES

<table>
<thead>
<tr>
<th>Components of the social domain</th>
<th>Middle SES</th>
<th>High SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>20.9 (2.4)</td>
<td>21.1 (2.4)</td>
</tr>
<tr>
<td>Parents &amp; Home Life</td>
<td>27.7 (2.5)</td>
<td>25.8 (2.8)</td>
</tr>
<tr>
<td>Financial resources</td>
<td>13.3 (2.1)</td>
<td>13.3 (2.7)</td>
</tr>
<tr>
<td>School Environment</td>
<td>26.5 (2.7)</td>
<td>23.0 (3.7)*</td>
</tr>
<tr>
<td>Social Acceptance (Bullying)</td>
<td>14.0 (2.0)</td>
<td>13.7 (1.4)</td>
</tr>
<tr>
<td>Social Support &amp; Peers</td>
<td>26.1 (2.8)</td>
<td>23.5 (4.1)</td>
</tr>
<tr>
<td>Total score social domain</td>
<td>55.4 (8.6)</td>
<td>45.8 (9.4) *</td>
</tr>
</tbody>
</table>

Mann Whitney U  *p=0.05  **p<0.01

A significantly better score is found for the children from low SES on the component “School Environment” (Mann Whitney U, \( Z = -2.6, p=0.010 \)) meaning they like going to school more, enjoy school life more and have better performances than children with higher socio economic status (table 3.17).
On individual items of the component “School Environment” significant relationships are found between children of middle or higher socio-economic status (table 3.18)

Table 3.18. Questions of the social domain on which a significant differences were found between middle and higher SES

<table>
<thead>
<tr>
<th>Do you get along with the teachers?</th>
<th>Middle SES</th>
<th>High SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasonably often</td>
<td>8%</td>
<td>60%</td>
</tr>
<tr>
<td>Always</td>
<td>75%</td>
<td>13%</td>
</tr>
<tr>
<td>Are you satisfied with your teachers?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mediocre</td>
<td>25%</td>
<td>40%</td>
</tr>
<tr>
<td>Totally</td>
<td>67%</td>
<td>13%</td>
</tr>
<tr>
<td>Are you able to be attentive in class?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>42%</td>
<td>60%</td>
</tr>
<tr>
<td>Always</td>
<td>50%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Mann Whitney U, Z between -2.2 and -2.5, p<0.05

Also on several other items significant differences were found between children from different socio-economic status. There is a significant difference in socio-economic background when it comes to the children reporting whether their parents to love them or not. Children with a middle SES background feel their parents love them more than children from higher SES (Mann Whitney U, Z=-2.8, p=0.03). They also report their parents to have more time for them than children from a high socioeconomic background (Mann Whitney U, Z=-2.2, p=0.046).

Table 3.19. Questions of the social domain on which a significant differences were found between middle and higher socio economic statuses

<table>
<thead>
<tr>
<th>Do your parents love you?</th>
<th>Middle SES</th>
<th>High SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totally</td>
<td>100%</td>
<td>50%</td>
</tr>
<tr>
<td>Do your parents have enough time for you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>17%</td>
<td>50%</td>
</tr>
<tr>
<td>Always</td>
<td>75%</td>
<td>29%</td>
</tr>
</tbody>
</table>

3.4.4. Family composition

There are 24 two parent families, three one parent families and two families that are co-parenting. These numbers are too small to make valid comparisons with.

3.5. The celiac disease specific factors that influence quality of life.

The celiac disease specific factors that might have an impact on quality of life are the age on which celiac disease was diagnosed, the amount of time the children had complaints before it came to diagnosis (early/late diagnosis) and whether or not the children stick to the diet (compliance). These are the factors of which the results will be given in this paragraph.
3.5.1. Age of diagnosis celiac disease.

3.5.1.2. Psychological domain.

On one item a significant difference is found. Children who are diagnosed at an early age are more content with themselves than children who are diagnosed at an older age (Spearman’s rho -0.411, p=0.037).

3.5.1.3. Social domain.

On two items of the subscale “Social Support & Peers” it did make a difference at what age the child was diagnosed with celiac disease. Children diagnosed at older age feel they have more time to spent with their friends (Spearman’s rho 0.395 p=0.046). Children diagnosed at older age can talk about everything with their friends more than the children diagnosed at younger age can (Spearman’s rho 0.437 p=0.023).

On two specific items from the subscale “Parent Relation & Home Life” significant differences were found. Children diagnosed at younger age feel more happy at home (Spearman’s rho -0.430 p=0.029). Children diagnosed at older age report to be more able to talk to their parents (Spearman’s rho 0.432, p=0.028).

3.5.2. Early or late diagnosis

Children that had complaints for a long time before being diagnosed report a lower general quality of life (Spearman’s rho -0.492 at a p=0.038). Apart from this significant relationship the speed of diagnosis was of influence only on the question whether the children would like to change their bodies. The children that had complaints for a long time before being diagnosed would like to change their bodies more than children that were quickly diagnosed (Spearman’s rho, r=-0.528, p=0.024).

3.5.3. Compliance

All but one did stick to the diet, so no further analysis is necessary.

3.6. The factors that influence quality of life, diabetes specific

In this paragraph the results of diabetes specific factors that might be of influence on the quality of life of the children will be given. The diabetes specific factors are the age on which diabetes was diagnosed, the number of glucose controls a day, the control the children have over their diabetes (metabolic control), the amount of hypoglycemic attacks and the nature of treatment.
3.6.1. Age of diagnosis diabetes

3.6.1.1. Physical domain

On several items relationships with the children diagnosed at different ages were found. From these items it can be concluded that diagnosis at a younger age leads to these children feeling they are less ruled by disease (Spearman’s rho -0.460, p=0.014). But it does bothers the ones diagnosed at younger age more when they have to explain what they can and cannot do (Spearman’s rho 0.377 p=0.048).

3.6.1.2. Psychological domain

On several items a significant relationship was found. On the question;”Do you have the feeling that everything in your life goes wrong?”, part of the component “Mood & Emotions” the children diagnosed with diabetes at a younger age have the feeling that everything goes wrong in their lives more than children diagnosed at older age (Spearman’s rho, r= 0.407, p=0.035). Part of the component “Self-Perception” is the question; “do you worry about your looks/appearance?”. It is found that children diagnosed at an older age worry more about their appearance than children diagnosed at younger age (Spearman’s rho, r= -0.488 p=0.010). Furthermore children diagnosed at older age were more confident about the future (Spearman’s rho, r= 0.440 p=0.019).

3.6.1.3. Social domain

On some items significant relationships were found (table 3.20).

Table 3.20. Questions of the social domain on which a significant relationship were found with age of diagnosis diabetes

<table>
<thead>
<tr>
<th>Were you able to talk to your parents when you wanted?*</th>
<th>Diagnosed with diabetes at the age of 3</th>
<th>Diagnosed with diabetes at the age of 7</th>
<th>Diagnosed with diabetes at the age of 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>67%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did you and your friends help each other?**</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>67%</td>
<td>67%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Have you been afraid of your peers?*</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>67%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Spearman’s rho, r between 0.4 and 0.5 *p<0.05 **p<0.01

3.6.1.5. Diabetes specific quality of life issues

A significant relationship was found on the total score of the subscale “Impact” from the Disabkids diabetes specific module (Spearman’s rho, r= -0.406, p=0.035). It can be concluded that the impact of diabetes is higher for the children diagnosed at older age, meaning their emotional reactions of needing to control everyday life are less positive and they have more problems to restrict their diet.
3.6.2. Number of glucose controls a day

3.6.2.1. Physical domain

The children who measure less score better on the total score of physical domain than children who measure their glucose level more often (Spearman’s rho, r=-0.396, p=0.037). This means that children who measure less feel more physically fit, healthy and energetic than children with a high number of glucose controls a day (table 3.21).

Table 3.21. Correlation T-scores of the Kidscreen with the number of glucose measurements

<table>
<thead>
<tr>
<th>Number of glucose measurements</th>
<th>Physical domain</th>
<th>Mental domain</th>
<th>Social domain</th>
<th>T-score total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical domain</td>
<td>-0.396*</td>
<td>-0.247</td>
<td>0.178</td>
<td>-0.021</td>
</tr>
<tr>
<td>Mental domain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social domain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T-score total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

On some specific items significant differences were found. The children that measure their glucose not so often report to have been more physically active then children that measure their glucose often (Spearman’s rho, r= -0.440, p=0.019). They also report to feel less tired because of the disease compared to children who have a high number of glucose controls a day (Spearman’s rho, r= -0.397 p=0.0405).

3.6.2.2. Psychological domain

On one item from the psychological domain, component “Psychological Well-being” a significant relationship was found. The question is; “have you been feeling happy?”. The children with less measurements felt happier (Spearman’s rho =-0.537  p=0.004).

3.6.2.3. Social domain

The score on the component “School Environment” shows a significant relationship with the number of glucose measurements (Spearman’s rho, r=0.393 p=0.039). It can be concluded that children who measure more like it at school more, report to have better performances, and enjoy school life more than children who measure less (table 3.22).

Table 3.22. Correlations between the number of glucose measurements and the Kidscreen’s social domains.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Component</th>
<th>Number of glucose measurements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social domain</td>
<td>Autonomy</td>
<td>-0.167</td>
</tr>
<tr>
<td></td>
<td>Parent Relationship &amp; Home Life</td>
<td>0.004</td>
</tr>
<tr>
<td></td>
<td>Financial resources</td>
<td>-0.56</td>
</tr>
<tr>
<td></td>
<td>School Environment</td>
<td>0.393*</td>
</tr>
<tr>
<td></td>
<td>You and others at school</td>
<td>0.005</td>
</tr>
<tr>
<td></td>
<td>Friends</td>
<td>0.255</td>
</tr>
</tbody>
</table>

Spearman’s rho *p<0.05
Also on some specific items significant relationships were found. Two of this items are part of the component “School Environment”. Here the children with more glucose measurements were more satisfied with their teachers (Spearman’s rho, $r=0.407\ p=0.032$) and could get along better with their teachers (Spearman’s rho, $r=0.420\ p=0.026$). On one more item, part of the component “Social Support & Peers” children that measure often also report their friends to enjoy being with them more than children that measure less (Spearman’s rho, $r=0.582\ p=0.001$).

3.6.2.4. Diabetes specific issues

On one item a significant different score is found. The children who measure less report to be bothered planning everything (Spearman’s rho, $r=0.395\ p=0.037$).

3.6.3. Metabolic control

3.6.3.2 Psychological domain

Some significant relationships were found between individual items and metabolic control. Children with a higher HbA1c value report to be able to do things, despite of their disease (Spearman’s rho, $r=0.530\ p=0.009$) and report that they are free to live the life as they please (Spearman’s rho, $r=0.415\ p=0.049$).

3.6.3.4 Diabetes specific quality of life issues

A significant relationship was found between the total score on the component “Treatment” and metabolic control (Spearman’s rho, $r=0.487\ p=0.029$). Based on this it can be concluded that the children with higher values are less troubled with their treatment (table 3.23). Furthermore there are some items on which a significant relationship was found. On the diabetes specific questionnaire children with a lower HbAc1 value are found to be ruled by diabetes more than the children with higher values (Spearman’s rho, $r=0.505\ p=0.017$). Children with higher values are less bothered carrying around the things they need for their diabetes (Spearman’s rho, $r=0.474\ p=0.026$).

<table>
<thead>
<tr>
<th>Table 3.23 Correlation of Disabkids disease specific –diabetes module on metabolic control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact</td>
</tr>
<tr>
<td>Regulation of metabolism</td>
</tr>
<tr>
<td>Treatment</td>
</tr>
<tr>
<td>0.134</td>
</tr>
<tr>
<td>0.487*</td>
</tr>
<tr>
<td>Spearman’s rho $^*p&lt;0.05$</td>
</tr>
</tbody>
</table>

3.6.4. Hypoglycemia

3.6.4.1. Physical domain

On one single item a significant relationship was found. Children with more hypoglycemic attacks worry less about their medication (Spearman’s rho=0.513 $p=0.007$).
3.6.4.3. Social domain

A significant relationship was found on the total score of the component “School Environment” (Spearman’s rho, r=0.409, p=0.031) and it shows that children with more hypoglycemic attacks like it at school, have good performances and enjoy school life better than children with less hypoglycemic attacks (table 3.18). No significant relationship was found between the other subscales of the social domain and hypoglycemia (Spearman’s rho, NS).

