Differences in quality of life across children and adolescents with different chronic illnesses and correlates of quality of life.

Master’s Thesis II submitted to obtain the degree of
Master of Science in Psychology, option Clinical Psychology
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This master’s thesis would not have been accomplished without the help of certain people. First, I would like to thank my promoter, Prof. Dr. Liesbet Goubert, for guiding me throughout this process. I would like to thank her and my copromotor, Dr. Eline Van Hoecke, for the feedback and advice I received the last two years.

Second, I would like to thank my family and friends for supporting me throughout my academic career and for keeping me motivated during the writing of this master’s thesis. A special thanks goes out to my mother for proofreading this thesis (and for meticulously correcting all the ‘misplaced’ commas in my references, unfortunately, APA style happens to really like commas).

Third, I am grateful for all the children, adolescents and parents that agreed to participate in the present study. Without them this study would not have been possible. Thanks as well to the psychologists at the University Hospital Ghent for the recruitment of the participants.
Abstract

The present study investigates (1) quality of life differences in Flemish children and adolescents across several chronic illnesses and (2 & 3) explores whether emotion regulation and parental distress are correlates of quality of life in chronically ill children and adolescents. Participants are 190 children and adolescents with juvenile rheumatic disease, diabetes, inflammatory bowel disease, a liver or kidney transplant or renal disease and 118 parents. The participants were asked to complete a number of questionnaires (PedsQL, life satisfaction thermometer, CERQ, PIP and HADS) in this cross-sectional study. With regard to the first research question, children and adolescents with juvenile rheumatic disease reported significantly lower quality of life than children with diabetes, renal disease, inflammatory bowel disease (and a healthy control group). No other illness groups differed significantly. Analyses regarding the second and third research question revealed that maladaptive emotion regulation and parental distress were negatively associated with quality of life after controlling for gender and age. Thus, maladaptive emotion regulation and parental distress were found to be correlates of quality of life. However, adaptive emotion regulation was found to be unrelated to quality of life and chronic illness was not found to be a moderator in the association between (mal)adaptive emotion regulation and quality of life. These results suggest that it might be relevant for clinical practice to focus on decreasing maladaptive emotion regulation strategies in chronically ill children and decreasing parental distress in their parents; however, longitudinal research is needed on this subject.
Dutch summary

Deze master thesis onderzoekt (1) de verschillen in levenskwaliteit tussen Vlaamse kinderen en adolescenten met diverse chronische ziektes en (2 & 3) gaat na of emotieregulatie en ouderlijke distress correlaten van levenskwaliteit zijn in de onderzochte populatie. Er namen 190 kinderen en adolescenten met reuma, diabetes, een (lever of nier) transplant, een inflammatoire darmziekte of een nierziekte en 118 ouders deel aan deze cross-sectionele studie. Er werd hen gevraagd om een aantal vragenlijsten in te vullen, namelijk de PedsQL, de levenstevredenheid thermometer, de CERQ, de PIP en de HADS. In verband met de eerste onderzoeksvraag, werd gevonden dat kinderen en adolescenten met reuma significant lagere kwaliteit van leven rapporteerden dan leeftijdsgenoten met diabetes, een nierziekte, een inflammatoire darmziekte (en een gezonde controle groep). Er werden geen significante verschillen gevonden tussen andere ziektegroepen. Analyses in verband met de tweede en derde onderzoeksvraag toonden aan dat maladaptieve emotieregulatie en ouderlijke distress negatief samenhangen met levenskwaliteit (en dus correlaten van levenskwaliteit waren) nadat er gecontroleerd werd voor leeftijd en geslacht. Adaptieve emotieregulatie bleek geen verband te vertonen met levenskwaliteit en de aanwezige chronische ziekte bleek geen moderator te zijn in de associatie tussen (mal)adaptieve emotieregulatie en levenskwaliteit. Deze resultaten suggereren dat het ontwikkelen van interventies gericht op het verminderen van maladaptieve emotieregulatie strategieën (bij kinderen) en ouderlijke distress (bij ouders) de levenskwaliteit van chronisch zieke kinderen en adolescenten ten goede zou kunnen komen. Om dit te bevestigen, is er echter longitudinaal onderzoek nodig.
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The present Master thesis has two aims. First, quality of life differences will be investigated across different childhood chronic illnesses, i.e., juvenile rheumatic disease, diabetes, inflammatory bowel disease, liver and kidney transplantation and renal disease. Second, two possible correlates of quality of life will be investigated, namely emotion regulation and parental distress.

Quality of Life

The concept of quality of life plays a central role in the present study. Therefore, a logical first step is to define this concept. Quality of life is a term that is often used, but finding a universal definition appears to be harder than expected. A possible reason for this is that the term is often interchanged with different concepts having similar meanings, for instance life satisfaction, well-being, functional status, health status or luck. These concepts could be components of quality of life, but are insufficient to completely defining it. It is remarkable that a lot of professionals and researchers have used this term without providing a definition (King & Hinds, 2011; Taylor, Gibson, & Franck, 2008).

The World Health Organization made a first attempt at clarifying the concept. The WHOQOL group (1995) defined quality of life as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p. 1405). This was a very broad definition representing physical health, psychological state, level of independence, social relations, personal beliefs and relation to characteristics in the environment (WHOQOL group, 1995). Furthermore, this definition highlights that quality of life is subjective, contains both positive and negative aspects of life and is multidimensional. Most researchers agree upon these three aspects of quality of life (WHOQOL group, 1995). Moreira et al. (2013) provide a good summary: “QoL has been conceptualized as a multidimensional and subjective construct that reflects an individual’s subjective assessment of several domains of his or her life, including physical, social, and psychological functioning” (p. 1471). The definition by the World Health Organization (WHO) has been cited by many other studies, but as Taylor et al. (2008) remark, it was not known whether the definition of quality of life, developed for adults, is also adequate for children.

More recently, Taylor et al. (2008) carried out a concept analysis of quality of life in young people with chronic illnesses. This study resulted in a definition closely resembling the original WHO definition, but incorporating developmental stage and the importance of family
and friends. These attributes are relevant to the target group in question, namely children and adolescents. The definition given by Taylor et al. (2008) is as follows:

HRQL in young people with chronic illness is subjective, multidimensional and dynamic. It is unique to each individual young person and includes aspects of physical, psychological and social function. It is dependent upon not only the stage of development but also the illness trajectory. This involves the achievement of goals and aspirations and the constraints imposed through ill-health and treatment. (p. 1831)

Taylor et al. (2008) state that their conceptualization is a new definition of quality of life (QOL) operating from a health perspective. For this reason, they use health-related quality of life (HRQOL) instead of QOL. This seems to be the most recent and best fitting conceptualization for the target group investigated in this study, which consists of chronically ill children and adolescents. It is important to be aware of the fact that some studies use the term QOL, others use HRQOL and some studies use both.

In the present study, quality of life is assessed by two different measures: the Pediatric Quality of Life Inventory (PedsQL) and the life satisfaction thermometer. These instruments respectively measure psychosocial functioning and life satisfaction. The PedsQL measures the multidimensional aspect of quality of life, namely how an individual scores on physical, social, emotional and school domains. The life satisfaction thermometer measures the subjective aspect of quality of life and gives an indication of general well-being (Davis et al., 2006; Koivumaa-Honkanen et al., 2000; Varni, Seid, & Kurtin, 2001). As stated before, life satisfaction is not enough to cover the whole concept of quality of life (Taylor et al., 2008). In the present study, however, life satisfaction complements the obtained results on the PedsQL, which gives an added value to the study. These instruments will be further discussed in the method section.

Quality of Life in Several Chronic Illnesses

This section will discuss what is already known about the quality of life in children and adolescents with a specific chronic illness. The chronic illnesses of interest in this study are juvenile rheumatic disease, diabetes, inflammatory bowel disease, liver and kidney transplant and renal disease.

Juvenile rheumatic disease. The first chronic illness investigated in this study is juvenile rheumatic disease. This is an umbrella term for a diverse group of rheumatic diseases in

\(^1\) In this section, either HRQOL or QOL will be used, depending on the term the referenced study used.
children. Chronic arthritis (otherwise known as juvenile idiopathic/rheumatoid arthritis; JIA) is the most common rheumatic disease in childhood. Other rheumatic diseases are systemic lupus erythematosus (SLE), dermatomyositis, vasculitis, infection-related disorders and autoinflammatory disorders (Haverman et al., 2012; Petty & Cassidy, 2001; Prince, Otten, & van Suijlekom-Smit, 2010).

A lot of studies have tackled the subject of quality of life in juvenile rheumatic disease and most studies have shown an impaired quality of life in children and adolescents with a rheumatic disease. For instance, in a study by Lundberg, Lindh, Eriksson, Petersen, and Eurenius (2012) it was found that more than half of the children with juvenile idiopathic arthritis (JIA) experienced suboptimal HRQOL, which was defined as a mean score less than 78.6 on the PedsQL. The researchers made use of both self-reports and parent proxy-reports\(^2\) of the PedsQL. In a study of Shaw, Southwood, Duffy, and McDonagh (2006) HRQOL was measured by the Juvenile Arthritis Quality of Life Questionnaire (JAQQ). The researchers concluded that adolescents with JIA showed less than optimal HRQOL, with gross motor function being impaired the most.

The aforementioned studies investigated HRQOL in patients with JIA. A couple of studies have also compared HRQOL between patients with JIA and a healthy control group. For example, a study by Bomba et al. (2013) compared children with JIA with a control group consisting of 80 healthy children matched to the chronically ill children for gender and age. Quality of life was measured by the PedsQL and the results indicated that children with JIA had lower quality of life scores compared to the healthy controls in physical, emotional, social and school functioning. In the study of Gutiérrez-Suárez et al. (2007), HRQOL was measured by the Child Health Questionnaire (CHQ) which assesses the physical, emotional and social components of health status of children. This study showed the same result as the study above; patients with JIA scored lower on all subscales of the CHQ compared to healthy children. The subscales that received the lowest scores were all related to the physical domain (global health, physical functioning, bodily pain/discomfort and general health perceptions).

The previous two studies compared the HRQOL of children with JIA with healthy controls. A study by Amine, Rostom, Benbouazza, Abouqal, and Hajjaj-Hassouni (2009) compared children with different subtypes of juvenile idiopathic arthritis. The researchers hypothesized that HRQOL would decrease with increased levels of disease activity and

\(^2\) Parent proxy-report is when a parent reports the quality of life of his or her child.
disability. HRQOL was measured by the JAQQ and functional disability by the children’s version of the child health assessment questionnaire (CHAQ). The results indicated that children with a milder clinical subtype showed better HRQOL than children with a more severe subtype. The milder subtype oligoarticular was characterised by better gross and fine motor function, less symptoms and less psychosocial impact compared to patients with the polyarticular or systemic subtype. In addition, HRQOL was worse in adolescents compared to children. This was assumed to relate to the fact that the older the patients were, the more pain they rated and the more disability they consequently experienced. However, recent studies have indicated that the correlation between pain intensity and disability is not necessarily strong (Garbi et al., 2014; Stefane, dos Santos, Marinovic, & Hortense, 2013). A large study by Oliveira et al. (2007) showed the same pattern; this time HRQOL was measured by the CHQ. This study used data from 6,639 children coming from 32 countries. They showed once again that patients with JIA had poorer HRQOL compared to healthy peers from the same country, in both physical and psychosocial domains. The study also showed that patients with the subtype persistent oligoarthritis were better off regarding HRQOL than patients with other subtypes of JIA.

Furthermore, a study in the Netherlands did not only compare children with JIA to healthy controls, but also to children with other chronic health conditions (Haverman et al., 2012). HRQOL was measured by the PedsQL and functional ability by the CHAQ. The results indicated that the JIA group reported lower HRQOL compared to both their healthy peers and children with other chronic illnesses. Approximately half of the patients with JIA had an impaired HRQOL in comparison with only 16 percent of the general population. This study differentiated between three age groups (6-7, 8-12, 13-18) and reported that only the 8-12 age group scored lower on HRQOL compared to children with other chronic health conditions. In all age groups physical and psychosocial functioning seemed to be most impaired, while emotional functioning seemed to be less affected. A shortcoming of this study is that it did not report which other chronic health conditions were used as control. Upon consulting the original study that provided the database for the control group, it was found that the most common chronic conditions in the sample were asthma, congenital defect, skin disease and migraine (Engelen, Haentjens, Detmar, Koopman, & Grootenhuis, 2009). A study by Norrby, Nordholm, Andersson-Gäre, and Fasth (2006) also compared the HRQOL between four diagnostic groups, i.e., asthma, diabetes, juvenile chronic arthritis and short stature. This study correspondingly found that children with juvenile chronic arthritis had the lowest quality of life as measured by the CHQ.
Most of the aforementioned studies have addressed HRQOL in JIA. This is the most common form of juvenile rheumatic disease but there are other forms as well. A study by Ruperto et al. (2004) assessed juvenile systemic lupus erythematosus (JSLE). HRQOL was assessed by the CHQ and the scores of children with JSLE were compared to a healthy group and a group of JIA patients aged 5 to 18. The results showed that children with JSLE reported lower HRQOL than their healthy peers in both physical and psychosocial domains. On the other hand, children with JSLE showed similar HRQOL as JIA patients. However, JSLE patients reported less intense and frequent bodily pain, worse scores on self esteem and according to parents worse overall health and illness. Varni et al. (2002) also conducted a study comparing different rheumatic diseases. They found significant differences between healthy children and children with rheumatic diseases, with the latter obtaining lower HRQOL scores. They also investigated whether differences could be found between specific rheumatic diseases. Both child and parent proxy-reports indicated that children with fibromyalgia scored lowest on HRQOL in comparison with dermatomyositis, JIA, JSLE and spondylarthitis.