Table 3.24 Correlation Spearman on the components of the social domain of the Kidscreen with the number of hypoglycemic attacks.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Component</th>
<th>Number of hypoglycemic attacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social domain</td>
<td>Autonomy</td>
<td>0.052</td>
</tr>
<tr>
<td></td>
<td>Parent Relationship &amp; Home Life</td>
<td>0.224</td>
</tr>
<tr>
<td></td>
<td>Financial resources</td>
<td>-0.061</td>
</tr>
<tr>
<td></td>
<td>School Environment</td>
<td>0.409*</td>
</tr>
<tr>
<td></td>
<td>Social Acceptance (Bullying)</td>
<td>-0.033</td>
</tr>
<tr>
<td></td>
<td>Social Support &amp; Peers</td>
<td>0.315</td>
</tr>
<tr>
<td>Spearman’s rho</td>
<td></td>
<td>* p=0.05 ** p=0.01</td>
</tr>
</tbody>
</table>

Apart from this significant relationship of the subscale “School Environment” with hypoglycemia, there are some items on which a relationship was found (table 3.25).

Table 3.25 Question of the social domain on which a relationship was found with the amount of hypoglycemic attacks.

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>2</th>
<th>4</th>
<th>12</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you able to talk to your parents when you wanted?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>25%</td>
<td>50%</td>
<td>75%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Can you talk to your friends about everything?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>25%</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Always</td>
<td>0%</td>
<td>0%</td>
<td>50%</td>
<td>0%</td>
<td>67%</td>
</tr>
<tr>
<td>Do your friends enjoy being with you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>100%</td>
<td>100%</td>
<td>25%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Always</td>
<td>0%</td>
<td>0%</td>
<td>75%</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>Do you get along with the teachers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reasonably often</td>
<td>75%</td>
<td>50%</td>
<td>50%</td>
<td>0%</td>
<td>33%</td>
</tr>
<tr>
<td>Always</td>
<td>0%</td>
<td>0%</td>
<td>50%</td>
<td>100%</td>
<td>67%</td>
</tr>
</tbody>
</table>
3.6.4.4. Celiac disease related quality of life issues

About celiac concerning issues the children with more or less hypoglycemic attacks differ on one sole item. The children with more attacks feel better thinking about gluten containing food than do children with less hypoglycemic attacks (Spearman’s rho, r= 0,488 p=0,010).

3.6.5. Nature of treatment : insulin pump

3.6.5.1. Physical domain

On individual items some differences were found between children injecting or children using a pump. Children with injections report to feel significantly more fit and healthy than children using a pump (Mann Whitney U, Z=-2,2, p= 0,038). On the question; ‘does your disease make you feel tired?’ from the subscale ‘Physical Limitation’ of the Disabkids generic specific questionnaire, 58% of the children who give injections reports to never feel tired, against 21% of the children who use pumps (Mann Whitney U, Z= -2,1, p=0,046).

<table>
<thead>
<tr>
<th>Do you feel tired because of your disease</th>
<th>% of children using injection</th>
<th>% of children using pump</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td>58</td>
<td>21</td>
</tr>
<tr>
<td>Almost always</td>
<td>0</td>
<td>14</td>
</tr>
</tbody>
</table>

3.6.5.2. Psychological domain

A significant difference is found on the subscale “Independence” of the Disabkids between children that inject themselves and children that use an insulin pump(Mann Whitney U, Z=-2,0, p=0,043). It appears that children who inject themselves have significantly higher scores and thus better quality of life concerning their confidence in the future and the impairments caused by their condition.

Apart from this significant difference there is one difference found on the question of the subscale “Emotion”; ‘Does it bother you that your life has to be planned?’, 38,5% of the children who give injections answer they are never bothered about the fact their life has to be planned whereas there are no children using a pump who are not bothered at all (Mann Whitney U, Z=-2,0 p= 0,048).

<table>
<thead>
<tr>
<th>Does it bother you your life has to be planned</th>
<th>%of children using injections</th>
<th>% of children using pump</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td>38,5</td>
<td>0</td>
</tr>
<tr>
<td>sometimes</td>
<td>7,7</td>
<td>50</td>
</tr>
</tbody>
</table>

3.6.5.3. Social domain

On one specific items a significant difference was found. Children with injections report to have more time to meet up with their friends compared to children who use a pump (Mann Whitney U, Z=-2,5, p=0,023).
3.7. Parental stress

In order to establish the impact of the child’s disorders on the parents, the parents were asked to fill in the Pediatric Inventory for Parents (PIP). The PIP consist of the subscales “Communication”, “Medical care”, “Role function” and “Emotional function”. The frequency (e.g., how often has the event occurred?) and the difficulty (e.g., how difficult was this event for you?) scores are generated for each subscale. Because the PIP was designed for parents of ill children, a comparison with parents from healthy children is not possible. The amount of stress in the parents of this research is therefore compared with parents from children with cancer, whose data was available.

3.7.1. Parental stress, how often did it occur?

A significant difference (t-test, t=2.485, p=0.020) was found on the frequency score of the subscale “Communication” between the parents of this research and the parents of children with cancer, as found in research by Streisand (68) (table 3.20). The parents of this research report a higher frequency of communication issues in comparison with parents of children with cancer. This means that parents from this research report to talk more to medical staff and family, they report to have more arguments and they report to be more confused by medical information as compared to the parents of children with cancer. The parents of the children with cancer report a higher frequency on items that measure “Emotional functioning” in comparison to the parents of the children from this research (t-test, t = -3.904, p = 0.001). This means they have more worries and sleeping problems and feel emotionally worse than the parents of this research. The parents do not differ on the frequency of medical care and role functioning, nor on the total frequency score (table 3.20).

3.7.2. Parental stress, how difficult has it been?

On the difficulty scales the parents from the children with cancer score higher on each subscale. Only on the difficulty of “Communication” there is no significant difference found (t-test, NS). All the others, “Medical care” (t-test, t= -2.9, p= 0.007), “Role function” (t-test, t = -8.5, p = 0.000), and “Emotional functioning” (t-test, t = -6.0, p = 0.000) as well as the total difficulty score (t-test, t = -4.4, p = 0.000) show a significant difference between the parents of this research and the parents of the children with cancer (table 3.20). The parents of the children with diabetes and celiac disease report less difficulties on all aspects of the subscales as compared to parents from children with cancer.

Table 3.20. scores of the subscale and total score of the Pediatric Inventory for Parents of the parents of this research (N=27) and the parents of children with cancer (N= 126)

<table>
<thead>
<tr>
<th>scale</th>
<th>PIP frequency, this research</th>
<th>PIP frequency, Randi Streisand</th>
<th>PIP difficulty, this research</th>
<th>PIP difficulty, Randi Streisand</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>20.6 (5.4)</td>
<td>18.0 (6.7)*</td>
<td>18.9 (6.4)</td>
<td>19.8 (7.4)</td>
</tr>
<tr>
<td>Medical care</td>
<td>18.1 (7.1)</td>
<td>16.1 (7.1)</td>
<td>15.6 (6.6)</td>
<td>19.3 (7.4)**</td>
</tr>
<tr>
<td>Role function</td>
<td>18.7 (5.3)</td>
<td>20.6 (8.1)</td>
<td>18.3 (7.1)</td>
<td>29.9 (9.3)**</td>
</tr>
<tr>
<td>Emotional function</td>
<td>32.1 (9.5)</td>
<td>39.2 (14.6)**</td>
<td>34.9 (11.8)</td>
<td>48.4 (14.5)**</td>
</tr>
</tbody>
</table>
3.8. The relationship between parental stress and the quality of life of the children

Is the level of stress of the parents related to the quality of life of the children? The results of this question will be presented in the next section. The results of the PIP have been compared with the outcomes of the children’s questionnaires, namely the Kidscreen, the Disabkids, the Disabkids for diabetes and the CDDUX. Only significant relationships will be mentioned.

3.8.1. Total frequency of events that cause stress with parents.

Parents with high frequency of stressful events have children with a lower overall total score on quality of life as measured by the Disabkids (Spearman’s rho, r = -0.390, p = 0.034) as compared to children of parents with a low frequency of stressful events. Apart from this significance on the total score of the Disabkids these children also score significantly lower than children whose parents experience less stressful events on the components “Physical limitation” (Spearman’s rho, r = -0.453, p = 0.018) and “Exclusion” (Spearman’s rho, r = -0.436, p = 0.023). A low score on the component “Physical limitation” means the children experience functional limitations, have difficulties sleeping perceive their health status as being less than children whose parents experience low stress levels. A low score on the component “Exclusion” means the children feel stigmatized and that they feel left out.

3.8.2. Total of difficulty ratings from stressful events.

The parents that have difficulties with stressful events also have children that score significantly lower on the total score of the Disabkids than children whose parents have no difficulties with stressful events. The total score on the quality of life of the children of the Disabkids shows a significant relationship with the difficulty ratings of the parents (Spearman’s rho, r = -0.399, p = 0.041). A significant relationship is also found on the component “Physical limitation” (Spearman’s rho, r = -0.384, p = 0.048) and the component “Exclusion” both of the Disabkids (Spearman’s rho, r = -0.435, p = 0.024). So first of all there is a relationship between parents having difficulties with stressful events and the children reporting an overall lower quality of life. Secondly there is a relationship between parents having difficulties with stressful events and their children reporting more functional limitations, difficulties sleeping and a negative perception of their health status. Then there is the relationship between parents having difficulties with stressful events and their children feeling stigmatized and left out.

3.8.3. Frequency of Communication

No relationships were found between the frequency of the subscale “Communication” and any total scores, subscales of the children’s quality of life questionnaires used (Spearman’s rho, NS). Even though the parents of the children from this research reported to have more frequent communication issues than the parents from the children with cancer, this does not have an impact on the total scores nor subscales of the quality of life of their children.
3.8.4. Difficulty of Communication

No relationships were found between the difficulty of the subscale “Communication” and any total scores, subscales of the children’s quality of life questionnaires used (Spearman’s rho, NS). A significant relationship was found on one single item. How difficult the events inventoried in the subscale “Communication” (such as arguments with family members, feeling misunderstood, talking to doctors or talking to family) is perceived by parents is correlated with the child wanting to change their body (Spearman’s rho, r = 0.468, p = 0.016). The more difficult it is for parents to talk to their children, the more difficult it is for them to argue or to be misunderstood, etc, the better the children feel about their bodies.

3.8.5. Frequency of Emotional functioning

A significant relationship was found between the total frequency score of the scale “Emotional functioning” of the parents and the total score of the Disabkids (Spearman’s rho, r = -0.45, p = 0.020). When the parents often worry, have sleeping problems, when they feel insecure and powerless and see their children are sad or scared or isolated from others, their children report an overall low quality of life as measured by the Disabkids. A significant relationship was also found between the frequency of “Emotional functioning” of the parents with the subscale “Physical limitations” of the Disabkids filled in by their children (Spearman’s rho, r = -0.451, p = 0.018). This means that also their children have difficulties sleeping, besides experiencing functional limitations and perceiving their health status in a negative way. Another significant relationship was found between the subscale “Exclusion” of the social domain of the Disabkids and the subscale “Emotional functioning” of the parents (Spearman’s rho, r = -0.456, p = 0.017). The children feeling stigmatized and left out is related to the emotional functioning of their parents. From the next items on which a significant relationship is found it can be seen that the children feel different and they feel treated differently by the teachers, but not by their friends. Teachers treat them different (Spearman’s rho, r = -0.462, p = 0.015). They feel different (Spearman’s rho, r = -0.442, p = 0.021). Positive is that they report their friends to enjoy their company (Spearman’s rho, r = 0.442, p = 0.024) and are not bothered taking their medication (Spearman’s rho, r = 0.413, p = 0.040). The last significant relationship was found between a subscale of the Kidscreen, namely the subscale “Mood & Emotions” of the psychological domain (Spearman’s rho, r = -0.439, p = 0.025) and the subscale “Emotional functioning” of the parents. A high frequency of emotional functioning events correlates with a low score on “Mood & Emotions” of the children, with children reporting to feel depressed, unhappy and in a bad mood. A significant relationship was found between the subscale “Financial Resources” of the Kidscreen and the scale “Emotional functioning” of the parents. The children report that they have not enough money to spent and report to feel their finances are restricting their lifestyle and feeling financially disadvantaged compared to children of parents with a low frequency of emotional functioning issues (Spearman’s rho, r = -0.429, p = 0.026).

3.8.6. Difficulty of Emotional functioning

Parents that find it difficult to deal with “Emotional Functioning” issues as sleeping problems and worries and seeing their children sad or scared or in pain have children who score low on the “Physical limitation” subscale of the Disabkids (Spearman’s rho, r = -0.449, p = 0.019) and also score low on the subscale “Exclusion” of the Disabkids (Spearman’s rho, r = -0.457, p = 0.017). Positive is that they feel their friends enjoy to be with them (Spearman’s rho, r =
0.468, p = 0.016) and they are not bothered taking their medication (Spearman’s rho, r = 
0.421, p = 0.036).

3.8.7. Frequency of Medical care

A significant relationship was found between the frequency of “Medical care” and “Physical 
limitations” (Spearman’s rho, r = -0.416, p = 0.031). The more frequent the parents have to 
pay attention as their child eats and otherwise help them with medical procedures the more 
their children report to have physical limitations.
A significant relationship was found between the frequency of “Medical care” reported by the 
parents and the subscale “Exclusion” filled in by their children (Spearman’s rho, r = -0.387, p 
= 0.046). The more medical care and help is needed from their parents the stronger the 
children feel stigmatized and left out.


Parents who have problems dealing with issues around giving medical care, have children 
who score low on overall quality of life as measured by the Disabkids (Spearman’s rho, r = - 
0.394, p = 0.042).
A relationship is found between the perception of difficulty of “Medical care” issues of the 
parents and the component “Exclusion” filled in by the children (Spearman’s rho, r=-0.445, 
p=0.020). In what way the children feel excluded is highlighted by the next significant items. 
The children report to feel different (Spearman’s rho, r = -0.394, p = 0.042) and they report to 
feel they cannot do the things as well as others (Spearman’s rho, r = -0.400, p = 0.039). They 
do report their friends to enjoy their company (Spearman’s rho, r = 0.422, p = 0.032).

3.8.9. Frequency of Role functioning issues.

Children from parents with high scores on the subscale “Role functioning”, that means they 
have experienced a high frequency of events such as not being able to go to work, or not 
being able to give enough attention to other family members or oneself, having financial 
problems and being away from home a lot, have children that score low on the component 
“Mood & Emotions” from the Kidscreen (Spearman’s rho, r = 0.506, p = 0.008) and on 
“Exclusion” from the Disabkids (Spearman’s rho, r = -0.408, p = 0.035). So there is a 
relationship between parents having to change their role play, such as not being able to work, 
having a different relationship with their partner and having less time for themselves and for 
other family members and their children feeling depressed, unhappy and in a bad mood. Also 
there is a relationship between the parent having to change their role play and their children 
feeling stigmatized and left out. A significant difference was found on an individual item: 
“Does the teacher treats you different?” (Spearman’s rho, r = -0.443, p = 0.021). Children 
with parents with high scores on “Role Functioning” report their teachers to treat them 
different as compared to children from parents with low scores on “Role Functioning”.

3.8.10. Difficulty of Role Functioning issues

Parents that report to have problems with issues concerning “Role Functioning” have children 
that score low on the subscale “Exclusion” of the Disabkids (Spearman’s rho, r = -0.391, p = 
0.044). So there is a relationship between these children feel stigmatized and left out and 
parents having difficulties with issues concerning “Role Functioning”.

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4 Discussion

4.1. The quality of life of children with celiac disease and diabetes

The children with celiac disease and diabetes report to have a level of quality of life not inferior than that of other chronically ill or healthy children. Former studies on quality of life with multiple chronic diseases found a decrease in quality in life with growing numbers of chronic disease (1:23). Since the children of this research have multiple chronic disease it was expected they would have more physical complaints, more social problems and more psychological problems than healthy children or children with one chronic disease. This was not according to the results of this research. The children of this research reported to be similar to healthy children and on some aspects they reported to do even better than other chronically ill children. It has been shown before that people with life threatening disease were found to have a stable and good quality of life. A number of researchers have documented that people with severe illness report a level of quality of life neither inferior nor better than that of less severely ill patients or healthy people. The mechanism possibly responsible for this is called ‘response shift’ (70). Faced with changes in health and illness people change their internal standards, values and conceptualization of quality of life. This might have been the case for the children with diabetes and celiac disease. Children with both celiac disease and diabetes report to have less problems with the fact they have celiac disease than the children with celiac disease only (change of value). Also they rate their subjective quality of life with higher grades than the children with celiac disease only. Even though one would expect it would be more difficult to have multiple diseases, with both diseases the burden of minding what you eat, the children who do have to deal with this report to have less impact of their treatment than other chronically ill children with one disease. So faced with multiple diseases one might lower the standard of tolerance, change values and see quality of live in a different way.

4.2. Which social demographic and illness related variables can explain differences between children?

4.2.1 Social demographic variables

The variables gender, age and SES explain differences between children’s quality of life on certain aspects. No conclusions can be drawn regarding the variable ‘family composition’ because there was too little variation in family composition.

Gender did explain differences in the School & Environment subscale. Girls are doing better and are feeling better at school. For most other diseases girls report a lower quality of live than boys. Why this is not the case for this group of children with celiac disease and diabetes remains unclear.

Age difference made a difference on assessment on the overall quality of life as measured by the Disabkids. Younger children asses their overall quality of life to be worse than the older children. Age also explained a difference in the physical domain: the younger children report to have more functional limitations, more difficulties sleeping and perceive their health status to be less than the older children. On the psychological domain age also made a difference:
younger children seem to be in a worse mental state, they are less happy. The older children have less emotional worries, concerns, anger and less problems because of their condition. Older children only worry more about their appearance. One explanation why the younger children are doing worse might be because they report to be teased more than the older kids and feel others have something against them. Their peers might be too young to understand and therefore tease them which than again makes the children depressed. An alternative explanation might be their own understanding is less which would make them worry more. Another explanation might be that early diagnosis means the disease is more severe resulting in lower quality of life.

SES explained differences on the social domain. The children from middle SES had overall better scores on the social domain compared to children from high SES. The children from middle SES report to feel and do better at school. Also concerning the relationship they have with their parents, they feel their parents love them more and have more time for them. These findings are not in agreement with most studies, where a low SES normally predicts a worse quality of life. In this research there only was a group of middle and high SES, there was no group of children from low SES, which might be an explanation for these unexpected findings. Why children from high SES are socially weaker than children from middle SES is unclear, it could be argued that children from high SES are socially weaker because they are not given enough attention by their parents.

4.2.2. Celiac disease specific variables

The age at which celiac disease was diagnosed made no difference for any aspect of quality of life. It was not shown that diagnosis with celiac disease at young age improves quality of life through better integration into the lifestyle. However, having to walk around for a long time with unexplained complaints makes the children appreciate their lives less as early diagnosis explained differences in the general quality of life ratings. Children who had complaints for a long time before being diagnosed rate their general quality of life significantly lower than children who were quickly diagnosed with CD.

4.2.3. Diabetes specific variables

Age of diagnosis, number of glucose measurements a day, metabolic control, amount of hypoglycemic attacks a month and the nature of treatment explain differences between the children on different aspects.

The impact of diabetes is higher for the children diagnosed with diabetes at older age, meaning their emotional reactions of needing to control everyday life are less positive and they have more problems to stick to their diet. An explanation might be that the younger children were more able to integrate the consequences of the disease into their lifestyle. Why this seems true for the age on which diabetes was diagnosed and not the age that celiac disease was diagnosed remains unclear. It might have nothing to do with the integration into the lifestyle. It might have to do with being a teenager. A teenager might be rebellious and rebel against set up rules and therefore will be negative about having to control their life and will be prone not to stick to their diet.

The number of glucose measurements made a difference on the physical domain. Children who measure less feel more physically fit, healthy and energetic than children with a high number of glucose controls a day. The expectation that high numbers of control a day will
have positive effects on the physical and psychological aspects of quality of life was not met in this research. One possible explanation could be that children that are not feeling fit, healthy and energetic need to check their glucose more because they want to improve their health. It does not seem that measuring more improves the physical aspect of quality of life because the diabetes is more under control.

Furthermore the number of glucose measurements made a difference on how the children report to perform at school. Children who measure more like it better at school, report to have better performances, and enjoy school life more than children who measure less. It seems the children that measure often are smart and responsible children, making an effort controlling their diabetes. That despite these efforts they report to be in worse physical health than children who measure less might be explained by these children being in a worse physical state to start with.

Metabolic control makes a difference on the diabetes specific treatment. Children with low HbAc1-values are more bothered with their treatment than children with high values. On individual items it was shown that children with low values feel more ruled by diabetes and are more bothered carrying the things they need for diabetes around compared to children with high values. This shows that the medical goal of treatment is not always associated with an improvement in quality of life. Even though a low HbAc1 value is achieved, the quality of life is lower because of the means to achieve this is a burden for the children.

The expectation that more hypoglycemic attacks would influence quality of life in a negative way was not met in this research. Children with more hypoglycemic attacks a month like it at school more, report to have better performances, and enjoy school life more than children with a lower amount of hypoglycemic attacks. It seems that the obvious symptoms of an attack make that the children are more able to talk to others about their disease and other things and thereby improve the quality of life they experience at school. Without the attacks the severity of the illness might not be understood by others and it does not show as much that the child is ill. The attacks give the child an immediate opportunity to explain and talk about themselves and their disease.

The nature of treatment made a difference on the physical domain. Children with injections seem to be doing better, they feel healthy and fit and are not as tired as the children using an insulin pump. Also on an aspect of the psychological domain, namely independence, a difference has been shown. The children using injections have more confidence in the future and they live with less impairments caused by their condition compared to children using an insulin pump. Even though the pump offers the most physiological insulin substitution, it is not an artificial pancreas. It might require more effort than injection therapy, the blood sugar has to be checked several times a day and the children have to learn to use the pump to deliver the extra insulin required when eating. This might cause the impairments experienced by the children using the pump. Another explanation might be that children who experience many impairments and feel unfit and unhealthy are prone to choose the insulin pump because they feel not confident enough to inject themselves and hope by choosing for the pump for a more adequate treatment to relieve their symptoms.
4.3. The impact of the disorders of the child on the parents

The biggest impact on parents is caused by having to talk to medical staff and by feeling misunderstood by friends and family. The parents of the children with celiac disease and diabetes report more frequently to have issues with communication than parents from children with cancer. This might be because in the case of cancer there is much more information available and also friends and family will have a better understanding of what it means to have that disease, while diabetes and celiac disease is not that familiar. Parents of children with celiac disease and diabetes feel more confused about medical information and therefore feel more need to talk with medical staff. A picture emerges of misunderstood parents, who themselves have problems understanding. Furthermore the parents report to give the same amount of medical care to their children and have to change their role (e.g. miss important events, unable to go to work) as often as parents of children with cancer. This shows the severity of impact of a child with diabetes and celiac disease on the parent. The parents of this research and the parents of the children with cancer do not differ on how difficult the communication issues with doctors, or family etc. are perceived. The parents of the children with cancer report to have more difficulties regarding emotional functioning (e.g., feeling helpless), medical care (e.g., bringing my child to clinic) and role functioning (e.g., missing important events, unable to attend work).

4.4. The impact of the parental stress on the general quality of life of the children

A definite relationship has been found between parental stress and the quality of life of their children. Whether the parental stress has an impact on the quality of life of the children or the quality of life of the children has a impact on parental stress remains a matter of discussion. It can be argued that parental stress has a definite impact on the quality of life of the children, with children reporting a lower quality of life when parents report to experience many difficult events. The stress of the parents possibly causes the children to experience a decreased quality of life. The relationship could also be the other way around; because the children are doing worse physically, feel excluded and report to have a worse quality of life, the parents experience many difficult events. Both options are possible and probably it works both ways. It is however beyond doubt that the more frequent and the more difficult events are perceived by parents the worse the quality of life of their children is, the more physical limitations the children report and the more excluded the children feel. Especially parents frequently reporting emotional problems and parents reporting to find it hard to deal with giving their child medical care have children that report a decreased quality of life.

A relationship has been found between children feeling excluded and parents reporting to have problems dealing with frequent emotional dysfunction, frequent dysfunction in their role play and frequently having to give medical care. Seeing their child is left out and stigmatized makes the parents feel helpless and makes them change their role (e.g. give less attention to other family members, unable to attend work) or maybe it is the other way around that the child receiving this medical care by their parents and seeing they give less attention to others makes them feel different? Again it may be working both ways.