As indicated by the results reported here, most studies have shown an impaired HRQOL in children and adolescents with juvenile rheumatic disease. However, a few studies have reported no significant difference in HRQOL or psychosocial functioning. The study by Grootenhuis, Koopman, Verrips, Vogels, and Last (2007), for instance, found that children with JIA did not report any difficulties on any of the investigated domains of QOL. However, two important remarks have to be made. First, QOL was measured by the TNO AZL Children’s Quality of Life questionnaire (TACQOL), which is a relatively new developed Dutch questionnaire. Second, many of the patients had the subtype oligoarticular which is known to have a lesser impact on HRQOL. It is important to keep in mind that studies not finding a difference in HRQOL represent a minority.

**Diabetes.** The second chronic illness investigated in this study is diabetes. Diabetes mellitus is a metabolic disease characterized by hyperglycemia. The two major categories of this disease are type 1 and type 2 diabetes. The former is caused by an absolute deficiency of insulin secretion, while the latter is caused by a combination of resistance to insulin action and an inadequate compensatory insulin secretory response. Type 2 diabetes is the most prevalent category of diabetes in the general population, while type 1 diabetes is one of the most common childhood chronic illnesses (American Diabetes Association, 2008; Reynolds & Helgeson, 2011). Type 1 diabetes usually appears during childhood, while type 2 usually appears in
adulthood. Since the present study focuses on childhood chronic illnesses, the focus will be on type 1 diabetes.

A lot of studies have investigated the quality of life in children and adolescents with diabetes. It is striking that a lot of studies have found nearly no difference or even better quality of life than a healthy control group. For instance, in a study of De Wit et al. (2007) adolescents were found to rate their QOL similarly compared to healthy controls, as measured by the CHQ. Adolescents with diabetes aged between 13 and 17 only reported lower scores on the subscales regarding role functioning-physical and general health, while the other eight subscales (for example mental health, role functioning-emotional, self-esteem…) were comparable to healthy controls. Hence, the authors concluded that Dutch adolescents with type 1 diabetes seem to function well and report a satisfactory quality of life comparable to healthy controls.

Studies using the PedsQL to measure QOL came to similar conclusions. For instance, Upton et al. (2005) used the PedsQL to assess HRQOL. They used a sample consisting of healthy children and children with a chronic illness (asthma, diabetes, inflammatory bowel disease or in remission from cancer) aged between 8 and 18 years. The results indicated that overall, children with a chronic illness reported lower HRQOL than healthy children. However, the total score of children with diabetes indicated no difference in HRQOL compared to healthy children. They only reported a lower score on the subscale physical health. Moreover, children with diabetes even reported higher scores on the subscales emotional and social functioning compared to healthy children, although these differences did not reach statistical significance. Laffel et al. (2003) also reported similar quality of life between children with diabetes and healthy controls, aged between 8 and 17. However, it is worth mentioning that parents of children with diabetes did report lower quality of life for their child compared to parents of healthy children. This difference was mainly caused by a lower psychosocial score.

This latter finding is not unique in the literature. For instance, a study by Hesketh, Wake, and Cameron (2004) has shown the same result. HRQOL was measured using the CHQ and Hesketh et al. (2004) reported that parents tend to rate their child’s HRQOL as lower than healthy children, while the adolescents themselves tend to report their health to be similar to that of healthy controls. This turned out to be a relatively stable finding, given that the authors measured HRQOL at two points in time, with a 2 year interval. A previous, quite similar study conducted by the same authors had already indicated the same result (Wake, Hesketh, & Cameron, 2000). This study found small differences between healthy adolescents and
adolescents with diabetes on the General Health and Family Activities scales, with the diabetic patients scoring lower.

Wagner, Müller-Godeffroy, von Sengbusch, Häger, and Thyen (2005) were the first researchers to find actual statistical significant evidence of better HRQOL in children (8-12) and adolescents (13-16) with type 1 diabetes compared to healthy children. HRQOL was assessed using the German KINDL-R questionnaire which consists of six subscales (physical and psychological well-being, self-esteem, family, friends and school). Children and adolescents with diabetes scored better on well-being in the school and psychological domain. The two groups did not differ on the other subscales. Wagner et al. (2005) also reported that children show better HRQOL than adolescents. A comparison with age-matched controls with other chronic illnesses (atopic dermatitis, asthma and obesity) was made as well. Children and adolescents with type 1 diabetes had better HRQOL compared to the control group.

Nevertheless, there have been studies indicating worse psychosocial health in children with diabetes. For instance Varni et al. (2003) found a significant difference between children with diabetes and healthy children (5 to 18 years old) on the PedsQL. All scales except physical and social functioning were impaired according to the children themselves, while parents reported all scales to be impaired. It has to be pointed out that this study used patients with both type 1 and type 2 diabetes as one group, while all other studies discussed here only used children with type 1 diabetes. It is likely that the different HRQOL could be attributed to this. Varni et al. (2003) did report that children with type 2 diabetes showed lower HRQOL scores than children with type 1. This was also confirmed in other studies, for instance in a study by Naughton et al. (2008) that included participants aged between 8 and 22. They concluded that patients with type 2 diabetes showed lower HRQOL (as measured by the PedsQL) than patients with type 1. Taking all abovementioned research into account, it seems that most studies agree that children and adolescents with diabetes tend to report similar quality of life as healthy controls. However, no consensus has been reached on whether or not they also report better quality of life.

**Inflammatory bowel disease (IBD).** Inflammatory bowel disease (IBD) is the third chronic illness represented in this study and comprises two major subtypes, namely Crohn’s disease (CD) and ulcerative colitis (UC) (Podolsky, 1991). However, a third smaller subtype is sometimes considered as well, namely indeterminate colitis (IC). According to Podolsky (2002),
the diagnosis of IC is used when it is impossible to diagnose UC or CD; this seems to occur in about 10 percent of IBD cases.

According to a relatively recent meta-analytic review, several studies regarding quality of life in children and adolescents report lower scores in children with IBD compared to their healthy peers (Greenley et al., 2010). An earlier review study by Mackner, Crandall, and Szigethy (2006) came to a similar conclusion. Mackner et al. (2006) concluded that children with IBD are more likely to have lower psychosocial functioning compared to healthy children. They do remark, however, that psychosocial difficulties are not found in all IBD patients but only in a subset of patients. Mackner et al. (2006) also state that the psychosocial difficulties found in their study are comparable to results found in studies investigating other chronic illnesses in children and adolescents.

The former studies were both either a meta-analytic or a review study, so it seems interesting to take a look at individual studies as well. Most studies compare the scores of IBD patients with healthy controls. For instance, Kunz, Hommel, and Greenley (2010) used the PedsQL to measure HRQOL in a sample of patients with IBD aged between 11 and 18 years. The results indicated that patients with IBD reported lower HRQOL scores than their healthy peers. Besides lower psychosocial functioning, IBD seemed to have especially adverse effects on the school functioning domain. A different study by De Boer, Grootenhuis, Derkx, and Last (2005) investigated the HRQOL in Dutch adolescents with IBD who were between 12 and 18 years old during testing. They used the Dutch Children’s AZL/TNO Quality Of Life Questionnaire, which measures family, physical, emotional and social functioning. De Boer et al. (2005) reported lower HRQOL for adolescents with IBD compared to healthy adolescents. They also found significant gender differences. Male adolescents scored lower on the total HRQOL score and on the emotional, physical and family functioning domain. On the other hand, female adolescents with IBD only scored lower on the family and emotional functioning domain. However, no gender differences were reported in a study by Haapamäki, Roine, Sintonen, and Kolho (2011).

Loonen, Grootenhuis, Last, Koopman, and Derkx (2002) used the generic TACQOL and the disease specific Impact-II for measuring HRQOL. They differentiated between the three IBD categories and also between a child group (8-11) and two adolescent groups (12-15 and 16-18). First, Loonen et al. (2002) found no significant HRQOL differences between the three IBD subcategories. Although it is interesting to note that children with CD scored lower than
children with UC on all IMPACT-II subscales expect body image. Second, children with IBD scored similarly to their healthy peers regarding HRQOL and even obtained a better score on cognitive functioning. Adolescents on the other hand obtained a lower score on HRQOL in comparison with their healthy peers with differences located on the subscales body complaints, motor functioning, autonomy and negative emotions. In other words, the researchers found an age difference, with children with IBD scoring better on the HRQOL measure than adolescents with IBD. The authors did call attention to the fact that the sample of children was rather small and consisted of children with mainly mild or moderate diseases. Recent studies have indeed indicated that more severe or active forms of disease are strongly associated with lower HRQOL (Haapamäki et al., 2011; Kunz et al., 2010). In line with the findings of Loonen et al. (2002) is a study by Haapamäki et al. (2011), showing that diagnosis of either CD or UC seems to have no influence on HRQOL. They used different instruments than Loonen et al. (2002), i.e., the 15D for adolescents older than 16, the 16D for adolescents between 12 and 15 years of age and the 17D for children aged 8. However, the age difference reported by Loonen et al. (2002) was not replicated. In this study, children with IBD did score lower on various dimensions compared to their healthy peers.

A study by Kunz et al. (2010) did not only compare children with IBD to healthy controls, but also to children with other chronic health conditions. This study found no difference in total HRQOL scores between children with IBD and children with another chronic illness. They did however find that IBD patients reported a higher score on the physical health summary scale and a lower social functioning score than a chronically and acutely ill group. Kunz et al. (2010) used a published comparison group from a previous study by Varni et al. (2001). This comparison group consisted of patients recruited in specialty clinics, namely orthopedics, cardiology, rheumatology and diabetes. To conclude, it appears that IBD patients have lower HRQOL scores compared to healthy controls. One study also reported similar HRQOL for IBD patients compared to other chronic illnesses, however, more research is needed on this subject.

Transplantation (liver and kidney). The fourth chronic illness investigated in this study is pediatric transplantation and the focus will be on quality of life after liver and kidney (or renal) transplantation. Transplantation is a life-saving procedure, but children and adolescents who underwent this are still considered patients with a chronic illness. This is because these patients keep experiencing chronic health problems, even after transplantation (Kim & Marks, 2014).
A study by Sundaram, Landgraf, Neighbors, Cohn, and Alonso (2007) investigated the HRQOL in both liver and kidney transplant patients. They measured HRQOL with the CHQ and obtained both adolescent (11-18) and parent proxy-report. In general, it was found that liver and kidney transplant patients had a good quality of life score. More specifically, adolescents with a liver transplant did not differ from a healthy population on both the physical health scale and the psychological scale. Adolescents with a kidney transplant on the other hand reported lower general health but a similar score on the psychological scale as the healthy population. However, parents of both transplant groups reported the physical functioning and general health of their adolescent to be significantly lower than the healthy comparison group.

Similar findings regarding quality of life in liver transplant patients have been reported in a review study by Taylor, Franck, Gibson, and Dhawan (2005). Taylor et al. (2005) found no significant differences in HRQOL between transplant patients and healthy populations. Surprisingly, they also found no significant differences in HRQOL between transplant patients and patients with other chronic illnesses. This seems peculiar because most studies show a difference in quality of life between chronically ill patients and healthy populations. If the HRQOL of transplant patients is similar to that of healthy children and adolescents, they should have better quality of life than the chronically ill group. Taylor et al. (2005) did state that HRQOL appeared to be worse in liver transplant patients compared to healthy controls and that HRQOL was similar or better in liver transplant patients compared to patients with other chronic illnesses. However, none of these findings reached statistical significance. The authors concluded that it seemed likely that liver transplantation negatively impacts some areas of HRQOL compared to healthy children and adolescents. They attribute the lack of statistical significance to the less favorable methodology in the studies used in the review article.

A more recent study by Taylor, Franck, Gibson, Donaldson, and Dhawan (2009) has shown different results. Here, HRQOL was measured by the CHQ and participants were aged 12 to 18. Liver transplant patients scored an average of 10 points lower in every domain measured in the CHQ, except for role/social-behavioral and family cohesion compared to the general population. Moreover, Taylor et al. (2009) stated that liver transplant patients scored similarly to patients with other chronic illnesses (asthma and diabetes). Thus, this study provided evidence for the suggestion expressed in the previous study by Taylor et al. (2005). Other studies have found similar findings as well. For instance, the study by Fredericks, Lopez, Magee, Shieck, and Opipari-Arrigan (2007) measured HRQOL in children aged 2 to 16.
PedsQL and CHQ scores indicated lower scores for liver transplant patients compared to healthy controls. The only inconsistent finding with regard to the study of Taylor et al. (2009) was that liver transplant patients reported significantly lower HRQOL scores compared to children with diabetes. Bucuvalas et al. (2003) found lower school functioning and psychosocial health scores for the liver transplant group (5-18) compared to other chronic illnesses, although the summary scores were similar. The comparison group contained patients recruited in specialty clinics (orthopedics, cardiology, rheumatology and diabetes; Varni et al., 2001).

Another study investigated HRQOL in liver transplant patients aged 12 to 17, using the PedsQL and CHQ. The results indicated that liver transplant patients had lower HRQOL than healthy children (Fredericks et al., 2008). A study investigating HRQOL in young children used the Infant Toddler Quality of Life Instrument (ITQOL) for children between 2 and 5 years and CHQ (parent version) for children who were 5 years of age and older. Liver transplant patients in the older age group had lower physical and general health than their healthy peers. Liver transplant patients in the younger age group scored lower than their healthy peers only on the subscales global health, general health perceptions and change in health, while they scored higher for discomfort and pain (Alonso et al., 2008).

Regarding kidney transplant patients, not all studies have come to the exact same conclusion as Sundaram et al. (2007). For instance, Anthony et al. (2010) investigated QOL in kidney transplant patients who were between 2 and 18 years old. They found that transplant patients scored lower than healthy controls on all subscales, as measured by the PedsQL. The only exceptions were adolescents (aged 13 to 18) scoring no different from healthy controls on the emotional function scale. Anthony et al. (2010) did however conclude that kidney transplant patients reported good overall QOL, but explicitly stated that QOL was clearly lower than healthy children. They also made the remark that QOL in kidney transplant patients was better than QOL in other chronic illnesses.