There is a relationship between the child being physically limited and the parents reporting to be dysfunctioning emotionally and the amount of medical care the parents are providing. In
this case it seems logic that seeing the child have physical limitations will make the parents feel helpless and will make that the parents more frequently provide medical care. The amount of times parents have issues regarding emotional functioning and the amount of time the parents have issues with role functioning are related to the child’s mood and emotions. When parents frequently dysfunction emotionally and have problems functioning in their roles, this has a negative impact on the mood and emotions of the child. So the more frequent the parent is upset, feels helpless and loses sleep is related to the child having a bad mood and feeling depressed. Which one comes first is again a matter of discussion and it can be that the two go hand in hand. Concerning the role functioning it might be that the parent having to change its role makes the child moody and depressed, it might also be that the parents decides to change its role, doesn’t go to work or has less time for other family members because the child is moody and depressed. Somehow the latter seems more logic.
H5 Conclusion


The quality of life as reported by the children with diabetes and celiac disease are comparable with healthy children and on some aspects better than other chronically ill children. The aspects on which they perform better compared to other chronically ill are that they deal better with their treatment and feel more independent. The children with celiac disease and diabetes feel better about having celiac disease than children with celiac disease only. They also give their life a higher grade on a 10-point Quality of life scale than the children with celiac disease only. They do not feel different on issues concerning diabetes compared to children with diabetes only.

5.2. Variables that can explain differences between children

Age and early diagnosis made a difference on respectively the overall and the subjective quality of life rating of the children. Early diagnosis improved the rating of the general quality of life rating given by the children and older age improved the overall quality of life reported.

Apart from that the younger children also report to have more functional limitations, more difficulties with sleeping and perceive their health status to be less than the older children. Age also made a difference on the mood and the emotions of the children. Younger children report to be more often in a bad mood and unhappy and they are being teased more than the older kids and they feel more rejected by other children. The older children have less emotional worries, concerns, anger and less problems because of their condition.

School performance and feeling well at school is related to several variables. First the socio economic background of the children. Children from middle SES reported to perform better at school than children from high SES. Secondly gender made a difference on school achievement and school life. Girls reported to perform and feel better at school than boys. Furthermore a high number of glucose measurements did improve the way children feel and perform at school. Also the children with many hypoglycemic attacks did report to perform and feel well at school, better than the children with less hypoglycemic attacks.

Whether the children feel physically fit, healthy and energetic has to do with several variables. First of all children with a high number of glucose measurements report to feel physically unfit and unhealthy. Secondly the nature of treatment is of influence. Children using injections report to feel more fit, healthy and energetic than children using an insulin pump.

Children using injections also report to have more confidence in the future and they live with less impairments caused by their condition compared to children using an insulin pump. The impact of diabetes is higher for the children diagnosed with diabetes at older age, meaning their emotional reactions of needing to control everyday life are less positive and they have more problems to stick to their diet.
Metabolic control makes a difference on the diabetes specific treatment. Children with low HbA1c values are more bothered with their treatment than children with high values. Children who are in better control feel their lives is ruled by diabetes more.

5.3. The impact of the disorders of the child on the parents

The biggest impact on parents is caused by having to talk to medical staff and by the feeling to be misunderstood by friends and family. The parents of the children with celiac disease and diabetes report to have issues with communication (doctors, social environment) more frequently than parents of children with cancer. Furthermore they just as frequently have to change their role (miss important events of other family members, unable to attend work) and to provide medical care more as compared to parents of children with cancer. This shows the severity of impact of a child with diabetes and celiac disease on the parent.

5.4. The impact of parental stress on the quality of life of the children

Parental stress and the quality of life of their children are linked. The more frequent and the more difficult events are perceived by parents the worse the quality of life of their children is, the more physical limitations the children report and the more excluded the children feel.

A relationship has been found between children feeling excluded and parents reporting to have problems dealing with frequent emotional dysfunction, frequent dysfunction in their role play and frequently having to give medical care.

There is a relationship between the child being physically limited and the parents reporting to be dysfunctioning emotionally and the amount of medical care the parents are providing.

The amount of times parents have issues regarding emotional functioning and the amount of time the parents have issues with role functioning are related to the child’s mood and emotions.

5.5. Recommendations

Special attention should be given to the younger children, since they report more sequelae. General practitioners should be made aware of the impact on quality of life of patients having vague, unexplained complaints for a long time and be more focused on the possibility of the diagnosis celiac disease. Not only among general practitioners, but also among the whole social environment a lot could be gained by providing more information about the impact of celiac disease and diabetes on patients. Especially more care and attention should be given to parents of children who suffer from the negative consequences of their disease.
Reference List


Ref Type: Magazine Article


Ref Type: Case


Ref Type: Magazine Article


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Bron; International Diabetic Federation; Auteur: redactie Nursing, Christie Klaucke
Appendix 1. Student’s tasks

The research has not been part of a bigger research. I wrote the project description, did the literature research, choose the questionnaires to be used plus additional questions, followed an SPSS-course, collected the data and did the analyses, discussion and conclusion all by myself. With questions I could always go to the supervisors and when finished writing a certain chapter this would be revised by the supervisor. I would like to thank Jelte Bouma for all of his time and advise.

Furthermore I would like to thank my parents for all their loving care, without which I would have not been able to work, and my two lovely children, for being my inspiration.
Appendix 2, Onderzoeksvoorstel

1. Inleiding

Het hebben van een chronische aandoening heeft een grote impact op het leven van een kind en diens omgeving. Naast de dreigende verstoring van de normale groei en ontwikkeling, zijn er vaak ingrijpende gevolgen voor het psychisch en sociaal functioneren.

De gevolgen voor een kind en diens omgeving van een chronische ziekte zijn in diverse studies voor meerdere aandoeningen onderzocht. Minder bekend is wat de gevolgen zijn indien een kind lijdt aan twee chronische aandoeningen (Fortin et al., 2007). Zo is de kwaliteit van leven van kinderen met zowel diabetes als coeliakie nog niet eerder onderzocht. Op verzoek van de Nederlandse Coeliakie Vereniging, de NCV, zal met dit onderzoek geacht worden dit in kaart te brengen.

1.1.1. Coeliakie

Bij coeliakie bestaat er een intolerantie voor gluten. Gluten ('lijm') is de verzamelnaam voor de in alcohol oplosbare eiwitten van tarwe, rogge, haver en spelt (wilde tarwe). De glutenintolerantie leidt tot beschadiging van het dunne darm slijmvlies als genetisch gepredisponeerde mensen glutenbevattende voeding gebruiken. Weglaten van gluten uit de voeding leidt tot herstel. Coeliakie heeft een sterke associatie met de HLA genen op chromosoom 6. Deze genen spelen een rol bij de regulatie van de immuun respons. De HLA-DQ2-heteromeer is aanwezig bij 95% van de coeliakie patiënten; bij de overigen wordt meestal DQ8 gevonden. Aangezien de HLA-DQ2- heteromeer ook bij 30% van de gezonde populatie voorkomt, gaat men er van uit dat andere genetische factoren en omgevingsfactoren betrokken zijn bij het ontstaan van coeliakie (Kneepkens, 2002).

Coeliakie komt ook in Nederland veel vaker voor dan tot voor kort werd aangenomen. Door toegenomen kennis en betere diagnostische methoden is de prevalentie van gediagnosticeerde coeliakie in ons land in de afgelopen twintig jaar opgelopen van 1:5000 tot 1:1400, maar dit is nog steeds het topje van de ijsberg. Uit bevolkingsonderzoek is duidelijk geworden dat de werkelijke prevalentie van coeliakie eerder 1:200 tot 1:300 is. Op elk kind met coeliakie telt Nederland nog steeds zeven kinderen met niet herkende coeliakie (Csizmadia et al., 1999).

Veel voorkomende symptomen van coeliakie zijn: (www.glutenvrij.nl)

- Chronische diarree
- Opgezette buik
- Smeuïge stinkende, vetige ontlasting (steatorroe)
- Verminderde eetlust
- Vertraagde puberteitsontwikkeling
- Ondergewicht
- Bloedarmoede
- Huilerigheid, depressiviteit
- Sterke stemmingswisselingen
- Vermoeidheid
- Dunne armen en benen
- Grootloosornissen
- Botontkalking
- Dermatitis herpetiformis

Groeiwijziging is slechts een van de mogelijke presentatie vormen. Het klassieke beeld van de magere, humeurige peuter met chronische vetdiaree, bolle buik en platte billen is relatief zeldzaam geworden. De eerste symptomen treden nog steeds vaak op peuter- of kleuterleeftijd op, maar ze kunnen ook pas op volwassen leeftijd tot uiting komen. Naast gastro-intestinale klachten als buikpijn, slechte eetlust en diarree kunnen zich ook extra-intestinale klachten voordoen maar veel patiënten hebben geen darmklachten en weinig andere symptomen. Bij klachten als recidiverende buikpijn, obstipatie en moeilijk behandelbare anemie moet men tevens aan coeliakie denken, ook al vallen lengte en gewicht binnen de norm. De huidvorm van coeliakie, dermatitis herpetiformis, is bij kinderen relatief zeldzaam (Kneepkens, 2002).

De behandeling bestaat uit een levenslang te volgen strikt glutenvrij dieet. Ook sporen gluten kunnen bij herhaaldelijk contact darmbeschadiging geven (Kneepkens, 2002).

1.1.2. Diabetes

Er zijn twee typen diabetes, type 1 en type 2. Type 1 diabetes wordt ook wel insuline afhankelijke diabetes genoemd. Het wordt veroorzaakt doordat de eilandjes van Langerhans in de alvleesklier geen insuline meer kunnen maken. Deze vorm van diabetes ontstaat vaak op jeugdige leeftijd. De aandoening ontstaat doordat het eigen afweerapparaat de betacellen, die insuline produceren, vernietigen. De oorzaak van de afwijkende reactie van het immuunsysteem is niet geheel opgehelderd. Zowel genetische als omgevingsfactoren spelen een rol. Bij diabetes bestaat de associatie met het HLA-gen en wel de DR en DQ loci. De diagnose wordt meestal gesteld naar aanleiding van klachten als dorst en veel plassen, jeuk en gewichtsverlies. Het bloedglucosegehalte is veel te hoog en soms zijn er ketonen in de urine. In ernstige gevallen kan verzuring van het bloed, en uiteindelijk coma optreden. Dit type diabetes komt voor bij ongeveer 6 op de 1000 mensen, dat is 0,6% van de Nederlandse bevolking.

Behandeling bestaat uit het injecteren van insuline, dat in deze situatie levensreddend is. Mensen met type 1 diabetes moeten meestal viermaal per dag insuline per injectie toedienen; meestal is dit snelwerkende insuline voor de hoofdmaaltijden, en middellang werkende insuline voor het slapen gaan. Daarnaast bestaat de behandeling uit beweging en een diëtisch dieet. Daarbij is vooral van belang dat zij met een bepaalde regelmaat (op dezelfde tijdstippen een aantal maal per dag) geschikte typen voedsel (een gebalanceerd dieet dat laag is in vet, cholesterol en simpele suikers) tot zich nemen.

Type twee diabetes mellitus werd vroeger ook wel niet-van-insuline-afhankelijke diabetes genoemd. Het is, in tegenstelling tot type 1, geen auto immuunziekte. Het lichaam maakt wel insuline maar de glucose kan toch niet in de cel opgenomen worden. Ook al maken de eilandjes van Langerhans voldoende insuline, de lichaamscellen zijn minder gevoelig voor insuline. Daardoor kan de glucose de cel niet voldoende of snel genoeg in. Men spreekt dan van insuline-resistentie. Dit betekent ‘weerstand tegen insuline’. Daarnaast maakt de lever extra glucose aan, ook al is de bloedsuikerspiegel reeds verhoogd. Deze spiegel zal daardoor nog verder stijgen.

Deze vorm van diabetes komt vooral voor bij mensen die veel te zwaar zijn; 85% van de mensen met type 2 diabetes heeft overgewicht, 15% heeft bij het vaststellen van de aandoening echter een normaal gewicht. Deze vorm van diabetes openbaart zich meestal pas op oudere leeftijd, gewoonlijk boven de 40 jaar. Echter door onze veranderende leef- en
De klachten en verschijnselen van type twee diabetes zijn dezelfde als die van type 1. De klachten treden echter alleen veel geleidelijker op. Type twee diabetes komt voor bij 30 tot 40 op de duizend mensen, dat is 3-4% van de Nederlandse bevolking.

Type twee wordt behandeld met gewichtsreductie, een diabetisch dieet en beweging. Als dat niet lukt wordt begonnen met orale medicatie. Wanneer die niet werken, zal er gestart worden met insuline (bovenstaande hoofdzakelijk uit www.diabetes.nl).

Diabetes is wereldwijd één van de meest voorkomende chronische aandoeningen bij kinderen. Het komt voor op verschillende leeftijden: bij baby’s, peuters en kleuters. Vaak wordt de diagnose te laat of verkeerd gesteld. Diabetes type 1 neemt elk jaar met 3% toe en diabetes type 2 met 5% bij kinderen onder de 6 jaar. Naar schatting krijgen wereldwijd 70.000 kinderen jonger dan 15 jaar elk jaar diabetes type 1, dat zijn 200 kinderen per dag. Van de geschatte 440.000 kinderen die wereldwijd diabetes type 1 hebben, leeft meer dan een kwart in Zuidoost Azie en meer dan een vijfde in Europa. Diabetes type twee werd tot voor kort enkel vastgesteld bij volwassenen. Vandaag de dag stijgt dit tipo onrustbarend bij kinderen en adolescenten. In een periode van 20 jaar is diabetes type twee verdubbeld in Japan. In Noord Amerika lijden (afhankelijk van de regio) 8 a 45% van de kinderen gedagnosticeerd met diabetes aan de type twee variant. In België hebben 2600 kinderen jonger dan 18 jaar diabetes type 1 en het aantal kinderen met diabetes type twee neemt gestaag toe (www.gezondheid.be).

Type 1 diabetes is naast astma de meest voorkomende chronische ziekte bij kinderen. De prevalentie van diabetes bij kinderen van 0-14 jaar in Nederland is volgens de huisartsen registratie CMR-Nijmegen e.o. 0,5 per duizend jongens en 1,8 per 1000 meisjes. Deze aantallen zijn afkomstig uit relatief kleine steekproeven bij kinderen. Landelijk incidentie onderzoek (van Wouwe et al., 2004) vertoont geen verschil in aantallen tussen jongens en meisjes. Het geconstateerde verschil tussen jongens en meisjes berust waarschijnlijk op toeval vanwege de kleine aantallen.

Naast deze huisartsenregistratie is ook een schatting te maken op basis van een landelijk onderzoek uit 1996-1999 onder kinderartsen, internisten en leden van de Diabetes Vereniging Nederland. De prevalentie van diabetes bij kinderen van 0-14 jaar in Nederland is volgens de huisartsen registratie CMR-Nijmegen e.o. 0,5 per duizend jongens en 1,8 per 1000 meisjes. Deze aantallen zijn afkomstig uit relatief kleine steekproeven bij kinderen. Landelijk incidentie onderzoek (van Wouwe et al., 2004) vertoont geen verschil in aantallen tussen jongens en meisjes. Het geconstateerde verschil tussen jongens en meisjes berust waarschijnlijk op toeval vanwege de kleine aantallen.

1.1.3. Coeliakie en diabetes mellitus type 1

Bij patiënten met diabetes mellitus type 1 komt coeliakie vaker voor. Al in 1969 werd deze
associatie voor het eerst gemeld (Holmes, 2002). De ziekten hebben een gezamelijke genetische achtergrond, beiden op het HLA gen. Coeliakie is gassocieerd met meerdere auto-immuunziekten, het kan zijn dat die ontstaan door de coeliakie en men pleit dan ook voor screening op coeliakie zodat dat te voorkomen valt (Not et al., 2001). Diabetes type twee is geen auto-immuun ziekte en heeft dan ook geen associatie met coeliakie. Wel is het zo, doordat type twee bij veel meer mensen voorkomt, er ook mensen zullen zijn die zowel diabetes type twee als coeliakie zullen hebben.

Holmes vergeleek 26 onderzoeken naar de prevalentie van coeliakie bij DM1 patiënten. De gevonden cijfers liepen uiteen van 0.97 tot 16.4%, met een gemiddelde van 4.5% (Holmes, 2002). Rostom vindt bij zijn meta-analyse cijfers bij biopsie uiteenlopend tussen 1.5 en 8 procent. Het feit dat de cijfers zo uiteenlopen heeft te maken met het de studie design en het hanteren van andere criteria bij het diagnosticeren van coeliakie (Rostom et al., 2004).

Van de circa 74.000 diabetes mellitus type 1 patiënten in Nederland, heeft dus bij benadering 4,5% coeliakie. Dit komt neer op zo’n 3300 mensen. Duidelijk moge zijn dat het gaat om een ruwe schatting. Vergeleken met een voorkomen van 0.5% in de bevolking komt coeliakie met 4.5% bij diabetes type 1 patiënten dus vaker voor.

Diabetespatiënten hoeven geen last van hun coeliakie te hebben. De diabetespatiënten met coeliakie komen vaak niet zelf bij de arts met klachten, maar lijden aan een ‘stille’ vorm van coeliakie. Deze patiënten hebben weinig klinische symptomen, wel hebben zij typische immunologische en histologische bevindingen die bij coeliakie passen (Schober et al., 2002).

Voorafgaand aan screening rapporteren deze patiënten (en hun ouders) geen symptomen (Holmes, 2002). De klassieke symptomen als diarree zijn afwezig, maar er kunnen wel vagere symptomen als buikpijn en anemie (bloedarmoede) bestaan (Book, 2002). Hierdoor wordt coeliakie bij diabetespatiënten niet altijd gediagnostiseerd. Ook worden de klachten vaak ten onrechte aan de diabetes toegeschreven (Greijdanus, 2006).

1.2. Kwaliteit van leven

De kwaliteit van leven als uitkomstmaat is steeds belangrijker aan het worden. Niet alleen de ziekte en de behandeling daarvan maar ook welke beperkingen een patiënt ondervindt en wat daaraan gedaan kan worden is van grote betekenis. Gezondheid is immers niet alleen afwezigheid van ziekte, maar een toestand van lichamelijk, psychisch en sociaal welbevinden (WHO, 1948). De meeste onderzoekers zijn het eens dat deze door het WHO genoemde aspecten, het lichamelijke, het psychische en het sociale aspect tezamen weergeven wat met kwaliteit van leven wordt bedoeld.

Door de kwaliteit van leven te meten kijken we patiëntgericht. Wanneer de problematiek bekend is kunnen gerichte interventies plaatsvinden. Er kan betere zorg gegeven worden. Door een beter begrip zal een betere arts-patiënt communicatie mogelijk zijn (de et al., 2007). De sociale omgeving kan met beter begrip van de problemen ook adequater reageren. Ook de overheid, zorgverzekeraars etc. kunnen veranderingen teweeg brengen indien beter bekend is wat de problematiek is.

1.2.1. Leven met een chronische aandoening: coeliakie

De kwaliteit van leven van kinderen met coeliakie is onderzocht door Kolsteren die concludeert dat de kinderen met coeliakie een adequaat niveau van leven hebben vergelijkbaar met de referentie groep gezonde kinderen (Kolsteren et al., 2001). Ook Grootenhuis vindt in haar onderzoek weinig verschil in gemiddelde scores vergeleken met de normgroep. Daarentegen scoren ze op sommige domeinen slechter (Grootenhuis et al., 2007).

Mearin wijst dit niet vinden van verschillen in vergelijking met een referentiegroep aan de gebruikte vragenlijst (Mearin, 2007). Nijholt vindt in haar onderzoek ook een goede
gemiddelde score in de Nederlandse interpretatie van die score (een 8.2), die bovendien boven de gouden standaard van Cummins ligt. Toch beoordelen de kinderen hun kwaliteit van leven hoger indien ze geen coeliakie zouden hebben. Dit geeft aan dat de coeliakie wel degelijk van invloed is op de kwaliteit van leven (Nijholt, 2006).

Leven met coeliakie vraagt een grote aanpassing op het gebied van eten. Men zal veel dingen niet meer kunnen eten en altijd bezig zijn met wat er in een bepaald product verwerkt zit. Soms veranderen produkten of de wijze waarop ze geproduceerd worden en dit betekent dat een patiënt daar altijd mee bezig is. Een spoortje gluten kan de klachten in stand houden. Een broodkruimel in de jam van de coeliakie patiënt is al te veel. Een eigen kuipje margarine, potje jam, altijd schoon bestek en bord, het zijn dan de noodzakelijke aanpassingen (www.coeliakie.info). Ook het verkrijgen van glutenvrije producten kan een probleem blijken als er weinig winkels in de buurt zijn of een supermarkt die gewoon weinig glutenvrije produkten in zijn assortiment heeft (Rashid et al., 2005). Uit eten gaan wordt moeilijk, en ook sociale contacten kunnen bemoeilijkt worden doordat de patiënt niet meer alles kan eten wat voorgeschoteld wordt. Hierdoor ervaren de meeste patiënten ook reizen als lastig (Lee & Newman, 2003). In het geval van kinderen zullen de ouders hier meer mee te maken krijgen en misschien kan het kind goed wennen aan het nieuwe dieet, omdat de smaak zich nog ontwikkelt, maar heeft het meer impact op de familie en zoja hoe staat dit dan in relatie tot de kwaliteit van leven van de kinderen?

1.2.2. Leven met een chronische aandoening: diabetes

Kinderen met diabetes ervaren een slechtere kwaliteit van leven in vergelijking met een gezonde referentiegroep maar in vergelijking met andere chronische zieke kinderen doen ze het beter (Varni et al., 2007). Ook Ausili vindt een vermindere kwaliteit van leven in vergelijking met een gezonde referentiegroep (Ausili et al., 2007). Het hebben van diabetes heeft een grote impact op het leven van een kind en zijn omgeving. Vaak zal er vier keer per dag gespoten moeten worden en ook de bloedglucosemeting moet een paar keer per dag gecontroleerd worden. Daarbij zal er regelmatig en via een vast patroon gegeten moeten worden, waarbij ook wat je eet van belang is. Bij meer beweging, sporten, of bij stress zal dit alles weer bijgesteld moeten worden. Dit alles vergt een grote aanpassing en discipline, van zowel het kind als de ouders.

Bovendien heeft de aandoening invloed op de ontwikkeling van een kind, de schoolprestaties en sociale activiteiten, zoals uitgaan (www.kinderdiabetes.nl)

1.2.3. Leven met meerdere chronische aandoeningen

Het hebben van meerdere chronische aandoeningen is geassocieerd met slechte uitkomstmaten. Patiënten ondervinden een vermindere kwaliteit van leven, langere ziekenhuisopnames, hogere gezondheidskosten en een hoger sterftecijfer (Fortin et al., 2007). Ook kinderen met meerdere chronische aandoeningen ondervinden meer mentale en fysieke gezondheidsproblemen dan andere kinderen. Zo stijgt met het aantal aandoeningen de prevalentie van ontwikkeling achterstanden, leerproblemen en emotionele en gedragsproblemen. Verder stijgt de medische consumptie (ziekenhuis, arts). Hoe meer aandoeningen hoe groter de verslechtering van de gezondheidsstatus, gemeten in aantal dagen in bed, afwezigheid op school en vermindering van activiteiten (Newacheck & Halfon, 1998). Het hebben van meerdere ziekten verandert niet de problemen die ervaren worden maar wel de ernst daarvan, de fysieke en sociale beperkingen nemen toe en ook psychisch vormt comorbiditeit een extra belasting (Heijmans, 2003). Ook de onderzoeken van Usai en Hauser
vinden een verslechtering van de kwaliteit van leven bij comorbiditeit (Usai et al., 2002; Hauser et al., 2007). Meerdere chronische ziektes hebben een negatieve invloed op de kwaliteit van leven, niet alleen op het gebied van hoe de mensen zich over het algemeen voelen over hun leven, maar ook op het gebied van psychologische stress (Walker, 2007).

Het hebben van zowel diabetes als coeliakie vergt een extra grote aanpassing. Behalve de regelmaat en het vele controleren van de bloedsuikers en het sputen van insuline worden de patiënten nu ook nog beperkerd in wat ze kunnen eten. Dit zal de kwaliteit van leven niet ten goede komen. Wat wel kan zijn is dat bij het diagnosticeren van coeliakie en het volgen van een glutenvrij dieet veel onbegrepen klachten verdwijnen en de kwaliteit van leven hierdoor juist verhoogd wordt (in ieder geval op het domein fysiek functioneren). Op het gebied van psychisch en sociaal functioneren zal dat tegen vallen.