Lower QOL scores in kidney transplant patients compared to healthy controls have been consistently found in other studies as well. Hamiwka, Cantell, Crawford, and Clark (2009) used the PedsQL to measure HRQOL (self-report and parent report) in patients aged 8 to 18. They found that kidney transplant patients scored lower on HRQOL than healthy controls similar in age and gender according to both the children themselves as their parents. Qvist et al. (2004) measured HRQOL with the 17D in children aged 6 to 17. The results also indicated that the overall HRQOL for healthy controls was significantly higher than HRQOL in kidney transplant patients.
patients. Lastly, Diseth, Tangeraas, Reinfjell, and Bjerre (2011) used the PedsQL (self and parent report) in kidney transplant patients aged 2 to 19. They also found that kidney transplant patients scored significantly lower on HRQOL than healthy controls, with the exception of the score on emotional functioning. To conclude, it appears that liver and kidney transplant patients do indeed have lower HRQOL scores compared to healthy controls. The difference with other chronic illnesses regarding QOL is not yet clear.

**Renal disease (nephrology).** Renal disease is the final pediatric chronic illness investigated in this study. It comprises a couple of chronic illnesses. Chronic kidney disease (CKD) is probably the most well-known, followed by nephrotic syndrome. CKD consists of 5 stages; the first stage is the least severe, in stages 2-4 chronic renal failure (CRF) and chronic renal insufficiency (CRI) manifest and stage 5 is the most severe stage. This stage is called end-stage renal disease (ESRD) and someone in this stage will require dialysis or a kidney transplant. CKD is known to be a silent disease, meaning that children who have it will not experience symptoms until they have severe renal dysfunction. With regard to the second renal disease, 90% of nephrotic syndrome cases fall under the subcategory steroid sensitive nephritic syndrome (SSNS) (Nanjundaswamy & Phadke, 2002; Warady & Chadha, 2007; Wong et al., 2014).

A study by Gerson et al. (2010) investigated 402 children with mild to moderate CKD (stages 1-4) who were between 2 and 16 years old. It was found that children with CKD had overall lower HRQOL than healthy controls, as measured by the PedsQL. Children with CKD scored significantly lower on all HRQOL domains (physical, school, emotional and social functioning) with the largest difference found on the school functioning domain. It was interesting that the researchers did not find evidence for their hypothesis that the severity of kidney damage would influence HRQOL impairment. They comment that different results might be obtained if a longitudinal study would be conducted instead of cross-sectional research. Another interesting finding was that children who had CKD for a longer period in their life reported their physical functioning to be better than children who had CKD for a shorter period of time. Their parents also reported better physical functioning and better emotional functioning. Thus, it appears that children accommodate to having CKD and find the negative impact of their chronic illness to decrease over time.

Studies investigating HRQOL in children with more advanced kidney disease have been more frequently conducted than with early kidney disease. The general pattern in these studies
indicates lower HRQOL in children with CKD than healthy controls. The following three studies measured HRQOL in patients aged 2 to 18. The study by Goldstein et al. (2006) investigated HRQOL in children with ESRD (stage 5). The total HRQOL score and all individual PedsQL domains were significantly lower in ESRD patients compared to healthy peers, matched for age and ethnicity. In the study by McKenna et al. (2006), the CKD population consisted of children with CRI (stage 2-4) and ESRD (dialysis or transplant; stage 5). All CKD patients scored lower than healthy controls on all PedsQL subscales, particularly the transplant patients. Marciano et al. (2011) also measured HRQOL in patients with CKD stage 2-5 compared to age-gender matched controls. They found that the CKD group had significantly lower scores in all PedsQL domains, except for the emotional domain (as reported by patients).

Two very recent studies provided further evidence for impaired HRQOL in CKD patients. Both studies used the PedsQL to measure HRQOL in children and adolescents aged 2 to 18. Lopes, Ferraro, and Koch (2014) investigated the HRQOL in CKD patients with stages 4 and 5. They found that CKD patients showed significantly lower HRQOL scores than their healthy peers in the physical, social and school functioning domain. They also found an age-difference, with older patients indicating more impairment in all four domains (emotional functioning was impaired as well). Kiliś-Pstrusińska et al. (2013) studied the HRQOL in children and adolescents with CKD stages 2-5. CKD patients scored significantly lower in all PedsQL domains compared to healthy children. In line with the findings of Gerson et al. (2010), the researchers did not report severity of kidney damage (as measured by CKD stage) influencing HRQOL.

However, not all studies have found impaired HRQOL in CKD patients. For instance, a study using the TACQOL questionnaire in children with ESRD aged 7 to 16 found no significant difference between ESRD patients (dialysis) and healthy age-matched controls. However, this study only measured HRQOL in 9 children (Eijsermans, Creemers, Helders, & Schröder, 2004). Another study investigating quality of life in 225 CKD patients (stage 3-5), found a better QOL score for CKD patients. Age range in this study was 6 to 18 and the Generic Children’s Quality of Life Measure (GCQ) was used to measure self-reported QOL. This questionnaire is specifically designed for child self-report and is said to measure psychosocial quality of life. The results of this study indicated that CKD patients reported significantly higher QOL scores than their healthy peers (Heath et al., 2011). It is important to note that both studies
used questionnaires that are not commonly used in the assessment of HRQOL in pediatric patients.

Finally, a study investigating HRQOL in SSNS was conducted by Rüth, Landolt, Neuhaus, and Kemper (2004). They used the TACQOL (child and parent form) in order to measure HRQOL in patients aged 3 to 19. This questionnaire measures 5 scales, namely physical complaints, basic motor functioning, autonomy, cognitive and social functioning. Rüth et al. (2004) concluded that QOL was impaired in children and adolescents with SSNS. Particularly parents reported an impaired QOL. They indicated their child to score lower compared to healthy controls on motor, cognitive, social and global positive emotional functioning. The patients themselves, on the other hand, only reported a lower score for social functioning compared to healthy controls. To conclude, it appears that children and adolescents with renal disease report lower quality of life than healthy controls. Studies comparing patients with renal disease to other chronic illnesses are more scarce to find. Varni et al. (2007a) reported lower HRQOL scores for ESRD patients compared to other chronic illnesses. They also found that kidney transplant patients obtained better HRQOL scores compared to CKD patients on dialysis. This study will be discussed in more detail in the section below.

In conclusion, it appears that pediatric patients with a chronic illness report overall lower quality of life than healthy controls. The only chronic illness that appears to report similar quality of life to their healthy peers is diabetes, while some questions still remain about the quality of life in transplant patients. In the next paragraph, studies comparing quality of life in children with different chronic illnesses will be discussed.

Differences in quality of life across children with different chronic illnesses. As mentioned in the paragraphs above, a couple of studies have put in a comparison component in their study. However, most of these studies compare chronic illnesses to a control group or compare one chronic illness to a group of other chronic illnesses (not separately) and in that way conclude that chronic illnesses obtain different results for quality of life. Studies specifically focusing on comparing quality of life across different chronic illnesses are more difficult to find. Above mentioned study by Varni et al. (2007a) is probably the most comprehensive; they compared scores of 2500 pediatric patients across 10 different chronic illnesses. The chronic illnesses in question are asthma, cancer, heart disease, cerebral palsy, diabetes, CKD (ESRD and kidney transplant patients), gastrointestinal conditions including IBD (called organic disorders), obesity, psychiatric disorder and rheumatic disease. Using the PedsQL, Varni et al. (2007a)
found that patients with diabetes reported the highest overall HRQOL. Focusing only on the chronic illnesses important in this study (with only liver transplant patients missing), the sequence of patient reports from highest to lowest total HRQOL is as follows: diabetes type 1 (81.64), kidney transplant (78.94), diabetes type 2 (77.46), SLE (76.95), IBD (75.41), JIA (73.73) and ESRD (69.30 or 70.70 dependent on type of dialysis). The sequence of parent reports is as follows: diabetes type 2 (77.71), diabetes type 1 (77.31), kidney transplant (75.57), SLE (75.25), JIA (73.48), IBD (68.75), ESRD (61.91 or 68.07 dependent on type of dialysis). Note that parents and patients report the same top 3 (although in a different order) and that parent report is consistently lower than patient self-report. Varni et al. (2007a) conclude by saying that the results show the differential effects of pediatric chronic conditions on HRQOL. It is important to note, that Varni et al. (2007a) did not investigate whether the differences between chronic illnesses were significantly different.

Two other studies assessing HRQOL across a subset of chronic illnesses, also used the PedsQL to measure HRQOL. The first study is by Ingerski et al. (2010) and the chronic illnesses investigated are obesity, eosinophilic gastrointestinal disorder, IBD, epilepsy, type 1 diabetes, sickle cell disease, kidney transplantation and cystic fibrosis. Focusing only on the chronic illnesses important for the present study, it was found that patients reported no significant differences in HRQOL (total score) across IBD, type 1 diabetes and kidney transplant. However, the results suggested a hierarchy of IBD (78.6), kidney transplant (75.2) and type 1 diabetes (73.7). Parents, on the other hand, did report a significant difference in HRQOL (total score) between IBD and kidney transplant, with the suggested hierarchy here being IBD (81.9), type 1 diabetes (74.2) and kidney transplant (66.4). Upton et al. (2005), on the other hand, did not investigate whether differences in HRQOL between chronic illnesses were significant, but they did compare the HRQOL scores with a healthy sample. The chronic illnesses investigated in this study were asthma, diabetes, cancer and IBD. Once more, the focus will be only on the chronic illnesses relevant to the present study. Children with IBD scored significantly lower than the healthy sample, while children with diabetes did not score significantly different than the healthy sample. Children with diabetes scored best on HRQOL (82.46), while children with IBD scored lowest (74.18). The two above mentioned studies report very different results, though the study by Varni et al. (2007a) and Upton et al. (2005) seem to reach agreement on the sequence of diabetes and IBD.

So far, liver transplant patients have not been included in the samples discussed above. A study by Limbers et al. (2011) specifically compared the HRQOL of 873 liver transplant
patients to patients with JIA, type 1 diabetes, cancer, cardiac disease, kidney transplant patients, ESRD and IBD. Children with a liver transplant obtained similar HRQOL scores as children with IBD, a kidney transplant and JIA. They obtained significantly lower HRQOL than children with type 1 diabetes and significantly higher HRQOL than children with ESRD. The suggested sequence for overall HRQOL according to the chronically ill children was as follows: type 1 diabetes (80.79), IBD (79.85), kidney transplant (78.94), liver transplant (77.21), JIA (73.50) and ESRD (69.77). The parents reported children with a liver transplant to have significantly higher HRQOL than children with ESRD and IBD, and no significantly different HRQOL than children with the other chronic illnesses. They reported a very similar sequence: type 1 diabetes (77.48), liver transplant (77.26), kidney transplant (75.57), JIA (73.43), IBD (70.54) and ESRD (64.27). The obtained sequence for parents in this study was exactly the same as the study by Varni et al. (2007a). The sequence reported by the children was very similar, with only IBD obtaining a different order in the sequence. It is important to keep in mind that this study only compared the HRQOL of liver patients to other chronic illnesses, and not all chronic illnesses to each other.

To conclude, not all studies seem to agree on the sequence of quality of life in children with a chronic illness, although the general pattern seems to indicate that children with diabetes report the highest and children with CKD the lowest quality of life. Transplant patients also appear to do generally well compared to other chronic illnesses, though less good than patients with diabetes. However, more research is needed that statistically compares quality of life across different chronic illnesses.

**Correlates of Quality of Life**

The second part of the present study focuses on investigating whether emotion regulation and parental distress are correlates of quality of life in children and adolescents with a chronic illness. Studies that are specifically investigating this subject are scarce. Most studies explore quality of life in a specific chronic illness and additionally check whether gender or age are associated with quality of life. Previous research has indicated that it is possible that gender and age could influence quality of life, therefore, the present study will control for these variables. In the next couple of paragraphs, first, research regarding the association between quality of life and gender and age in chronically ill samples will be considered. Second, studies investigating the relation between emotion regulation and quality of life will be discussed. Finally, research regarding the association between parental distress and quality of life will be considered.
Gender and age. With regard to gender, Lundberg et al. (2012) found no gender difference in quality of life scores in children with JIA. Laffel et al. (2003) explored predictors of HRQOL in children with diabetes type 1 and found that male or female gender was not associated with better or worse HRQOL. Norrby et al. (2006) measured HRQOL in a sample including JIA, diabetes, asthma and short stature. Similar to the previous two studies, no gender difference in quality of life in any of the four groups was found. Varni et al. (2007a) came to similar conclusions as Norrby et al. (2006), they also found that gender did not influence quality of life in children with JIA, diabetes, CKD, kidney transplant and IBD. It has to be noted though, that in this study IBD was part of the disease cluster gastrointestinal disorders which also comprised functional abdominal pain and irritable bowel syndrome. However, Haapamäki et al. (2011) investigated possible gender differences in patients with IBD and found no influence of gender as well. Finally, Alonso et al. (2008) found no gender difference in HRQOL in liver transplant patients.

Nevertheless, some studies did report a gender difference in chronically ill patients. Gerson et al. (2010) investigated predictors of HRQOL in children with CKD. They found that girls with CKD obtained higher school functioning scores than boys. Wagner et al. (2005) provided evidence for gender differences in diabetes type 1. Boys reported better HRQOL than girls for the subscales friends and chronic illness. Upton et al. (2005) found a gender difference in self-report in a sample consisting of children with asthma, diabetes and IBD. Girls reported significantly lower emotion functioning than boys. In a different study with only an IBD sample, gender differences were found with male adolescents scoring lower than female adolescents on HRQOL (De Boer et al., 2005). To conclude, it appears that more studies report the absence of gender differences in samples with chronic illnesses. If studies do report a gender difference, it is not clear whether boys or girls generally obtain a better HRQOL score.