Het is nogal wat als de diagnose coeliakie wordt gesteld terwijl je al diabetes hebt. Levenslang strikt glutenvrij eten is niet makkelijk, helemaal niet als je ook nog rekening moet houden met diabetes. Veel voedingsmiddelen met koolhydraten die bij diabetes worden aangeraden bevatten gluten, denk aan; brood, crackers, deegwaren. Vaak moet iemand met een hypo, een te laag bloedsuiker als gevolg van diabetes, na het innemen van drijvesuiker nog iets met koolhydraten eten. In geval van coeliakie moet dat glutenvrij zijn; een questie van voorbereiding. Altijd iets meenemen dus, een paar rijstewafels, glutenvrije crackers of iets dergelijks zodat de hypo goed opgevangen kan worden (www.coeliakie.info)

Een glutenvrij dieet kan de psychologische stress in kinderen met diabetes verhogen. Kinderen en adolescenten met coeliakie antwoorden in een onderzoek dat ze minder vrienden hadden, zich ongemakkelijk voelden omdat ze anders zijn en jaloers zijn op de onafhankelijkheid van hun vrienden. Deze bevindingen zijn ook vaker aangetoond in de psychologische profielen van kinderen met diabetes. Daarom is het mogelijk dat een tweede chronische ziekte waarbij weer voedsel een rol speelt en die veel gewone activiteiten van kinderen bemoeilijkt de psychologische stress die al ervaren wordt nog versterkt (Freemark & Levitsky, 2003).

2. Het onderzoeks model en de factoren.

In onderhavig onderzoek wordt gekeken naar ziektegerelateerde en sociaal demografische factoren en hoe deze factoren verschillen kunnen verklaren tussen kinderen in de verschillende aspecten van kwaliteit van leven. In dit onderzoek wordt gekeken naar de aspecten sociaal, psychisch en fysiek functioneren. Naast het kijken naar de verschillende aspecten van kwaliteit van leven, zal ook een totaalcijfer worden gegeven voor de algemene kwaliteit van leven, als subjectief oordeel van de patiënt. Het ligt niet in de mogelijkheden ook de intermediërende factoren erin te betrekken, wegens de beperkte beschikbare tijd en gezien het feit dat dit ingewikkelde concepten zijn waarbij ook weer veel vragenlijsten nodig zijn, teveel om de kinderen voor te leggen. Gekozen is om naast de kwaliteit van leven van de kinderen ook te kijken naar de kwaliteit van leven van de familie en naar de impact die de ziekten van het kind op hen hebben.

2.1. De factoren die kwaliteit van leven beïnvloeden.

2.1.1. Sociaal demografische factoren.

2.1.1.1. Sexe verschillen.
Uit onderzoek van Kolsteren blijkt dat bij kinderen met coeliakie meisjes een verlaagde kwaliteit van leven rapporteren maar zich beter aan het dieet houden (Kolsteren et al., 2001). Bij diabetes patiënten blijkt uit meerdere onderzoeken dat vrouwelijke patiënten een slechtere kwaliteit van leven ervaren dan mannen (Wandell, 2005; Graue et al., 2005). Dit komt overeen met resultaten van andere patiëntengroepen, maar ook in de gezonde populatie geven mannen vaak een hogere kwaliteit van leven aan (Greijdanus, 2006).

2.1.1.2. Leeftijdsverschillen

In een onderzoek van Graue komt naar voren dat leeftijd van belang is voor de kwaliteit van leven (Graue et al., 2005). Hoe jonger de patiënt hoe beter de kwaliteit van leven beoordeeld wordt (Ausili et al., 2007).

2.1.1.3. Sociaal Economische Status (SES)

Het opleidingsniveau is een goede indicator voor de sociaal-economische status van een persoon/gezin. Het opleidingsniveau van ouders heeft indirect betrekking op het kind (Mayer, 1997). In de drie modellen die Smith, Brooks-Gunn en Jackson beschrijven wordt ervan uitgegaan dat meer economische middelen het welzijn van de kinderen direct of indirect zullen verbeteren. De verwachting op basis van deze literatuur en andere onderzoeken (Lasheras et al., 2001; Theunissen et al., 1998) is dat kinderen uit gezinnen met een hoge SES (ouders met hoger opleidingsniveau) hun kwaliteit van leven hoger beoordelen dan kinderen met een lage SES (ouders met laag opleidingsniveau).

2.1.1.4. Gezinssamenstelling

In hoeverre heeft de gezinssamenstelling invloed op kwaliteit van leven. Verwachting hierbij is dat één oudergezin, daar de ouder al een grotere belasting heeft, meer moeite zal hebben met de belasting die de aandoeningen met zich mee brengen en dat dat de kwaliteit van leven zal doen verminderen.

2.1.2. Ziektespecifiek coeliakie

2.1.2.1. Leeftijd en snelheid diagnose

Hoe eerder coeliakie ontdekt wordt, hoe beter dat is voor de levenskwaliteit van de kinderen omdat ze dan minder lang met (onbegrepen) klachten rond hoeven te lopen, eerder kunnen wennen aan het dieet en aan het omgaan met de ziekte (Horvitz & Gold, 2006; Zarkadas et al., 2006) en ze zich beter aan het dieet houden (Hogberg et al., 2003).

2.1.2.2. Compliantie

In hoeverre houdt de patiënt zich aan het dieet. Het dieet is bij coeliakie de behandeling, en bij goede navolging ervan kan de darm zich herstellen en verdwijnen de fysieke klachten. De relatie tussen fysieke klachten en kwaliteit van leven is duidelijk: de kwaliteit van leven verbetert indien men minder fysieke klachten heeft. Daar bij goede navolging van het dieet de klachten verminderen zou je dezelfde relatie verwachten tussen compliantie en kwaliteit van leven. Dit ligt echter gecompliceerder.
Indien patiënten zich houden aan het dieet zullen de fysieke klachten verminderen en treedt er groeiverbetering op (Rashid et al., 2005; Sanchez-Albisua et al., 2005; Amin et al., 2002; Sanchez-Albisua et al., 2005; Saadah et al., 2004; Acerini et al., 1998). Het hebben van minder klachten geeft een groter welbevinden (Hallert & Lohiniemi, 1999) (Hallert et al., 1998; O'Leary et al., 2004). De verwachting dat een goede compliantie ook een betere kwaliteit van leven zou geven wordt ondersteund door de resultaten van verschillende onderzoeken (Usai et al., 2002; Hauser et al., 2007; O'Leary et al., 2004). Toch zijn er ook onderzoeken die geen verband vinden tussen compliantie en kwaliteit van leven (Hallert et al., 1998) (Casellas et al., 2005) (O'Leary et al., 2004) of zelfs een negatief verband laten zien. Zo houden vrouwen zich beter aan het dieet maar hebben een slechtere kwaliteit van leven dan mannen. Een uitleg hiervoor zou kunnen zijn dat het je houden aan het dieet sociale beperkingen geeft, waardoor je kwaliteit van leven vermindert. Of misschien is het zo dat mensen die minder sterk in hun schoenen staan, qua zelfbeeld en sociale steun e.d. ook meer moeite hebben met eigen verzorging en diët.

2.1.3. Ziektespecifiek diabetes

2.1.3.1. Leeftijd diagnose

Hoe eerder de diabetes ontdekt wordt, hoe beter de resultaten op de fysieke en psychische domeinen van kwaliteit van leven (Ausili et al., 2007).

2.1.3.2. Aantal glucose metingen

Ausili vindt verband tussen aantal glucose metingen per dag en kwaliteit van leven: hoe meer metingen des te beter de kwaliteit van leven (Ausili et al., 2007).

2.1.3.3. Metabole instelling

Uit onderzoek blijkt dat controle over metabolisme een betere kwaliteit van leven geeft (Ausili et al., 2007). Rosello voegt hieraan toe dat een adequate metabole instelling geassocieerd is met minder complicaties (Rossello & Maysonet, 2006). De grootste studie met adolescenten met diabetes laat zien dat een goede metabole instelling een verbeterde kwaliteit van leven geeft terwijl een slechte metabole instelling is geassocieerd met angst (anxiety), depressie, laag zelfbeeld en angst over diabetes (de & Swift, 2006).

2.1.3.4. Hypo’s

Bij een te laag bloedsuiker, als de patiënt te weinig gegeten of te veel insuline heeft gespoten ontstaat er een hypo. Hierbij treden verschijnselen op zoals transpireren, beven, hoofdpijn, wazig zien, hartkloppingen en hongergevoel. Patiënten met meer hypos ervaren een lagere kwaliteit van leven (Davis et al., 2005).

2.1.3.5. Aard behandeling: Insulinepomp

In een review artikel, uitgevoerd door Barnard (Barnard et al., 2007), worden wisselende resultaten gevonden bij drie van de vijf studies. In een onderzoek wordt verbetering gevonden en in een andere studie wordt geen bewijs gevonden voor verbetering van de kwaliteit van leven in vergelijking tot spuiten.
Dirlewanger vindt verbetering van de kwaliteit van leven en wel doordat het pompje meer flexibiliteit geeft en er zich minder hypo’s voordoen (Dirlewanger et al., 2007).

2.1.4. Intermediërende factoren

2.1.4.1. Meerdere psychosociale factoren

Er zijn meerdere psychosociale factoren die de kwaliteit van leven kunnen beïnvloeden. Voorbeelden daarvan zijn copinggedrag, adaptatievermogen, gezondheidsovertuigingen, ouderlijke zorg en betrokkenheid, ouderlijke controle, gezins functioneren, sociale steun, sociale netwerk en levensloop (Stam et al., 2006; Bullinger et al., 2002) (Graue et al., 2005; Hoare et al., 2000; Goldbeck et al., 2001). Het zal te ver voeren om deze psychosociale factoren in dit onderzoek te betrekken.

2.1.5. Impact op de familie.

Behalve de impact op de kinderen zelf zal er een impact zijn op de familie (Lee & Newman, 2003; Hoare et al., 2000). De ouders zullen, vooral bij kleine kinderen, ervoor moeten zorgen dat de kinderen zich aan het dieet houden, de controles uitvoeren, de medicatie verzorgen. Zij zullen het zijn die de boodschappen doen en glutenvrije producten uitzoeken, zij zullen naar de apotheek moeten. Dit naast alle zorgen en stress die een ouder zal ervaren wanneer zijn/haar kind ziek is. Hoe groot is de impact van coeliakie en diabetes van het kind op de familie? Is dit gerelateerd aan de kwaliteit van de kinderen? De verwachting is dat de impact op de familie groot is. Zij zullen veel moeten laten of eerder niet doen omdat zij extra zorg hebben of omdat het kind dat niet kan. De verwachting is ook dat dit gerelateerd is aan de kwaliteit van leven van de kinderen. Hoe beter de ouders in hun vel zitten, hoe beter ook de kinderen zich voelen. Uit onderzoek van Hoare blijkt dat meer dan een derde van de variantie in kwaliteit van leven tussen kinderen te wijten is aan de impact op de familie (Hoare et al., 2000).

Hieruit volgt het volgende model:
3. Vraagstelling:

De hoofdvraag is nu in welke mate en op welke gebieden het hebben van deze twee chronische aandoeningen van invloed is op de kwaliteit van leven van de kinderen. In de eerste plaats zal hiervan een beschrijving gegeven worden en zullen de kinderen vergeleken worden met gezonde kinderen, met kinderen met alleen diabetes en met kinderen met alleen coeliakie. De verwachting hierbij is dat kinderen met zowel coeliakie als diabetes een slechtere kwaliteit van leven aan zullen geven dan de andere drie groepen. In de tweede plaats zal gekeken worden in hoeverre de verschillende variabelen (zie onderzoeksmodel) de verschillende aspecten van kwaliteit van leven beïnvloeden. Dit in een poging de verschillen tussen de kinderen te verklaren. De verwachtingen omtrent de
variabelen volgen uit de eerder gegeven beschrijvingen van deze variabelen in hoofdstuk twee. Daarnaast zal nog gekeken worden naar de impact van de aandoeningen van het kind op de familie.

De volgende vragen zijn geformuleerd:

1. Wat is de kwaliteit van leven van kinderen met coeliakie en diabetes?

2. Door welke in het model genoemde variabelen kunnen verschillen tussen kinderen verklaard worden?

3. Wat is de impact van de aandoeningen van het kind op de familie?


Relevante informatie is verzameld via pubmed met de zoektermen celiac, diabetes, multimorbidity, comorbidity, chronic, quality, quality of life en combinaties hiervan en met ingevoerde limit kinderen 0-18.

Patiënten: de NCV beschikt over de namen en adressen van ruim 40 kinderen met beide aandoeningen (en ouders) die bereid zijn aan het onderzoek deel te nemen. Daarnaast wordt via diverse ingangen (oa de website) ouders gevraagd zich voor het onderzoek aan te melden. Vragenlijst: de vragenlijst bevat een aantal standaard vragenlijsten, aangevuld met voor de onderzoeker interessante vragen. Er zijn verschillende kwaliteit van leven vragenlijsten. Om de vergelijking te maken met gezonde kinderen is een generieke vragenlijst nodig (Raat et al., 2006). Hiervoor zal de Kidscreen gebruikt worden (Ravens-Sieberer et al., 2007). Om de vergelijking met chronisch zieke kinderen te maken zal de generieke chronisch module van de Disabkids gebruikt worden (de et al., 2007; Bullinger et al., 2002). Deze vragenlijsten vragen naar de verschillende aspecten van kwaliteit van leven, te weten het fysieke, het sociale en het psychische aspect.