In contrast to gender differences, more studies seem to report the presence of an age difference. For instance, Norrby et al. (2006) found an age difference in HRQOL in a sample including JIA, diabetes, asthma and short stature. Since the median age in the patient sample was 13, they divided the patient group in those who had and those who had not reached puberty. It was found that the older group (those who had reached puberty) obtained lower scores on mental health and self-esteem than the younger group. Varni et al. (2007a) found an age difference for IBD (child self-report), JIA and diabetes (parent proxy-report). Younger children obtained significantly higher HRQOL scores compared to older children and adolescents.
Wagner et al. (2005) provided further evidence for an age difference in diabetes type 1, because children (8-12) reported higher total HRQOL than adolescents (13-16). This result was primarily the result of the high score on the school functioning scale for children. Gerson et al. (2010) found an age difference for CKD patients, who rated their HRQOL to be higher with increasing age. Every additional two years of age were associated with a higher overall HRQOL score by an average of 2.1 points. In the parental assessment, a different age difference was reported. Here, age was negatively associated with school functioning, namely every additional two years of age were associated with a lower school functioning score of 1.4 points on average.

Nevertheless, some studies did not report an age difference. For instance, Laffel et al. (2003) explored predictors of HRQOL in children with diabetes type 1. Age was not associated with better or worse HRQOL. Varni et al. (2007a) reported no age differences in a group consisting of CKD and kidney transplant patients. Finally, Alonso et al. (2008) found no age difference in HRQOL in liver transplant patients. In conclusion, the literature comprises quite a lot of conflicting results with regard to the association between quality of life and gender and age. Forming a decisive conclusion about whether or not age and gender differences are present, is made even more difficult by the fact that most studies focus on one or two chronic illnesses instead of making a comparison across different chronic illnesses. Furthermore, a lot of different measures for quality of life are used. Taking all results into account, the literature seems to indicate that there is more evidence for an age difference and less for a gender difference. The age difference indicates that children seem to do better on quality of life than adolescents. However, this difference does not seem to be illness transcendent, but rather illness specific since most studies with diabetes seem to indicate an age difference, but studies with transplant patients showed no age difference at all. As for the rest, results regarding JIA, CKD and IBD are not unambiguous. To conclude, it seems best to control for these variables in the present study in order to obtain the unique contribution of emotion regulation or parental distress on quality of life.

**Emotion regulation.** The first potential correlate of quality of life is emotion regulation. According to Thompson (1994), emotion regulation is a broad concept consisting of the processes that are responsible for monitoring, evaluating and modifying emotional reactions. Garnefski, Kraaij, and Spinhoven (2001) have stated that Thompson’s definition of emotion regulation is rather broad. They focus on the cognitive components of emotion regulation which they define as “the cognitive way of managing the intake of emotionally arousing information” (p. 1313). Other definitions of emotion regulation include behavioral coping as well as cognitive
coping, for instance Lazarus and Folkman (as cited in Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth; 2001). However, in the present study, the focus will be on cognitive coping as defined by Garnefski et al. (2001).

The categorization for emotion regulation that will be used in the present study, is the one put forward by Garnefski et al. (2001). They assessed emotion regulation using their self-invented Cognitive Emotion Regulation Questionnaire, which measures nine emotion regulation strategies. They categorized emotion regulation strategies as either adaptive (‘acceptance’, ‘refocus on planning’, ‘positive refocusing’, ‘positive reappraisal’ and ‘putting into perspective’) or maladaptive (‘self-blame’, ‘blaming others’, ‘rumination or focus on thought’ and ‘catastrophizing’). However, to make sense of the literature on emotion regulation, it is important to realize that different categorizations have been put forward. For instance, a second classification by Lazarus and Folkman (as cited in Jaser and White, 2011) divides emotion regulation in problem-focused coping (strategies trying to modify the cause of stress) and emotion-focused coping (strategies trying to regulate negative emotions; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). A third distinction by Reid, Dubow, and Carey (1995) is between approach-coping (strategies trying to change how someone thinks about the problem) and avoidance-coping (strategies denying or avoiding the stressful situation or trying to relieve tension; Ebata & Moos, 1991). A final classification by Compas, Jaser, Dunn, and Rodriguez (2012) divides emotion regulation in primary control coping (strategies tackling the cause of stress or the emotions associated with it), secondary control coping (strategies trying to adapt to the cause of stress) and disengagement coping (strategies trying to stay clear from or deny the stressful event).

Very few studies have assessed the association between emotion regulation and quality of life in pediatric chronic illnesses, although the link between emotion regulation and psychosocial functioning in healthy children and adolescents has been shown in the literature. Zeman, Cassano, Perry-Parrish, and Stegall (2006) reviewed the literature examining emotion regulation in relation to social and psychological functioning. They concluded that components of emotional competence are strongly associated with social functioning and psychological functioning. They also stated that children with either internalizing or externalizing psychological difficulties showed different deficits in emotion regulation. Garnefski et al. (2001) reported that the more adaptive strategies showed a negative relationship with depression and anxiety, while the less adaptive strategies showed a positive relationship. However, these
findings were reported in a healthy sample of adolescents and did not investigate exactly the outcome variable of interest in the present study, namely quality of life.

It is reasonable to assume that children and adolescents with a chronic illness have to use emotion regulation more regularly and differently than healthy children, because they have to cope with having a chronic illness and its consequences. Therefore, results regarding healthy children might not be so relevant to compare. Only a handful of studies have investigated the association between emotion regulation and quality of life in chronically ill children and adolescents. The reported studies focus mainly on diabetes and investigate specific emotion regulation strategies. For instance, Graue, Wentzel-Larsen, Bru, Hanestad, and Sovik (2004) found that the strategies ‘self-blame’, ‘aggressive coping’, ‘mental disengagement’ and ‘behavioral disengagement’ (emotion focused coping) were related to lower quality of life. Regarding the problem-focused strategies, only ‘active coping’ was related to better quality of life in adolescents with diabetes (age 13-18). Grylli, Wagner, Hafferl-Gattermayer, Schober, and Karwautz (2005) found that the strategies ‘self-criticism’ and ‘wishful thinking’ were related to lower quality of life in adolescents with diabetes. An unexpected result was found regarding ‘blaming others’. The use of this strategy led to more problem awareness, but also to more joy in living. The other coping strategies were found to be unrelated to quality of life. Edgar and Skinner (2003) found that higher use of ‘cognitive restructuring’ and ‘social support’ was related to better well-being. No other coping strategies were found to be related to well-being (for example ‘self-criticism’, ‘blaming others’, ‘wishful thinking’).

To our knowledge, the only study investigating this association in another chronic illness relevant to the present study is by Garnefski, Koopman, Kraaij, and ten Cate (2009). They examined a sample of adolescents with JIA aged 12 to 18 years. They found that ‘rumination’ was associated with lower QOL. This finding suggests that it is maladaptive for adolescents with JIA to cope with having a chronic illness by ruminating. Up until now, all reported research has investigated the association between quality of life and individual strategies. Jaser and White (2011) on the other hand, investigated the combined influence of certain emotion regulation strategies in children with type 1 diabetes. They found that use of primary control strategies and secondary control strategies was associated with better quality of life. Disengagement strategies were unrelated to quality of life. The observation can be made that most studies are conducted on adolescents (or adults). A possible reason for this, is that the ability to use complex emotion regulation strategies develops during childhood and adolescence. When children grow older, they gain metacognitive capacities allowing them to
use different and more complex coping strategies (Compas et al., 2001). For instance, Reid et al. (1995) state that complex cognitive self-control abilities are needed in order to use various avoidance strategies, which seem to develop during adolescence.

A couple of interesting studies have been conducted with adult patients. For instance, a study by McCraty, Atkinson, and Lipsenthal (2000) provides some evidence for the influence of emotion regulation on quality of life in diabetic adults. They found that overall quality of life significantly improved after implementing a stress reduction and emotional self-regulation intervention program. A study by Gillanders, Wild, Deighan, and Gillanders (2008) showed that in adult patients with ESRD, well-being was influenced by the particular emotion regulation strategy used. A review by de Ridder, Geenen, Kuijer, and van Middendorp (2008) sheds some more light on the influence of emotion regulation on psychological adjustment in chronic illness. They state that how well people adjust to their illness is influenced by how they cope with negative emotions related to their chronic illness. Two emotion regulation strategies have been investigated; the ‘expression and acknowledgment of emotions’ strategy and the ‘avoidance and inhibition of emotions’ strategy. Better outcomes were found for the former strategy, although the opposite pattern was found in Asian cultures. The authors also mention that psychological interventions in chronically ill patients often comprise the expression of emotions. After disclosure, beneficial effects have been found in diverse chronic conditions including cancer, HIV, asthma and rheumatoid arthritis. This also provides evidence that emotion regulation plays a role in psychosocial functioning. These findings are interesting, but it is not known if the results are comparable to children and adolescents. Much more research is needed about the relationship between emotion regulation strategies and quality of life in chronically ill children and adolescents.

**Parental distress.** Parental distress is the second correlate of quality of life investigated in the present study. Caring for a child or adolescent with a chronic illness can have considerable psychosocial consequences for parents. For instance, it can put a strain on their social and professional life, it can lead to feelings of emotional distress (e.g. fear, depression, stress) and it can lead to lower parental quality of life or impaired parental health (Grootenhuis & Bronner, 2009; Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag, and Grootenhuis, 2008). In the present study, the focus will be on parental distress, i.e., emotional distress with regard to parenting a child or adolescent with a chronic illness. There have been indications in the literature that parental distress is related to poor adjustment outcomes in children with chronic illnesses, for instance in children with spina bifida (Friedman, Holmbeck, Jandasek, Zukerman,
& Abad, 2004), leukemia (Kazak & Barakat, 1997), diabetes (Chaney et al., 1997) and cancer (Colletti et al., 2008). Research also suggests that the level of parental stress can be influenced by the specific chronic illness present in the child (Fredericks et al., 2007; Hullmann et al., 2010; Hung, Wu, & Yeh, 2004). However, psychosocial adjustment is not a synonym of quality of life (Falger et al., 2008).

Hardly any studies have investigated the association between parental distress and quality of life in chronically ill children and adolescents. In a study by Herzer, Denson, Baldassano, and Hommel (2011), parental distress was found to be a predictor of poor HRQOL in adolescents with IBD. This relationship was mediated by depressive symptoms reported by the adolescents. Laffel et al. (2003) found that children with diabetes who reported higher diabetes-specific family conflict also reported lower quality of life. These results were obtained for both child and parent report. Moreira, Frontini, Bullinger, and Canavarro (2014) found that parenting stress was negatively related to general quality of life for children with diabetes. Falger et al. (2008) found that maternal distress (but not paternal distress) was negatively associated with a number of subscales of child reported quality of life in children with a kidney transplant. And finally, a prospective, longitudinal study by Wu, Follansbee-Junger, Rausch, and Modi (2014) found that parental stress had a negative effect on HRQOL in a sample of children with epilepsy aged 2 to 12. Interestingly, they found that parental stress had more effect on HRQOL during the first year of diagnosis, while the effect on HRQOL decreased two years later. Studies that investigate the relationship between parental distress and quality of life in children with chronic illnesses are limited; much more research is needed regarding this subject.

The Present Study

The innovative value of the present study. As mentioned before, the first part of the present study will measure quality of life in five chronic illnesses and compare quality of life across the different illnesses. Quite a lot of studies have already investigated quality of life in pediatric chronic illness samples, but studies conducted in Flanders and studies comparing quality of life across different illnesses are missing in the literature. The present study will add to the existing literature by comparing quality of life between juvenile rheumatic disease, diabetes, inflammatory bowel disease, liver and kidney transplant patients and renal disease in a Flemish sample.

The second part of the present study will investigate two possible correlates of quality of life in children and adolescents with a chronic illness. A serious gap in the literature exists
regarding emotion regulation and parental distress as possible correlates of quality of life. Very few studies have reported results for the target group relevant to the present study. To our knowledge, the present study will be the first to specifically investigate whether emotion regulation and parental distress are correlates of quality of life in a chronically ill group consisting of juvenile rheumatic disease, diabetes, inflammatory bowel disease, liver and kidney transplant and renal disease, while controlling for gender and age.

**Research questions and hypotheses.**

*Comparison of quality of life across different chronic illnesses.* The first research question in the present study states: is it true that children and adolescents with specific chronic illnesses systematically obtain better quality of life scores than children and adolescents with other chronic illnesses? First of all, the chronically ill group will be compared with a healthy control group. Secondly, quality of life will be compared across the five different chronic illnesses. The first hypothesis states that chronically ill children and adolescents will obtain worse QOL scores than their healthy peers. Based on previous research, the second hypothesis states that children and adolescents with diabetes will report better quality of life than children with rheumatic disease, IBD, a kidney or liver transplant and renal disease.

*Emotion regulation as a correlate of quality of life.* The second research question is: is emotion regulation a correlate of quality of life in children and adolescents with a chronic illness? The first hypothesis states that chronically ill children and adolescents who use more adaptive emotion regulation strategies have better quality of life than those who use less adaptive emotion regulation strategies. Thus, adaptive emotion regulation is thought to be a protective factor for quality of life. The second hypothesis states that the association between emotion regulation and quality of life differs from illness to illness (moderation effect).

*Parental distress as a correlate of quality of life.* The third research question is: is parental distress a correlate of quality of life in children and adolescents with a chronic illness? The first hypothesis states that chronically ill children and adolescents with parents who experience a lot of parental distress have worse quality of life than their chronically ill peers with parents who experience less parental distress. Thus, parental distress is assumed to be a risk factor for worse quality of life.
Method

Participants

The present study. Both children and their parents were recruited in the present study, which led to a separate child and parental sample. The main focus of the present study will be on the child sample, but the parental sample will be used for the third research question. A total of 210 children and adolescents with a chronic illness and 187 parents were recruited through Ghent University Hospital. The present study used a sample of this study group and this resulted in a total of 190 children and adolescents and 157 parents. First, the child sample will be discussed, which contained 104 boys (54.7 %) and 86 girls (45.3 %). The mean age was 12.77 (SD: 2.99, age range 7-19). 34 patients reported renal disease (17.9 %), diabetes was reported by 60 patients (31.6 %), 27 patients reported having had a liver or kidney transplant (14.2 %), JIA was reported by 48 patients (25.3 %) and 21 patients reported IBD (11.1 %). For 32 children and adolescents (16.8 %), child and parent report of both mother and father were available. Child and parent report of either mother or father was available for 60 participants (31.6 %) and for 98 participants (51.6 %), only child report was available.

Second, the parental sample consisted of 157 parents, more specifically 101 mothers (64.3 %) and 56 fathers (35.6 %). In case of divorce, (step)parents who spend most time with the child or adolescent were asked to participate. From this sample, one parent per child was randomly selected, which resulted in a sample of 118 parents (81 mothers and 37 fathers). For 26 parents, no child report was obtained. Mean parental age for mothers was 42.12 (SD: 5.25, range 30-56) and 43.95 for fathers (SD: 5.06, range 30-53). Seventeen parents (14.4 %) reported having very low or low education, 31 parents reported medium education (26.3 %) and high or very high education was reported by 70 parents (59.3 %). Fifteen parents (12.7 %) reported being unemployed or a stay at home parent, 78 parents (66.1 %) reported being a labourer, clerk or assistant and 18 parents (15.2 %) reported being self-employed or working at senior management. Most of the parents reported their child to have Belgian nationality (94.9 %), while six children were from the Netherlands. 95 children took medication at the moment of the study (80.5 %) and the mean time since diagnosis for the children and adolescents in this sample was 6.18 years (SD: 4.39). Thirteen parents reported having a child with renal disease (11 %), 43 children had diabetes (36.4 %), 14 children had a liver or kidney transplant (11.9 %), 35 children had JIA (29.7 %) and 13 children had IBD (11 %).

3 Diseases not included in the present study: inborn errors of metabolism and acquired brain injury. See ‘Procedure’ for an explanation.
4 Data regarding profession was missing for seven parents.
The present study was approved by the ethical committee of Ghent University Hospital. Participants were eligible for the study if they spoke Dutch, were between 5 and 18 years old and suffered from one of the following chronic illnesses, i.e., juvenile rheumatic disease, diabetes, inflammatory bowel disease, liver or kidney transplant or renal disease. Signing an informed consent was required in order to start filling out the questionnaires and this was either given online or on paper. Participation was voluntary and no payments or other rewards were provided for those participating. No information is available on response rate or non-responders.

The control group. As control group, the present study used a sample of a large study conducted by Professor Dr. Liesbet Goubert and Dr. Tine Vervoort. This study consisted of 456 children and adolescents from the general population. Participants were recruited through 16 schools in Flanders; 10 middle schools and 6 high schools. 143 participants were middle school students (31.4 %) and 313 participants were high school students (68.6 %). The mean age of children and adolescents in the control group was 13.33 (SD: 2.52, range 8-20) with 176 boys (38.6 %) and 280 girls (61.4 %). The children and adolescents from this study were matched with the present study. This resulted in a control sample of 190 participants; 104 boys (54.7 %) and 86 girls (45.3 %) matched in gender and age to the participants in the present study. The mean age in this sample was 12.90 (SD: 2.81, range: 8-18). It is important to keep in mind that only a matched control group was created for the child sample of the present study and not for the parental sample.

This study was approved by The Ghent University Faculty of Psychology and Educational Sciences. Participants in the control sample were eligible if they spoke Dutch and were between 8 and 18 years old (they had to be in fourth grade at least). Signing an informed consent was required in order to start filling out the questionnaires and this was given online. Participation was voluntary and if both the child and one (step)parent participated in the study, they could win a price. The study had a response rate of 10.77 % (no data was available on non-responders).

Measurements

The present study is part of a large-scale study conducted at Ghent University Hospital. Only questionnaires relevant to the present study will be discussed, i.e., the Pediatric Quality of Life Inventory (PedsQL), the Cognitive Emotion Regulation Questionnaire (CERQ), the
Pediatric Inventory for Parents (PIP) and the Hospital Anxiety and Depression Scales (HADS).\(^5\) Socio-demographic information was also reported by parents and included a number of variables. For instance, their health, profession, education, family situation and the child’s diagnosis, medication use, time of diagnosis etc. All questionnaires from the present study can be found in the Appendix (A-H).

**Health-related quality of life.** In the present study, health-related quality of life was assessed by two different measures, namely the Pediatric Quality of Life Inventory and the Life Satisfaction Thermometer.

**Pediatric quality of life inventory (PedsQL).** Children’s health-related quality of life was assessed using the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999), an instrument developed by James W. Varni. The PedsQL integrates generic core scales and disease-specific modules, but the present study only used the former module. The generic core scales can be used with acutely ill, chronically ill and healthy children and adolescents. The present study used a validated Dutch version of the PedsQL 4.0 generic core scales, translated by Bastiaansen and Koot (Bastiaansen, Koot, Bongers, Varni, & Verhulst, 2004).

This instrument contains 23 items that are scored on a five-point Likert-scale, with answers ranging from ‘never’ to ‘almost always’. Each answer corresponds to a fixed score; ‘never’ (100), ‘almost never’ (75), ‘sometimes’ (50), ‘a lot’ (25) and ‘almost always’ (0). The PedsQL 4.0 Generic Core Scales comprises a physical (eight items), social (five items), emotional (five items) and school functioning scale (five items). Scale scores are computed by adding together the different item scores and dividing this obtained score by the number of items answered. Three summary scores can be obtained as well, i.e., a physical health score, a psychosocial health score and a total scale score. The first summary score is equivalent to the above-mentioned physical functioning scale score. The second summary score is computed by adding the items in the emotional, social and school functioning scales and dividing the obtained score by the number of items answered. The total scale score is computed by summing

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\(^5\) In the large-scale study, parents additionally had to complete the PedsQL disease specific modules, the Positive and Negative Affect Scale (PANAS), the Strength and Difficulties Questionnaire (SDQ), the CERQ, the Acceptance and Action Questionnaire (ACQ) and the Interpersonal Mindfulness in Parenting Scale (IM-P). Children (aged 8 to 12) also had to fill in the PedsQL disease specific modules and the PANAS-C. Adolescents (aged 13 to 18) additionally had to complete the PedsQL disease-specific modules, the PANAS-C, the SDQ and the HADS.
all items and dividing this obtained score by the number of items answered. The total scale score varies between 0 and 100 and a higher score indicates better quality of life. Only the total scale score was used in the present study. The PedsQL has two formats; a child self-report and a parent proxy-report format, and both formats were used in the present study. For child self-report, children have to be aged 5 to 18. For parent proxy-report, the children can be between 2 and 18 years of age (Bastiaansen et al., 2004; Varni et al., 1999; Varni et al., 2001).

The reliability and validity of the PedsQL has been shown in healthy and chronically ill samples (Varni et al., 2001). Engelen et al. (2009) found the reliability and construct validity of the PedsQL to be adequate in a Dutch sample. In the present study, the PedsQL was filled in by all parents (for children aged 5 to 18 years). Children aged 8 to 18 also filled in a self-report version. Cronbach’s alphas in the present study were $\alpha = .90$ for child self-report (both child and teenager version) and $\alpha = .93$ (child version) and $\alpha = .91$ (teenager version) for parent proxy-report. Exemplary items for self-report are: ‘It is difficult for me to play sports or do physical activities’ (physical functioning scale) and ‘I worry about what will happen to me’ (emotional functioning scale). Exemplary items for parent proxy-report are ‘In the past month, did your child experience problems of getting along with other children?’ (5-7 and 8-12 years; social functioning scale) and ‘In the past month, did your teenager forget things?’ (13-18; school functioning scale). The standard instructions for the PedsQL were used.

**Life satisfaction thermometer.** Life satisfaction was assessed by child self-report and parent proxy-report using a Linear Analogue Scale in the form of a ladder. This measure was based on an item (‘general QOL’) from the Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q; de Wit et al., 2012). In the present study, both parents and children and adolescents were asked to rate their general quality of life on a scale from 0 to 10. A score of 0 meant the worst possible quality of life, while a score of 10 meant the best possible quality of life. Additionally, parents were asked to rate the general quality of life of their child as well.

This assessment consists of only a single question, so it is logical to wonder whether this is sufficient enough to grasp the concept. A study by de Boer et al. (2004) examined the validity, reliability and responsiveness of a Visual Analog Scale item measuring quality of life. They found that the global assessment on the basis of a single item was a valid, reliable and
responsive measurement of general quality of life. Moreover, the scale showed moderate to high correlations with indicators of physical, psychological and social aspects of quality of life. Sloan, Aaronson, Cappelleri, Fairclough, and Varricchio (2002) stated that researchers should not be forced to choose between a single or multiple item measurement, but that both types can be used in the same study as complementary data.

Emotion regulation. The Cognitive Emotion Regulation Questionnaire (CERQ; Garnefski et al., 2001; Garnefski, Kraaij, & Spinhoven, 2002) was used to measure children’s emotion regulation using child self-report. The instrument was developed in Dutch and is appropriate for children and adolescents aged 12 years and older. The CERQ can be used to measure general cognitive coping style and a more specific response to a specific event or situation, only the latter was assessed in the present study (Garnefski et al., 2002). Two versions of this instrument are available, a regular 36-item version and a shorter 18-item version. In the short version, the number of items per subscale is reduced from four to two, which is the only difference (Garnefski & Kraaij, 2006a).

The CERQ contains nine subscales and each subscale measures a cognitive emotion regulation strategy. The strategies are self-blame, blaming others, acceptance, refocus on planning, positive refocusing, rumination or focus on thought, positive reappraisal, putting into perspective and catastrophizing. The CERQ contains 36 items that are scored on a five-point Likert-scale with answers ranging from ‘(almost) never’ to ‘(almost) always’. Each answer corresponds to a fixed score; ‘(almost) never’ (1), ‘sometimes’ (2), ‘regularly’ (3), ‘often’ (4) and ‘(almost) always’ (5). Each subscale consists of four items. A subscale score can be acquired by adding up the scores of the four corresponding items and varies between a score of 4 and 20 (Garnefski et al., 2001). The CERQ-short contains 18 items, each subscale consists of two items and a subscale score varies between 2 and 10 (Garnefski & Kraaij, 2006a). A higher subscale score indicates a higher use of the specific strategy.

The reliability and validity of the CERQ has shown to be good in the general population (Garnefski et al., 2001) and has been found to be suitable for use with chronically ill adolescents (Garnefski et al., 2002). The reliability and validity of the CERQ-short has been supported by research as well (Garnefski & Kraaij, 2006a). In the present study, the CERQ-short is used to measure how someone copes with having a chronic illness. The standard instructions were used, with the exception that instead of asking ‘how do you cope with events’, the question ‘how do you cope with your disease’ was used. Exemplary items for the different subscales are: ‘I feel
that I am the one who is responsible for what has happened’ (self-blame), ‘I feel that others are responsible for what has happened’ (blaming others), ‘I think that I have to accept the situation’ (acceptance), ‘I think about how to change the situation’ (refocus on planning), ‘I think of something nice instead of what has happened’ (positive refocusing), ‘I am preoccupied with what I think and feel about what I have experienced’ (rumination or focus on thought), ‘I think I can learn something from the situation’ (positive reappraisal), ‘I tell myself that there are worse things in life’ (putting into perspective) and ‘I keep thinking about how terrible it is what I have experienced’ (catastrophizing).

In line with Garnefski et al. (2001), the present study categorized acceptance, refocus on planning, positive refocusing, positive reappraisal and putting into perspective as adaptive emotion regulation, while self-blame, blaming others, rumination and catastrophizing were categorized as maladaptive emotion regulation. For each participant, a mean score was computed for adaptive emotion regulation and for maladaptive emotion regulation (range 2-10). A higher score indicates higher use of emotion regulation strategies. In the present study, Cronbach’s alphas were $\alpha = .76$ for adaptive emotion regulation and $\alpha = 82$ for maladaptive emotion regulation. There are a couple of reasons why the present study used this distinction. First, this approach has been successfully used in a number of studies (Besharat, & Shahidi, 2014; Hoorelbeke, Marchetti, De Schryver, & Koster, 2016; Miiklósi, Szabó, Martos, Galambosi, & Perczel Forintos, 2013; Vanderhasselt et al., 2014). Second, this approach has the benefit that less analyses have to be conducted when emotion regulation is being investigated; two (adaptive versus maladaptive emotion regulation) instead of nine (emotion regulation strategies). Third, because the CERQ-short was used in the present study, subscale scores are only based on two items. However, by using this approach, the adaptive and maladaptive emotion regulation are respectively based on 10 and 8 items.

**Parental distress.** Parental distress was measured by two questionnaires, namely the Pediatric Inventory for Parents and the Hospital Anxiety and Depression Scales.

**Pediatric inventory for parents (PIP).** Parental stress with regard to parenting a child or adolescent with a serious illness was assessed by means of the Dutch version of the Pediatric Inventory for Parents (PIP; Streisand, Braniecki, Tercyak, & Kazak, 2001). The original PIP was developed by Randi Streisand and it was translated and adapted in Dutch by Jantien Vrijmoet-Wiersma (Vrijmoet-Wiersma et al., 2010).
The PIP contains 42 items and each item is rated twice, once regarding the frequency of the item (‘how often did this situation occur in the last 7 days?’) and once regarding the difficulty associated with the item (‘how difficult was this situation for you or how difficult is this situation generally?’; Lewin et al., 2005). Both times, the item is scored on a 5-point Likert scale with answers ranging from ‘never’ to ‘very often’ on the frequency scale and ‘not at all’ to ‘extremely’ on the difficulty scale. All items should be filled in while keeping the past week in mind. Each answer corresponds to a fixed score; ‘never/not at all’ (1), ‘seldom/a little’ (2), ‘sometimes/somewhat’ (3), ‘often/very’ (4) and ‘very often/extremely’ (5). The items can be grouped in four domain scales, i.e., communication (9 items), emotional functioning (15 items), medical care (8 items) and role function (10 items). The four scale scores can be added together into a total frequency score and a total difficulty score. A higher total score (range 42-210) indicates more parental stress (Streisand et al., 2001; Vrijmoet-Wiersma et al., 2010). The standard instructions were used. Exemplary items for each subscale are ‘Speaking with the doctor’ (communication), ‘Feeling numb inside’ (emotional functioning), ‘Helping my child with physical care, for instance washing’ (medical care) and ‘Not being able to go to work’ (role function).