Daarnaast zal gevraagd worden een cijfer te geven voor de algemene kwaliteit van leven. Kwaliteit van leven is een ervaringskenmerk, een waarde oordeel die iemand geeft over het leven. Gekeken zal worden hoe de verschillende aspecten gerelateerd zijn aan dit in in totaal genomen toegekende cijfer.

Om de problemen van de kinderen volledig in kaart te kunnen brengen zullen ook nog ziekte specifieke vragenlijsten gebruikt worden, de CDDUX en de Disabkids diabetes module (Baars et al., 2005). Hiermee kan een vergelijking worden getrokken met de normwaardes van die testen en kunnen de kinderen vergeleken worden met kinderen met alleen coeliakie en met kinderen met alleen diabetes. Voor het kijken naar de impact op het gezin gaat of de Impact on Family scale van Stein en Riessman gebruikt worden (Williams et al., 2006). Deze zal voorgelegd worden aan de ouders.

5. Taken van de student:

Literatuuronderzoek
Onderzoeksopzet
Vragenlijst opstellen
Verwerking SPSS
Student voert het onderzoek in zijn totaal geheel zelf uit en kan voor vragen terecht bij begeleiding.

6. Tijdsschema:

17 weken.
Wijzigingen in de beschrijving.

Wijzigingen in deze beschrijving: ipv de Impact on Family scale van Stein en Riessman is de Pediatric Inventory for Parents (PIP) gebruikt. Deze wijziging heeft twee redenen. De begeleider van het AMC, Martha Grootenhuis was er geen voorstander van dat ik deze vragenlijst zelf zou gaan vertalen. Daarnaast heeft is op de financiële administratie de betalingsopdracht verdwenen. Hier kwam ik na twee maanden achter, daar ik tegen die tijd de vragenlijst verwachtte. Om opnieuw een betaling te regelen zou wederom twee maanden duren. Besloten is toen de PIP te gebruiken.

Daarnaast zouden er 40 mensen bereid zijn mee te doen aan het onderzoek, wat een misverstand bleek te zijn tussen mijn begeleider en de Nederlands Coeliakie vereniging. De Nederlandse Coeliakie vereniging had 40 adressen van kinderen met zowel coeliakie als diabetes, deze hadden nog niet toegestemd mee te doen.
Appendix 3, The children’s questionnaire

Rijksuniversiteit Groningen Wetenschapswinkel
Geneeskunde en Volksgezondheid
UMCG
Universitair Medisch Centrum
Groningen

Nederlandse Coeliakie Vereniging
Noord Nederland

Vragenlijsten

Kwaliteit van leven van diabetes- en Coeliakiepatiënten

Een onderzoek onder kinderen met zowel diabetes als coeliakie en hun ouders/verzorgers
Hallo,

Hoe gaat het met je? Hoe voel je je?

Graag willen we dat van je weten.

Lees elke vraag goed door en kies het antwoord dat het beste bij jou past. Denk niet te lang over de vragen na.

Wanneer je een datum niet precies weet kan je deze aan je ouders vragen.

Belangrijk: Dit is geen examen! Er zijn geen goede of foute antwoorden. Het is wel belangrijk dat je de vragenlijst helemaal en zo duidelijk mogelijk invult. Probeer bij het antwoorden aan de afgelopen week te denken.

Je hoeft je antwoorden aan niemand te laten zien. Niemand die je kent zal deze vragenlijst kunnen inzien nadat je hem hebt ingevuld en in de envelop gedaan.
1. **Lichamelijke activiteiten en gezondheid**

1. Hoe is je gezondheid in het algemeen?
   - Heel erg goed
   - Erg goed
   - Goed
   - Redelijk
   - Slecht

   **Denk aan de afgelopen week...**

2. Heb je je fit en gezond gevoeld?
   - helemaal niet
   - bijna niet
   - gemiddeld
   - nogal
   - helemaal

3. Ben je lichamelijk actief geweest (bijvoorbeeld, hardlopen, sporten, fietsen)?
   - helemaal niet
   - bijna niet
   - gemiddeld
   - nogal
   - helemaal

4. Heb je goed kunnen rennen?
   - helemaal niet
   - bijna niet
   - gemiddeld
   - nogal
   - helemaal

**Denk aan de afgelopen week...**

nooit    bijna nooit    soms    redelijk    altijd
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Heb je je vol energie gevoeld?
## 2. Gevoelens

Denk aan de afgelopen week:

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<tr>
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<th>helemaal niet</th>
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<th>nogal</th>
<th>helemaal</th>
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<tbody>
<tr>
<td>1. Is je leven plezierig geweest?</td>
<td>O</td>
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<td>2. Heb je je blij gevoeld dat je leeft?</td>
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<td>3. Heb je je tevreden gevoeld over je leven?</td>
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<td>4. Ben je in een goed humeur geweest?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
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<td>5. Heb je je vrolijk gevoeld?</td>
<td>nooit</td>
<td>bijna nooit</td>
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<td>6. Heb je lol gehad?</td>
<td>nooit</td>
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3. **Humeur**

Denk aan de afgelopen week...

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<tr>
<td>1. Heb je het gevoel gehad dat je alles verkeerd doet?</td>
<td>nooit</td>
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<td>2. Heb je je verdrietig gevoeld?</td>
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<td>3. Heb je je zo naar gevoeld dat je helemaal niks wilde doen?</td>
<td>nooit</td>
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<td>4. Heb je het gevoel gehad dat alles in je leven misgaat?</td>
<td>nooit</td>
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<tr>
<td>5. Ben je het wel eens zat geweest?</td>
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<td>bijna nooit</td>
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<td>6. Heb je je eenzaam gevoeld?</td>
<td>nooit</td>
<td>bijna nooit</td>
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<td>7. Heb je het gevoel gehad dat je onder druk stond?</td>
<td>nooit</td>
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## 4. Over jezelf

### Denk aan de afgelopen week...

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<tbody>
<tr>
<td>1. Ben je tevreden geweest met jezelf?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
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<td>2. Ben je tevreden geweest over je kleding?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
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<tr>
<td>3. Heb je je zorgen gemaakt over je uiterlijk?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
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<tr>
<td>4. Ben je jaloers geweest op het uiterlijk van andere jongeren?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
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<td>O</td>
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<td>0</td>
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<tr>
<td>5. Zou je iets willen veranderen aan je lichaam?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
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## 5. Vrije tijd

### Denk aan de afgelopen week...

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<tbody>
<tr>
<td>1. Heb je voldoende tijd voor jezelf gehad?</td>
<td>nooit</td>
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<td>Soms</td>
<td>redelijk vaak</td>
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<td>Soms</td>
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<tr>
<td>2. Heb je in je vrije tijd de dingen kunnen doen die je wilt doen?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>Soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
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<td>Soms</td>
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</tr>
<tr>
<td>3. Heb je genoeg de gelegenheid gehad om buiten te zijn?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>Soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
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<td>Soms</td>
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<tr>
<td>4. Heb je voldoende tijd gehad</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>Soms</td>
<td>redelijk vaak</td>
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</table>
om vrienden te ontmoeten?  

nooit  bijna nooit  soms  redelijk vaak  altijd

5. Heb je zelf kunnen bepalen wat je in je vrije tijd doet?

O  O  O  O

6. Familie en thuis

Denk aan de afgelopen week...

1. Heb je het gevoel gehad dat je ouders je begrijpen?

helemaal niet  bijna niet  gemiddeld  nogal  helemaal

2. Heb je het gevoel gehad dat je ouders van je houden?

helemaal niet  bijna niet  gemiddeld  nogal  helemaal

3. Heb je je thuis gelukkig gevoeld?

nooit  bijna nooit  soms  redelijk vaak  altijd

4. Hebben je ouders voldoende tijd voor je gehad?

nooit  bijna nooit  soms  redelijk vaak  altijd

5. Hebben je ouders je eerlijk behandeld?

nooit  bijna nooit  soms  redelijk vaak  altijd

6. Heb je met je ouders kunnen praten als je dat wilde?

nooit  bijna nooit  soms  redelijk vaak  altijd

7. Geldzaken

Denk aan de afgelopen week...

1. Heb je genoeg geld om

nooit  bijna nooit  Soms  redelijk vaak  altijd
<table>
<thead>
<tr>
<th>dezelfde dingen te doen als je vrienden?</th>
<th>nooit</th>
<th>bijna nooit</th>
<th>soms</th>
<th>redelijk vaak</th>
<th>vaak</th>
<th>nooit</th>
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<tbody>
<tr>
<td>2. Heb je genoeg geld gehad voor je uitgaven?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>vaak</td>
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<td>-------------</td>
<td>------</td>
<td>---------------</td>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>3. Heb je genoeg geld gehad om dingen met je vrienden te doen?</td>
<td>helemaal niet</td>
<td>bijna niet</td>
<td>gemiddeld</td>
<td>nogal</td>
<td>helemaal nicht</td>
<td>bijna niet</td>
</tr>
</tbody>
</table>
8. **Vrienden**

Denk aan de afgelopen week...

<table>
<thead>
<tr>
<th></th>
<th>nooit</th>
<th>bijna nooit</th>
<th>soms</th>
<th>redelijk vaak</th>
<th>altijd</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Heb je tijd doorgebracht met je vrienden?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td></td>
</tr>
<tr>
<td>2. Heb je dingen met andere jongeren ondernomen?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td></td>
</tr>
<tr>
<td>3. Heb je plezier gehad met je vrienden?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td></td>
</tr>
<tr>
<td>4. Hebben jij en je vrienden elkaar geholpen?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td></td>
</tr>
<tr>
<td>5. Heb je met je vrienden over alles kunnen praten?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td></td>
</tr>
<tr>
<td>6. Heb je op je vrienden kunnen vertrouwen?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td></td>
</tr>
</tbody>
</table>
9. **School en leren**

**Denk aan de afgelopen week...**

<table>
<thead>
<tr>
<th></th>
<th>helemaal niet</th>
<th>bijna niet</th>
<th>gemiddeld</th>
<th>nogal</th>
<th>helemaal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Heb je het naar je zin gehad op school?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>2. Is het goed gegaan op school?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>3. Ben je tevreden geweest over je leraren?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>4. Heb je goed kunnen opletten?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5. Ben je graag naar school gegaan?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>6. Kon je goed overweg met de leraren?</td>
<td>nooit</td>
<td>bijna nooit</td>
<td>soms</td>
<td>redelijk vaak</td>
<td>altijd</td>
</tr>
<tr>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>
10. **Jij en de anderen op school**

<table>
<thead>
<tr>
<th>Denk aan de afgelopen week...</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ben je bang geweest voor andere jongeren?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>2. Hebben andere jongeren je uitgelachen?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>3. Ben je door andere jongeren gepest?</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
**CD DUX –Kind-**

_wij willen graag weten hoe jij je de laatste tijd voelt._

Kun je bij iedere vraag aangeven hoe dat gevoel is?
Zet een rondje om het gezichtje dat het beste past.
Er zijn geen foute antwoorden mogelijk. Het gaat erom wat jij zelf vindt.

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>Als ik aan eten denk waar wel gluten in zitten, voel ik me …</td>
<td>![Smiley face]</td>
<td>![Smiley face]</td>
<td>![Neutral face]</td>
<td>![Sad face]</td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>Als ik op school eten met gluten krijg, vind ik dat …</td>
<td>![Smiley face]</td>
<td>![Smiley face]</td>
<td>![Neutral face]</td>
<td>![Sad face]</td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Met andere kinderen over mijn coeliakie praten, vind ik …</td>
<td>![Smiley face]</td>
<td>![Smiley face]</td>
<td>![Neutral face]</td>
<td>![Sad face]</td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>Niet zomaar alles kunnen eten, vind ik …</td>
<td>![Smiley face]</td>
<td>![Smiley face]</td>
<td>![Neutral face]</td>
<td>![Sad face]</td>
</tr>
<tr>
<td><strong>5</strong></td>
<td>Als ik iets aangeboden krijg dat ik niet mag eten, voel ik me …</td>
<td>![Smiley face]</td>
<td>![Smiley face]</td>
<td>![Neutral face]</td>
<td>![Sad face]</td>
</tr>
<tr>
<td><strong>6</strong></td>
<td>Als ik moet uitleggen wat coeliakie is, voel ik me …</td>
<td>![Smiley face]</td>
<td>![Smiley face]</td>
<td>![Neutral face]</td>
<td>![Sad face]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>7</td>
<td>Praten over coeliakie vind ik ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Mijn leven lang het dieet volgen, vind ik ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Zelf goed letten op wat ik eet, vind ik ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Dat ik coeliakie heb, vind ik ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Dat ik niet alles kan eten zoals anderen, vind ik ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Het dieet volgen, vind ik ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Bedankt voor het invullen en tot ziens!
De volgende vragen gaan over je persoonlijke situatie

Wat is de hoogstgevolgde opleiding die je ouders hebben afgemaakt? (als je dit niet weet, kan je dit aan je ouders vragen)

<table>
<thead>
<tr>
<th>Moeder:</th>
<th>Vader:</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Basisonderwijs</td>
<td>o Basisonderwijs</td>
</tr>
<tr>
<td>o Mavo</td>
<td>o Mavo</td>
</tr>
<tr>
<td>o Vbo</td>
<td>o Vbo</td>
</tr>
<tr>
<td>o Havo/vwo</td>
<td>o Havo/vwo</td>
</tr>
<tr>
<td>o Mbo</td>
<td>o Mbo</td>
</tr>
<tr>
<td>o Hbo</td>
<td>o Hbo</td>
</tr>
<tr>
<td>o Wo</td>
<td>o Wo</td>
</tr>
</tbody>
</table>

Kun je aangeven in welke groep je ouders hoort?

Moeder
- o zij is werkend, ….uur per week
- o zij is scholier/student
- o zij is werkzoekend
- o zij is (geheel of gedeeltelijk) arbeidsongeschikt
- o zij is ziek/ zit in de ziektewet
- o zij is huisvrouw
- o zij is gepensioneerd/ met vervroegd pensioen (VUT)
- o anders,namelijk………………………………………………………………………
  ....

Vader
- o hij is werkend, ….uur per week
- o hij is scholier/student
- o hij is werkzoekend
- o hij is (geheel of gedeeltelijk) arbeidsongeschikt
- o hij is ziek/ zit in de ziektewet
- o hij is huisman
- o hij is gepensioneerd/ met vervroegd pensioen (VUT)
- o anders,namelijk………………………………………………………………………
  ....

Gezinssamenstelling; hoe ziet jullie gezin eruit?

- o Tweeoudersgezin met ..... kind(eren)
- o Eenoudergezin met .....kind(eren)
- o Co-ouderschap
- o Anders, namelijk………………………………………………………………………
Hoe oud was je toen coeliakie ontdekt werd?
……..jaar

Hoe lang had je klachten voordat coeliakie ontdekt werd?
……..jaar en ……..maanden

Hoe oud was je toen de diabetes ontdekt werd?
……..jaar

Volg je een glutenvrij dieet?

 o ja
 o nee, ga naar de volgende bladzijde

Hoe vaak eet je glutenvrij?

 o Altijd
 o Regelmataig
 o Af en toe

Hoe voel je je lichamelijk sinds je glutenvrij eet, vergeleken met daarvoor?

 o beter dan voor ik glutenvrij at
 o hetzelfde als voor ik glutenvrij at
 o slechter dan voor ik glutenvrij at

Welke klachten krijg je als je (per ongeluk) gluten binnenkrijgt? (meerdere antwoorden mogelijk)

 o geen
 o buikpijn, opgezette buik, misselijk
 o diarree of andere problemen met de ontlasting
 o je voelt je niet lekker, niet goed in je vel
 o je wordt geïrriteerd/ chagarijnig
 o je diabetes raakt ontregeld/ de regulatie van de bloedsuiker wordt moeilijker
 o anders, namelijk
 ……………………………………………………………………………………………………………………………
 ……………………………………………………………………………………………………………………………
 ……………………………………………………………………………………………………………………………

Hoe lang heb je klachten als je (per ongeluk) gluten eet?
……..dagen / ……..weken

Hoe moeilijk vind je het om je aan het dieet te houden?
Cijfer van 1 tot 10 waarbij 1 niet moeilijk en 10 heel moeilijk (of juist andersom?)
………..

Als je je niet altijd aan het dieet houdt, kun je zeggen waarom niet?
……………………………………………………………………………………………………………………………………
Heb je diabetes type 1 of type 2?
  - type 1
  - type 2
  - weet ik niet

Hoe vaak meet je je glucose per dag?
………keer

Gebruik je insuline?
  - ja
  - nee

Insuline wordt toegediend door
  - injecties
  - pomp

Hoe vaak heb je een hypo gehad (gevoeld) gedurende de laatste maand?
…..keer

Weet je welke waarde je HbA1c gemiddeld heeft?
Je kan bijvoorbeeld de gemiddelde waarde nemen van de afgelopen drie keer controle
  - ja, namelijk……
  - nee, dat weet ik niet

Hoe constant is je HbA1c- waarde, als je kijkt naar de afgelopen jaren?
  - HbA1c is hoger geworden
  - HbA1c is lager geworden
  - HbAc1 is gelijk gebleven
  - Weet ik niet

Heb je sinds je glutenvrij eet verandering gemerkt in je bloedsuiker regulatie?
  - ja, is makkelijker
  - ja, is moeilijker
  - er is geen verschil
  - weet ik niet

Heb je naast coeliakie en diabetes nog andere ziektes (meerdere antwoorden mogelijk)
  - geen
  - schildklieraandoening
  - autoimmuun hepatitis
  - primair biliaire cirrose
  - primair scleroserende cirrose
  - reuma
  - anders nl.……………………..
  - anders nl.……………………..
  - anders nl.……………………..
Zou je de volgende vragen weer willen beantwoorden door het geven van een rapportcijfer.
Omcirkel één cijfer op de schaal hieronder, die het beste bij je past

Hoe zou je in het algemeen je kwaliteit van leven beoordelen? (ben je tevreden met je leven?)

😊                    😐                    😞
10  9  8  7  6  5  4  3  2  1  0

Hoe tevreden met het leven zou je zijn wanneer je geen coeliakie had? (maar nog wel diabetes)

😊                    😐                    😞
10  9  8  7  6  5  4  3  2  1  0

Hoe tevreden zou je met je leven zijn wanneer je geen diabetes had? (maar nog wel coeliakie)

😊                    😐                    😞
10  9  8  7  6  5  4  3  2  1  0

Hoe tevreden zou je met je leven zijn wanneer je geen coeliakie en geen diabetes meer had?

😊                    😐                    😞
10  9  8  7  6  5  4  3  2  1  0
Voel je je in eerste plaats coeliakie of diabetes patiënt?

- je voelt je diabetespatiënt
- je voelt je coeliakiepatiënt
- je voelt je beide
- je voelt je geen van beide
- anders, namelijk………………………………………………………..

Dit is het einde van de vragenlijst.
Dank je voor het invullen.
Heb je iets op te merken, kan je dat hieronder kwijt.
Appendix 5, Letter accompanying questionnaire

Bedum, februari 2008-02-25

Betreft: enquête kwaliteit van leven bij coeliakie en diabetes

Geachte heer/mevrouw,

Graag wil ik uw aandacht voor het volgende. Onlangs zijn we, de Nederlandse Coeliakie Vereniging/afdeling Noord-Nederland, na overleg met onderzoekers van de Rijksuniversiteit Groningen, tot de slotsom gekomen dat het een goede zaak zou zijn onderzoek te doen naar de groep kinderen die zowel coeliakie als diabetes heeft. De belangrijkste reden is dat er vrijwel geen onderzoek gedaan is naar de groep kinderen met deze combinatie.

De onderzoekers willen graag weten wat het effect is van het hebben van coeliakie en diabetes op het functioneren van kinderen. Hoe voelen ze zich? Met welke problemen krijgen ze te maken? We denken dat we met de te verzamelen gegevens beter in staat zijn de belangen van de kinderen te behartigen.

Daarnaast willen de onderzoekers graag weten wat het effect is van de ziekte van het kind op de ouders/verzorgers. Wat is de impact van de ziekte op u?

Mocht u zich niet zelf aangemeld hebben dan staat in het bestand van de Nederlandse Coeliakie vereniging geregistreerd dat uw kind zowel diabetes als coeliakie heeft. Mocht dit niet zo zijn, dan hoeven de vragenlijsten niet ingevuld te worden. Wilt u op de vragenlijst schrijven dat u niet tot de doelgroep behoort, en terugsturen aan de onderzoekers? Dan weten wij waarom u niet meedooet.

We hopen dat u aan dit onderzoek mee wilt doen. Het invullen van de lijst voor ouders kost ongeveer 10 minuten, die van de kinderen kost ongeveer 30 minuten. Zou u aan uw kind willen vragen of deze de betreffende vragenlijst in zou willen vullen? In principe kan hij/zij dit zelfstandig doen. Voor het onderzoek is het ook het beste als uw kind dit zo zelfstandig mogelijk invult.

Er zouden redenen kunnen zijn waarom u liever niet aan het onderzoek mee zou willen doen. Uiteraard zullen we dat respecteren. Indien u nog steeds niet aan het onderzoek mee wilt doen, dan verzoeken we u deze brief als niet geschreven te beschouwen. Indien u wel bereid bent de vragenlijst voor ouders in te vullen en uw kind de vragenlijst voor kinderen voor te leggen (en deze stemt daarin toe), dan kunnen de ingevulde lijsten gezamenlijk in de portvrije envelop, geheel anoniem, naar de onderzoekers van de Rijksuniversiteit Groningen worden verstuurd. Daar de lijsten door mij opgestuurd zullen worden krijgen de onderzoekers geen naam noch adres te zien. U stuurt de lijsten naar de onderzoekers zodat die gegevens voor ons weer onzichtbaar blijven. Ook bij de latere presentatie van de gegevens wordt ervoor gezorgd dat individuele personen onherkenbaar zullen zijn. De publicatie van de uitzonden van het onderzoek zal via het blad van de vereniging geschieden en via de website van de Wetenschapswinkel Geneeskunde en Volksgezondheid van de RuG. We zullen u daar t.z.t. over berichten.

Voor vragen over het onderzoek kunt u contact opnemen met mevr. Maria Strating (tel 050-3637882; e-mail m.y.strating@med.umcg.nl) of bij dr. Jelte Bouma (tel 050-3633109; e-mail j.bouma@med.umcg.nl). Voor andere vragen kunt u altijd bij mij terecht.

We zouden het op prijs stellen als het lukt de vragenlijsten binnen ongeveer een week aan de onderzoekers te retourneren.

Bij voorbaat met dank voor uw medewerking.

Mevr. H. Slager, Namens de Nederlandse Coeliakie Vereniging/afdeling Noord Nederland
Appendix 6, Reminder

Geachte heer / mevrouw,

Twee week geleden is er namens de Wetenschapswinkel Geneeskunde en Volksgezondheid van de Rijksuniversiteit Groningen een vragenlijst naar u verstuurd. De vragenlijst was bestemd voor kinderen met zowel coeliakie als diabetes. Ook was er een vragenlijst voor de ouders/verzorgers bijgesloten.

Als u de vragenlijst al heeft ingevuld en opgestuurd, dan wil ik u hier heel hartelijk voor danken.

Als het invullen en terugsturen er, om welke reden dan ook, nog niet van gekomen is zou ik u willen vragen dit alsnog te doen.

Met de resultaten kunnen we de belangen van de kinderen behartigen en onder de aandacht te brengen. Door kwaliteit van leven en problemen in kaart te brengen hopen we materiaal in handen te krijgen om enerzijds de situatie om zodoende er ook iets aan te kunnen veranderen. Daarnaast komt het onderzoek op internet en bij eerdere onderzoeken over coeliakie is dit een veelbezochte site geweest en worden zo veel mensen geïnformeerd.

Om een duidelijk beeld te kunnen krijgen van de kwaliteit van leven van kinderen met diabetes en coeliakie, en de dagelijkse problemen waarmee deze specifieke groep dagelijks te maken heeft, is het van belang dat zoveel mogelijk mensen meedoen aan dit onderzoek.

Wilt u de vragenlijst wel invullen, maar kan dat niet omdat deze is zoekgeraakt of weggegooid dan kunt u met mij contact opnemen. Er wordt dan zo spoedig mogelijk opnieuw een vragenlijst opgestuurd.

Indien er nog vragen zijn met betrekking tot het onderzoek, dan kunt u contact opnemen met mevr. Maria Strating (050-3637882 of m.y.strating@med.umcg.nl).

Voor andere vragen kunt u bij mij terecht (050-3013441).

Met vriendelijke groet,

Mevr. H. Slager
Namens de Nederlandse Coeliakie Vereniging
Afdeling Noord