The reliability and validity of the original instrument has been shown to be adequate in pediatric cancer, diabetes and sickle cell disease (Lewin et al., 2005; Logan, Radcliffe, & Smith-Whitley, 2002; Streisand et al., 2001; Streisand, Swift, Wickmark, Chen, & Holmes, 2005). Furthermore, Alderfer et al. (2008) state that the PIP is a well-established measure for assessing the impact of pediatric chronic illness on the family. The reliability and validity of the Dutch PIP version was found to be satisfactory as well (Vrijmoet-Wiersma et al., 2010). In the present study, Cronbach’s alphas were $\alpha = .95$ for the frequency subscale and $\alpha = .96$ for the difficulty subscale.

**Hospital anxiety and depression scales (HADS).** Overall emotional distress in parents of chronically ill children and adolescents was assessed by means of the Dutch version of the Hospital Anxiety and Depression Scales (HADS; Zigmond & Snaith, 1983). The original HADS was developed by Zigmond & Snaith and different Dutch translations and adaptations can be found online (Maters, Sanderman, & Coyne; 2013). The present study used the Dutch version by Spinhoven et al. (1997), which was designed for use in scientific research. The HADS was originally developed to screen for anxiety and depression in medical out-patients seeing a doctor. Therefore, all items referring to physical symptoms were excluded. This way, the medical condition present in the patient could not bias the depression or anxiety score.
(Spinhoven et al., 1997; Zigmond & Snaith, 1983). In the present study, the HADS was not used to screen for anxiety or depression, but to measure overall distress in parents of chronically ill children and adolescents.

The HADS consists of 14 items that are scored on a four-point Likert-scale and each item has different answer possibilities. All items should be filled in while keeping the past week in mind. Each answer corresponds to a fixed score, for instance ‘most of the time’ (3), ‘a lot of times’ (2), ‘from time to time’ (1), ‘not at all’ (0) or ‘definitely as much’ (0), ‘not quite so much’ (1), ‘only a little’ (2), ‘hardly at all’ (3), etc. The HADS comprises two subscales; an anxiety subscale and a depression subscale. Each subscale consists of 7 items and a subscale score is computed by adding together the different item scores (range 0-21). A total HADS score can be computed by adding together the two subscales (range 0-42). In the present study, only a total HADS score was used. A higher total score indicates more overall distress (Johnston, Pollard, & Hennessey, 2000; Spinhoven et al., 1997; Zigmond & Snaith, 1983).

Exemplary items for the two subscales are ‘I get a sudden feeling of panic’ (anxiety subscale) and ‘I feel cheerful’ (depression subscale).

The HADS was found to be a reliable and valid screening measure for anxiety and depression in medical patients and in the general population (Bjelland et al., 2002; Herrmann, 1997). These are review studies taking into account numerous studies using different languages. The reliability and validity of the Dutch version of the HADS was also found to be satisfactory in different populations (medical, psychiatric and healthy; de Croon, 2005; Spinhoven et al., 1997). However, more recent studies have identified difficulties regarding the validity of the two subscales and concluded that it might be better to use the HADS to measure overall distress instead of anxiety and depression independently (Cosco, Doyle, Ward, & McGee, 2012; Matters et al., 2013; van der Geest et al., 2013). Therefore, in the present study, only the total HADS score was used. Cronbach’s alpha was $\alpha = .89$ in the present study.

Procedure

The present study. The present study was part of a large-scale study regarding quality of life in children and adolescents with a chronic illness. The larger study did not only contain aforementioned illnesses, but also inborn errors of metabolism and acquired brain injury. Due to the small sample size (two children, zero parents), inborn errors of metabolism was excluded from the present study. Furthermore, it was decided not to include acquired brain injury to keep this master’s thesis from becoming too extensive. This group was excluded because it had the
lowest sample size for children of the remaining six illness groups, namely 18 participants. The procedure for collecting data was largely the same for all pediatric diseases. Every month, a list was made of patients eligible for participation, containing the date/hour of the nearest consultation, place (poly or day clinic), date of birth and phone number. The psychologist in charge called the patient or his parents in order to offer information about the study. If they agreed to participate, either a psychologist working at the hospital or a psychology student went to see the family during their consultation. At that time, the psychologist (or student) gave information about the study both verbally and by means of an information bundle. It was explained to the participants that the aim of the study was to measure quality of life in chronically ill children and adolescents and to investigate which factors help determine the quality of life. It was also made clear that both parental and child-report were to be obtained and that anonymity and confidence were guaranteed. If they wished, the participants could be informed about the results of this research on group level after the study was finished.

After this explanation, the student or psychologist asked once more if the child or adolescent and his or her parents were willing to participate. In case of consent, the information bundle was given and the email addresses of the child/teenager and both parents were written down. Children until the age of 12 participated on site with the use of an Ipad or computer under the guidance of a student or psychologist. If possible, teenagers from the age of 13 and parents filled in the questionnaires on a computer at home. If not possible, they were given home a paper version. Informed consent had to be given online and was required to start the questionnaires. In case of a paper version, the informed consent had to be signed on the last page of the information bundle. The participants who filled in the questionnaires at home received a standard mail with a link to the website. In case of a paper version, the psychologists and the participant agreed how the completed questionnaires would be returned. In case of no initial response, the psychologist responsible sent out a standard reminder by email. The responsible psychologists in the study were Eline Van Hoecke (IBD and liver transplant), Elke De Bruyne (rheumatism, nephrology and kidney transplant) and Jolien Laridaen (diabetes).

The control sample. The control sample was part of a large study conducted by Prof. Dr. Liesbet Goubert and Dr. Tine Vervoort. In this study, schoolchildren were asked to complete a number of questionnaires on different subjects (i.e., quality of life, pain experience, somatic complaints, parental parenting behavior). Parents were included as well and were also requested to complete various questionnaires on similar subjects. In the present study, only child self-report scores of quality of life (PedsQL and life satisfaction thermometer) were included.
Three students and two interns of the Faculty of Psychology and Educational Sciences contacted 28 schools in West and East Flanders. The schools were initially contacted by means of a letter at the end of January and the beginning of February in 2014. A few days after the letter was sent, the schools were contacted by phone as well. A protocol for the phone conversation was developed to guarantee uniformity. In this conversation, information was given about the study and the student/intern asked if the school was willing to participate. If they agreed, this meant that they gave permission to the researchers to visit the school and an appointment was made. A couple of schools were not reachable and were contacted later on. A few schools asked for time to think or extra information, which was provided to them by phone or email. Eventually, 16 schools were willing to participate and were visited between February and the beginning of April 2014.

The researchers asked the school if it was possible to personally provide each class with information about the study. They hoped this would increase the chance that children and their parents would actually participate. Most of the schools agreed. However, two schools only agreed to visiting of a couple of classes and in four schools no information was provided in class, mainly because of refusal from the school or lack of time. Each student received a letter with information about the study that they had to show at home. This way, their parents were reached as well. Letters were given out by the researchers themselves or by the secretariat. Each letter contained a personal code (which was different for each participant) and a link that led to the informed consent and the questionnaires. The researchers tried to increase participation by giving out rewards. If both the child and one (step)parent participated, they could win a film ticket (50 were handed out), an iPod (3 were handed out) or an iPod mini (1 was handed out). The winners were chosen at random.

**Statistical Analysis**

All data was analyzed using the software program IBM statistics SPSS 23. First, mean scores, standard deviations and internal consistencies for all parent and child measures of the clinical and control sample were computed. Subsequently, mean scores of the present study were compared to mean scores of previous studies using Independent-Samples T tests and one-sample T tests. Second, Pearson correlations between all variables in the present study were calculated. Third, quality of life differences were investigated across five childhood chronic illnesses (first research question). A MANOVA and a Dunnett’s test were used to investigate whether children and adolescents with a chronic illness have worse quality of life scores than
their healthy peers (hypothesis 1). Next, a MANOVA and a Tukey Kramer test were conducted to investigate whether children with diabetes report better quality of life than children with other chronic illnesses (hypothesis 2). Fourth, emotion regulation was investigated as a possible correlate of quality of life (second research question). Multiple hierarchical regression analyses were conducted to examine if children and adolescents with a chronic illness who use more adaptive emotion regulation strategies obtain better quality of life scores than those who use less adaptive emotion regulation strategies (hypothesis 1). Next, a moderation analysis was conducted to investigate whether chronic illness is a moderator in this association (hypothesis 2). Finally, parental distress was investigated as a possible correlate of quality of life (research question 3). Again, multiple hierarchical regression analyses were conducted to examine if children and adolescents with a chronic illness in families with a lot of parental distress obtain worse quality of life scores than their peers in families with less parental distress (hypothesis 1).

The present study controlled for gender and age when conducting the multiple hierarchical regression analyses, because previous research has indicated that these two variables could be associated to quality of life. A significance level of .05 was used for all statistical tests.
Results

Descriptive Statistics

Mean scores, standard deviations and internal consistencies for all parent and child measures of the clinical and the control sample can be found in Table 1. All internal consistencies were higher than the acceptable value of 0.70 for Cronbach’s alpha. It is important to remark, that the control sample only reports quality of life scores and consists only of children, there is no parental control sample. Independent-Samples T tests were used to compare the mean scores in the present study to mean scores reported in previous studies. One-sample T test were used only when not all necessary information was available to conduct an Independent-Samples T test.

First, the results regarding child report will be discussed. Children and adolescents in the clinical sample reported a mean PedsQL score of 76.37 (SD = 15.17) and a mean score of 7.65 (SD = 1.70) on the life satisfaction thermometer. The mean PedsQL score in the clinical sample was found to be similar to a chronically ill sample from a previous study (M = 77.19, SD = 15.53, N = 367; t(555) = -0.64, p = .520; Varni et al., 2001). Studies using the life satisfaction thermometer are more difficult to find. However, the mean score in the clinical sample was similar to a previous study in children with diabetes (M = 7.52, SD = 1.41, N = 94; t(272) = 0.07, p = .940; de Wit et al., 2012). Children in the control sample reported a mean PedsQL score of 82 (SD = 11.94) and a mean score of 7.83 (SD = 1.45) using the life satisfaction thermometer. The mean PedsQL score in the control sample was significantly lower than a different healthy sample (M = 87.61, SD = 12.33, N = 717; t(902) = -5.58, p < .001; Varni et al., 2001).

Regarding emotion regulation, adolescents in the present study reported higher mean scores on adaptive emotion regulation (M = 5.60, SD = 1.52) than on maladaptive emotion regulation (M = 3.51, SD = 1.44). This pattern is consistent with other research using the CERQ (Garnefski et al., 2009; Garnefski and Kraaij, 2006b). However, the participants in the present study obtained significantly lower adaptive and maladaptive emotion regulation scores than a Dutch chronically ill sample described by Garnefski et al. (2009). In this sample, the mean adaptive coping score was 11.5, t(111) = - 41.19, p < .001 and the mean maladaptive coping score was 6.66, t(111) = -23.17, p < .001. These analyses were conducted using a one-sample T

7 Cronbach’s alpha could not be calculated for the life satisfaction thermometer, because this variable was computed using only one question.

8 The maladaptive coping score was based on the subscales self-blame, rumination and catastrophizing.
test, because the necessary information regarding the standard deviation for adaptive and maladaptive emotion regulation was not available.

Second, the results regarding parent report will be discussed. Keep in mind that the quality of life scores are always regarding child quality of life and not parental quality of life. Parents proxy-reported a lower mean quality of life score than the children and adolescents (PedsQL: \( M = 73.27, SD = 16.23 \); life satisfaction thermometer: \( M = 7.36, SD = 1.40 \)). PedsQL scores in the present sample are similar to findings reported in previous research (\( M = 74.22, SD = 18.40, N = 662; t(778) = -0.53, p = .60 \); Varni et al., 2001). In general, parents proxy-reported lower quality of life scores than the children themselves. There are three exceptions to this finding; children with diabetes reported lower quality of life than parents using the PedsQL and children with juvenile rheumatic disease or a transplant reported lower quality of life than parents using the life satisfaction thermometer. See Table 2 for all mean scores and standard deviations for quality of life in the different chronic illnesses in the present study.

In addition, parents reported a mean score of 91.26 (\( SD = 25.80 \)) on the frequency scale of the PIP and a mean score of 79.19 (\( SD = 25.97 \)) on the difficulty scale. These results were compared to a sample of Dutch parents of chronically ill children by Vrijmoet-Wiersma et al. (2010). The comparison sample obtained significantly higher scores on the frequency subscale (\( M = 115.4, SD = 26, N = 174; t(290) = -7.81, p < .001 \)) and the difficulty subscale (\( M = 101.7, SD = 28.5, N = 174; t(290) = -6.86, p < .001 \)). Finally, parents in the present study reported a mean score of 10.04 (\( SD = 6.69 \)) on the total HADS score. When comparing this mean score to a sample of the general population (Spinhoven et al., 1997), it was found that the comparison sample obtained a significantly lower score (\( M = 8.4, SD = 6.3, N = 199; t(315) = 2.19, p = .030 \)).
Table 1

Mean scores, standard deviations (SD) and internal consistencies (Cronbach’s α) for all child and parent measures of the clinical sample and the control sample.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Clinical sample</th>
<th>Control sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>α</td>
</tr>
<tr>
<td>Child report:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pediatric quality of life inventory</td>
<td>190</td>
<td>.90/90$^a$</td>
</tr>
<tr>
<td>Life satisfaction thermometer</td>
<td>190</td>
<td>/</td>
</tr>
<tr>
<td>Cognitive emotion regulation questionnaire</td>
<td>112</td>
<td>.82</td>
</tr>
<tr>
<td>Adaptive coping</td>
<td>112</td>
<td>.76</td>
</tr>
<tr>
<td>Maladaptive coping</td>
<td>112</td>
<td>.82</td>
</tr>
<tr>
<td>Parent report:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pediatric quality of life inventory</td>
<td>118</td>
<td>.93/91$^a$</td>
</tr>
<tr>
<td>Life satisfaction thermometer</td>
<td>118</td>
<td>/</td>
</tr>
<tr>
<td>Pediatric inventory for parents</td>
<td>118</td>
<td>.97</td>
</tr>
<tr>
<td>Frequency</td>
<td>118</td>
<td>.95</td>
</tr>
<tr>
<td>Difficulty</td>
<td>118</td>
<td>.96</td>
</tr>
<tr>
<td>Hospital anxiety and depression scales</td>
<td>118</td>
<td>.89</td>
</tr>
</tbody>
</table>

Note. * p < .05, ** p < .001

$^a$ Two Cronbach’s α are reported. The first α indicates the internal consistency regarding the child version of the PedsQL, the second α indicates the internal consistency regarding the teenager version.

$^b$ Different n in the clinical and (matched) control sample due to missing data.
Table 2
Mean scores and standard deviations for quality of life in the different chronic illnesses in the present study.

<table>
<thead>
<tr>
<th>Condition</th>
<th>n</th>
<th>PedsQL M</th>
<th>SD</th>
<th>Life satisfaction thermometer M</th>
<th>SD</th>
</tr>
</thead>
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<tr>
<td>Child report</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Juvenile rheumatic disease</td>
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<td>69.15</td>
<td>17.65</td>
<td>7.09</td>
<td>1.76</td>
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<tr>
<td>Diabetes</td>
<td>60</td>
<td>79.15</td>
<td>15.42</td>
<td>8.05</td>
<td>1.62</td>
</tr>
<tr>
<td>Inflammatory bowel disease</td>
<td>21</td>
<td>80.21</td>
<td>11.26</td>
<td>7.41</td>
<td>1.64</td>
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<tr>
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<td>14.16</td>
<td>7.72</td>
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</tr>
<tr>
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<tr>
<td>Parent report</td>
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<tr>
<td>Juvenile rheumatic disease</td>
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<tr>
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<td>66.49</td>
<td>19.58</td>
<td>7.00</td>
<td>1.97</td>
</tr>
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</table>

Correlations

There are two assumptions for using Pearson correlations; there has to be normality of data and variables of at least interval level are needed. The Central Limit Theorem states that no matter what the population distribution looks like, the sample mean will be approximately normally distributed if the sample is larger than 30 participants (Field, 2013, pp. 52-54). The clinical sample used in the present study consists of 190 participants and is therefore large enough to assume normality of data. Regarding the second assumption, all variables are measured using Likert scales. Strictly speaking, Likert scales are of ordinal level. In practice, however, Likert scales are often treated as interval scales. Taking the two assumptions into account, Pearson correlation coefficients will be used.

In Table 3, Pearson correlation coefficients for all child and parent measures for the clinical sample are reported. First, the correlations of the child measures will be discussed. The two measures for quality of life were positively correlated ($r = .38, p < .001$). The present study hypothesized that adaptive emotion regulation would be positively correlated with quality of life. Contrary to expectations, quality of life was not associated with adaptive emotion.
regulation. The results indicated a non-significant, negative relationship. On the other hand, the present study did find a significant negative correlation between maladaptive emotion regulation and quality of life. A moderate correlation was found when using the PedsQL \( (r = -.39, \ p < .001) \) and a smaller correlation was found when using the life satisfaction thermometer \( (r = -.20, \ p = .037) \). Important to note is that a significant positive correlation was found between adaptive and maladaptive emotion regulation \( (r = .33, \ p < .001) \).

Finally, the correlations for the parental report will be discussed. A large and positive correlation was found between the PedsQL and the life satisfaction thermometer \( (r = .57, \ p < .001) \). Small to moderate significant, negative correlations were found between the PedsQL and the HADS \( (r = -.20, \ p = .027) \), the PIP-difficulty subscale \( (r = -.38, \ p < .001) \) and the PIP-frequency subscale \( (r = -.50 \ p < .001) \). Using the life satisfaction thermometer, the same pattern was found, although the correlations are generally smaller \( \text{HADS: } r = -.18, \ p = .048; \text{PIP-Difficulty: } r = -.38, \ p < .001; \text{PIP-Frequency: } r = -.34, \ p < .001 \). The present study hypothesized that the two measures of parental distress (HADS and PIP) would be negatively correlated with quality of life. The results were in accordance with this hypothesis.

Table 3

*Pearson correlation coefficients for all child and parent measures for the clinical sample*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
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<td>2. Life satisf. ther.</td>
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<td></td>
<td>-.18</td>
<td>-.39**</td>
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<td>3. CERQ - Adaptive</td>
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<td>4. CERQ - Maladaptive</td>
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<tr>
<td><strong>Parent report</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1. PedsQ</td>
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<td></td>
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</tr>
<tr>
<td>2. Life satisf. ther.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. PIP - Difficulty</td>
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<td>.57**</td>
<td></td>
<td>-.38**</td>
<td>-.50**</td>
</tr>
<tr>
<td>4. PIP - Frequency</td>
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<td></td>
<td></td>
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<td>5. HADS</td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. *\( p < .05, \ **p < .001; \text{PedsQL = Pediatric quality of life inventory; CERQ = Cognitive emotion regulation questionnaire; PIP = Pediatric inventory for parents; HADS = Hospital anxiety and depression scales*
Comparison of Quality of Life Across Different Chronic Illnesses

Before conducting the analyses, it is important to note that the present study will mostly focus on child reported quality of life⁹. There are different reasons for this decision. First, child self-report is considered to be a better measure for child quality of life than parent proxy-report (Norrby et al., 2006; Varni, Limbers, & Burwinkle, 2007b). Second, the parental sample did not have a control group with parents of healthy children to compare with. Third, the child sample was considerably larger than the parental sample. Fourth, by doing so the number of analyses was kept manageable.

In the following paragraph, three statistical analyses are conducted (MANOVA, Dunnett’s test and the Tukey-Kramer test). The relevant assumptions must be checked before carrying out these analyses (Field, 2013, pp. 192-195 & 642-643). First, there has to be multivariate normality, which can be checked by inspecting the univariate normality for each dependent variable. As stated before, normality of data can be assumed in the present study, because the sample size is larger than 30. Additionally, because the present study investigates only two dependent variables, a sample size of 190 participants is adequate enough for MANOVA (which assumes that each group has more participants than there are dependent variables). Second, the dependent variables should be of at least interval level. The present study measures quality of life using Likert scales. As stated before, in practice, these are treated as interval scales. Third, the independent variable should consist of at least two categorical and independent groups. The present study used a healthy control group to compare with the clinical sample and these groups are of nominal level. Fourth, there has to be independence of observations. This assumption is met, because the participants in the control sample are independent from the participants in the chronically ill group. Fifth, the relationship between the dependent variables should be linear. This assumption was checked twice, once using a scatterplot matrix and once using a scatterplot while assessing homogeneity of variance as well (which is the sixth assumption). The assumption of linearity seems to have been met. However, the assumption of homogeneity is not that unambiguous. Therefore, a boxplot for both dependent variables was produced and these graphs seemed to indicate homogeneity of variance. The assumption of homogeneity of variance could also be checked by using the Levene’s test, however, Field (2013, p. 195) states that this test is not useful in large samples, because it can reach statistical significance even when the group variances are quite similar. The above mentioned scatterplots can be found in Appendix I. The seventh assumption is

⁹ There is one exception: both self- and parent proxy-report of quality of life will be discussed while analyzing the parental distress hypothesis.
homogeneity of covariances. This could be checked using Box’s Test, however, the same problem arises as for Levene’s test. Field (2013, p. 643) states that Box’s Test can be disregarded if the used samples are equal in size. However, then it can be assumed that Hotelling’s and Pillai’s statistics are robust. In the present study, both the clinical and the control sample consist of 190 participants. The final assumption refers to multicollinearity. Inspection of the correlations in Table 3 shows that the dependent variables only moderately correlate (between 0.30 and 0.60), indicating that there is no problem of multicollinearity.

The first hypothesis in the present study states that chronically ill children and adolescents will obtain worse QOL scores than their healthy peers. In order to investigate this hypothesis, a one-way MANOVA was conducted to compare the chronically ill group to the healthy control group. There was a statistically significant difference in quality of life between the chronically ill group and the healthy control group (Pillai’s Trace = 0.05, $F(2,372) = 8.84$, partial $\eta^2 = .05$, $p < .001$). However, univariate tests revealed that only the PedsQL scores were significantly different between the clinical and control sample ($F(1,373) = 17.46$, $p < .001$), while the life satisfaction thermometer scores were not ($F(1,373) = 1.17$, $p = .280$). Keeping in mind the mean scores of the chronically ill group ($M = 76.37$) and the control group ($M = 82$), it can be concluded that chronically ill children and adolescents obtained significantly worse QOL scores than their healthy peers, when using the PedsQL. Thus, hypothesis 1 was confirmed. However, this difference in QOL was obtained using the combination of all five illness groups. It seemed relevant to compare the different illness groups individually to the healthy control group as well. Using a Dunnett’s test (post-hoc test), it was found that only children and adolescents with juvenile rheumatic disease obtained significantly lower QOL scores than the control group. These results were obtained by using both the PedsQL ($p < .001$) and the life satisfaction thermometer ($p = .020$). Mean scores for the different illness groups and the significance levels can be found in Table 4 (see also Figure 1 for a visual representation of the data).

The present study also hypothesized that children with diabetes would report better quality of life than children with other chronic illnesses. In order to investigate this hypothesis, first, a MANOVA was executed to analyze whether the five illness groups statistically differed on the two quality of life measures. If this statistic analysis turned out to be insignificant, it would be irrelevant to conduct a post-hoc analysis. This analysis showed significant differences amongst illness groups (Pillai’s Trace = 0.11, $F(8,370) = 2.633$, $p = .008$), so consequently, all illness groups were compared using the Tukey test (Tukey-Kramer modification). This
procedure was chosen because the variances of the different study groups are assumed to be equal and the sample sizes of the different disease groups are unequal, but not very different (range 21-60). Using the PedsQL, this post-hoc procedure indicated that the diabetes group only obtained significantly higher quality of life scores than the juvenile rheumatic disease group \((p = .002)\). Furthermore, this result was not exclusively found in the diabetes group, but the IBD group \((p = .021)\) and the renal disease group \((p = .017)\) reported significantly higher quality of life scores than the juvenile rheumatic disease group as well. Using the life satisfaction thermometer, this post-hoc procedure indicated that only the diabetes group obtained significantly higher quality of life scores than the juvenile rheumatic disease group \((p = .022)\).

In conclusion, the diabetes group did not systematically obtain significantly higher quality of life scores than all other chronic illnesses (only juvenile rheumatic disease). Therefore, this hypothesis could not be confirmed.

Table 4

<table>
<thead>
<tr>
<th>Condition</th>
<th>(n)</th>
<th>(M)</th>
<th>Sig.</th>
<th>(M)</th>
<th>Sig.</th>
</tr>
</thead>
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<tr>
<td></td>
<td></td>
<td>PedsQL</td>
<td>Life satisfaction thermometer</td>
<td></td>
<td></td>
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<td>Healthy children</td>
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<td></td>
<td>7.83</td>
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<td>(.000^{**})</td>
<td>7.09</td>
<td>(.020^{*})</td>
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<td>(.523)</td>
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<td>(.865)</td>
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<td>(.982)</td>
<td>7.41</td>
<td>(.739)</td>
</tr>
<tr>
<td>Liver and kidney transplant</td>
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<td>77.13</td>
<td>(.324)</td>
<td>7.72</td>
<td>(.999)</td>
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<td>Renal disease</td>
<td>34</td>
<td>78.81</td>
<td>(.664)</td>
<td>7.82</td>
<td>1.000</td>
</tr>
</tbody>
</table>

*Note. \(* p < .05, ** p < .001; PedsQL = Pediatric quality of life inventory*
Figure 1  Histogram of the mean scores of QOL, measured by the PedsQL and the life satisfaction thermometer. All disease groups were compared to the healthy control sample.

Note. * p < .05, ** p < .005, *** p < .001 for the illness group in comparison to the healthy control group

Emotion Regulation as a Correlate of Quality of Life

Association between emotion regulation and quality of life. Before conducting multiple hierarchical regression analyses, the assumptions of this statistical analysis were checked (Field, 2013, pp. 309-312 & 348-350). First, as stated before, normality can be assumed in the present study based on the Central Limit Theorem. The residuals of the regression line have to be normally distributed as well. This assumption was checked by looking at Normal P-P Plots and was assumed to be met. Second, the variables should be of at least interval level. As stated before, the variables in the present study were measured using Likert scales and these are treated as interval scales. Third, scatter plots indicate that the assumptions of linearity and homoscedasticity were met as well. Fourth, there should be no auto-correlation. This assumption was checked by using the Durbin-Watson statistic, all $d$’s were deemed adequate (range 1.53-1.99). Fifth, there should be no multicollinearity. Variance-inflation factors of all regression analysis were small (range 1.00-2.07), indicating that there was no problem of collinearity (see Appendix J for the scatter plots and Normal P-P Plots that were used to prove that the assumptions for the regression analysis with emotion regulation were met in the present study). These assumptions were also checked for the parental distress regressions. The same results were obtained and the relevant scatter plots and Normal P-P Plots were added in Appendix K.
Hierarchical regression analyses were performed to examine the unique role of emotion regulation in explaining quality of life scores, after controlling for gender and age. In a first step gender (female was coded as 0, male was coded as 1) and age were entered, to control for the effect of sociodemographic variables. In the next step adaptive emotion regulation and maladaptive emotion regulation were entered. This regression analysis was done twice, once using the PedsQL as dependent variable and once using the life satisfaction thermometer as dependent variable. Variance-inflation factors (VIF) varied between 1.01 and 1.18, indicating that there was no problem of collinearity. Results from this regression analysis can be found in Table 5. Using the PedsQL as dependent variable, it was found that quality of life was not predicted by the sociodemographic variables. Emotion regulation on the other hand, did contribute to the explanation of quality of life and accounted for 13.2 % of the variance in quality of life ($\Delta F(2,107) = 8.66, p < .001$). However, only maladaptive emotion regulation significantly contributed to the explanation of quality of life ($\beta = -.33, p = .001$), indicating that adolescents with higher levels of maladaptive emotion regulation, reported lower levels of quality of life. The explanation of adaptive emotion regulation was non-significant ($\beta = -.09, p = .363$). Using the life satisfaction thermometer as dependent variable, no significant predictors for quality of life were found ($\Delta F(2,107) = 1.71, p = .19$).

Table 5

<table>
<thead>
<tr>
<th>Dependent Variable</th>
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<th>Predictor</th>
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<th>$\Delta R^2$</th>
<th>Adj $R^2$</th>
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<td>0.15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maladaptive emotion regulation</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life</td>
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<td>Gender</td>
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<td>0.02</td>
<td>0.01</td>
</tr>
<tr>
<td>(Life Satisfaction Thermometer)</td>
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<td>Age</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Adaptive emotion regulation</td>
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<td>0.03</td>
<td>0.02</td>
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<tr>
<td></td>
<td></td>
<td>Maladaptive emotion regulation</td>
<td>-0.17</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. * $p < .05$, ** $p < .01$, *** $p < .001$; gender is coded as follows: female=0, male=1; standardized $\beta$’s from the last step in the analyses are displayed.
Moderation effect. The second hypothesis investigates whether chronic illness is a moderator in this association. To investigate this hypothesis, a regression analysis was conducted (using the GLM menu dialog). The regression analysis consisted of quality of life as dependent variable, gender and illness group as fixed factors and gender and emotion regulation as covariate. Main effects that were included in the model were gender, age, emotion regulation and illness group. An interaction term was created for illness group and emotion regulation, to reflect the difference in effect of emotion regulation on quality of life in the different illness groups. The analyses were done separately for adaptive emotion regulation and maladaptive emotion regulation.

First, the results using the PedsQL to measure quality of life will be reported. The interaction term was not significant for adaptive emotion regulation \((F(4,100) = 0.81, p = .520)\), nor for maladaptive emotion regulation \((F(4,100) = 2.43, p = .052)\), indicating that there is no evidence for a moderation effect. It is important to note that maladaptive emotion regulation was close to statistical significance. Because of the relevance of this hypothesis for the clinical practice, it seemed interesting to take a closer look at the parameter estimates of the different illness categories. The directions of these associations were in line with the expectations, namely, that more maladaptive emotion regulation was associated with lower quality of life in all illness groups. The interaction was strongest in the juvenile rheumatic disease group \((b = -6.68, p < .001)\) and in the IBD group \((b = -11.04, p = .013)\). The interaction was smaller in the diabetes group \((b = -1.92, p = .122)\), the transplant group \((b = -1.63, p = .389)\) and the renal disease group \((b = -3.18, p = .199)\). However, bear in mind that the (general) interaction term did not reach statistical significance, these results are therefore reported purely out of interest and out of possible clinical relevance.

Second, the results using the life satisfaction thermometer to measure quality of life will be reported. The interaction term was not significant for neither adaptive emotion regulation \((F(4,100) = 0.59, p = .670)\) nor maladaptive emotion regulation \((F(4,100) = 0.25, p = .910)\), indicating that there is no evidence for a moderation effect. In conclusion, it can be stated that the hypothesis regarding a moderation effect could not be confirmed.

Parental Distress as a Correlate of Quality of Life

Hierarchical regression analyses were performed to examine the unique role of parental distress in explaining quality of life scores, after controlling for gender and age. Multiple regression analyses were done for the PIP and the HADS separately. The regression analysis
using the PIP contained the following steps. In a first step, gender (female was coded as 1, male was coded as 2) and age were entered, to control for the effect of sociodemographic variables. In the next step, the difficulty subscale (PIP) and the frequency subscale (PIP) were entered.

The regression analysis using the HADS contained the following steps. In a first step, gender (female was coded as 1, male was coded as 2) and age were entered, to control for the effect of sociodemographic variables. In the next step, the total score of the HADS was entered. Both regression analyses were done twice, once using the PedsQL as dependent variable and once using the life satisfaction thermometer as dependent variable. Initially, these analyses were conducted using parent proxy-report of child quality of life. Afterwards, this was done again, this time using child self-report of quality of life. In order to do this, a database was made linking the parental distress scores to the quality of life scores as reported by the child or adolescent. This database contained 92 parent-child pairs. It seemed interesting to compare the two analyses and examine if different results were obtained when using different respondents of quality of life.

**Parent proxy-report of child quality of life.** Results from this regression analysis can be found in Table 6. First, the regression analyses using the PIP to measure parental distress will be discussed. Variance-inflation factors varied between 1.01 and 2.07, indicating that there was no problem of collinearity. Using the PedsQL as dependent variable, it was found that the sociodemographic variables did not predict quality of life. Parental distress, however, did contribute to the explanation of quality of life and accounted for 25.3 % of the variance in quality of life ($\Delta F(2,113) = 19.25, p < .001$). However, only the frequency of difficult events significantly contributed to the explanation of quality of life ($\beta = -.48, p < .001$), while the reported difficulty associated with these events did not ($\beta = -.05, p = .698$). These results indicate that parents who experience more difficult events, report their child’s quality of life scores to be lower. The perceived difficulty associated with these stressful events did not seem to be related to the child’s quality of life.

Using the life satisfaction thermometer as dependent variable, different results were obtained. A negative relationship was found between age and quality of life ($\beta = -.18, p = .04$), indicating that parents rated older children to have lower quality of life. Parental distress was found to be a significant predictor of quality of life as well and accounted for 16 % of the variance in quality of life ($\Delta F(2,113) = 11.11, p < .001$). Here, the results were reversed compared to the previous findings. The perceived difficulty associated with stressful events contributed to the explanation of quality of life ($\beta = -.26, p = .039$), while frequency of difficult
events did not ($\beta = -0.18, p = 141$). These results indicate that parents who experience more difficulty with certain events, reported their child’s quality of life to be lower than parents who experience less difficulty with certain events. Parents who experience more stressful events, did not report their child’s quality of life to be lower.

Second, the regression analyses using the HADS to measure parental distress will be discussed. Variance-inflation factors varied between 1.000 and 1.001, indicating that there was no problem of collinearity. Using the PedsQL as dependent variable, it was found that the sociodemographic variables did not predict quality of life. Parental distress on the other hand, did contribute to the explanation of quality of life ($\beta = -0.20, p = 0.028$) and accounted for 4.2 % of the variance in quality of life ($\Delta F(1,114) = 4.98, p = 0.028$). These results indicate that parents who experience more parental distress, report their child’s quality of life scores to be lower.

Using the life satisfaction thermometer as dependent variable, similar results were obtained. The results showed that the sociodemographic variables did not predict quality of life. Parental distress, however, was found to be a significant predictor of quality of life ($\beta = -0.18, p = 0.046$) and accounted for 3.4 % of the variance in quality of life ($\Delta F(1,114) = 4.08, p = 0.046$). As stated above, these results indicate that parents who experience more parental distress, report their child’s quality of life to be lower.

**Child self-report of quality of life.** Results from this regression analysis can be found in Table 7. First, the regression analyses using the PIP to measure parental distress will be discussed. Variance-inflation factors varied between 1.01 and 2.07, indicating that there was no problem of collinearity. Using the PedsQL as dependent variable, it was found that the sociodemographic variables did not predict quality of life. Parental distress on the other hand, did contribute to the explanation of quality of life and accounted for 8.1 % of the variance in quality of life ($\Delta F(2,87) = 3.88, p = 0.024$). However, only the frequency of difficult events contributed to the explanation of quality of life ($\beta = -0.33, p = 0.029$), while the perceived difficulty associated with these stressful events did not ($\beta = -0.06, p = 0.696$). These results indicate that children report lower quality of life if their parents experience more stressful events. The perceived difficulty associated with these stressful events did not seem to be associated with the child’s quality of life. These results show the exact same pattern as the results using parent proxy-report of child quality of life. There is one important difference, namely, that the strength of this reported relationship is a lot stronger when using parent proxy-report of child quality of life.
Using the life satisfaction thermometer as dependent variable, different results were obtained. The sociodemographic variables were found to account for 8.4 % of the variance in quality of life ($\Delta F(2,89) = 4.07, p = .02$). However, only a significant, negative relationship was found between age and quality of life ($\beta = -.27, p = .009$), indicating that older children rated their quality of life to be lower than younger children. Parental distress was not found to be a significant predictor of child quality of life ($\Delta F(2,87) = 1.38, p = .258$). This result differs from the outcome that was obtained using parental report of child quality of life, where parental distress was found to be a significant predictor of quality of life.

Second, the regression analyses using the HADS to measure parental distress will be discussed. Variance-inflation factors varied between 1.00 and 1.02, indicating that there was no problem of collinearity. Using the PedsQL as dependent variable, neither the sociodemographic variables ($\Delta F(2,89) = 0.67, p = .513$) nor parental distress ($\Delta F(1,88) = 2.77, p = .10$) were found to be predictors of quality of life. These results differ from the results obtained using parent proxy-report of child quality of life, where parental distress was found to be a significant predictor of quality of life.

The use of the life satisfaction thermometer as dependent variable, revealed a different outcome. The sociodemographic variables were found to account for 8.4 % of the variance in quality of life ($\Delta F(2,89) = 4.07, p = .02$). However, only a significant, negative relationship was found between age and quality of life ($\beta = -.27, p = .01$), indicating that older children rated their quality of life to be lower than younger children. Parental distress was not found to be a significant predictor of child quality of life ($\Delta F(1,88) = .07, p = .791$). These results differ from the results obtained by using parent proxy-report of child quality of life, where parental distress was found to be a significant predictor of quality of life and the sociodemographic variables were not.
Table 6

Results of hierarchical regression analysis of parental distress and quality of life – parental report of child QOL

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Step</th>
<th>Predictor</th>
<th>β</th>
<th>ΔR²</th>
<th>Adj R²</th>
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</thead>
<tbody>
<tr>
<td>Quality of life (PedsQL)</td>
<td>1</td>
<td>Gender</td>
<td>0.02</td>
<td>0.00</td>
<td>-0.01</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Age</td>
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<td></td>
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<tr>
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<tr>
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<td></td>
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<td>HADS – Total</td>
<td>-0.18*</td>
<td>0.03*</td>
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</tr>
</tbody>
</table>

Note. * p < .05, ** p < .01, *** p < .001; gender is coded as follows10: female=1, male=2; standardized β’s from the last step in the analyses are displayed.

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10 Keep in mind that different datasets were used for child and parent report. This is why a different gender coding is reported (in comparison with the emotion regulation hypothesis).
Table 7

Results of hierarchical regression analysis of parental distress and quality of life – child report of QOL

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Step</th>
<th>Predictor</th>
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<th>ΔR²</th>
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<td>Age</td>
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<tr>
<td></td>
<td>2</td>
<td>HADS – Total</td>
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<td>0.00</td>
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</table>

Note. * p < .05, ** p < .01, *** p < .001; gender is coded as follows: female=1, male=2; standardized β’s from the last step in the analyses are displayed.
**Discussion**

The present study had two aims. First, quality of life differences were investigated across different childhood chronic illnesses, i.e., juvenile rheumatic disease, diabetes, inflammatory bowel disease, liver and kidney transplantation and renal disease. It was hypothesised that (1) children and adolescents with a chronic illness have worse quality of life than their healthy peers and (2) that children with diabetes have better quality of life than transplant patients, renal disease patients and children with rheumatic disease and inflammatory bowel disease. Second, emotion regulation and parental distress were investigated as possible correlates of quality of life. It was hypothesised that (1) children and adolescents with a chronic illness who use more adaptive emotion regulation strategies report better quality of life than those who use less adaptive emotion regulation strategies (protective factor), (2) that chronic illness is a moderator in this association (moderation effect), and (3) that chronically ill children and adolescents with parents who experience a lot of parental distress have worse quality of life scores than their chronically ill peers with parents who experience less parental distress (risk factor). The present study used self and parent report questionnaires to investigate the hypotheses (cross-sectional design).

**Comparison of Quality of Life Across Different Chronic Illnesses**

Children and adolescents in the present study with either juvenile rheumatic disease, diabetes, IBD, a transplant or renal disease, had similar quality of life as chronically ill children described in previous studies (Limbers et al., 2011; Varni et al., 2007a). However, in the present study, children with renal disease had higher quality of life (child self-report) and children with juvenile rheumatic disease had lower quality of life (parent-proxy report) than the previous studies. It is also striking that parents generally reported lower quality of life than the children. This finding is in accordance with previous studies (Dey, Landolt, & Mohler-Kuo, 2013; Ingerski et al., 2010). However, in the present study, children with diabetes (using the PedsQL) and children with juvenile rheumatic disease or a transplant (using the life satisfaction thermometer) reported lower quality of life than the parents, although the differences in quality of life were rather small.

The present study provided support for the first hypothesis, as the results indicated that the chronically ill group had significantly lower quality of life than the healthy control group. This finding is similar to lots of other research (e.g., Upton et al., 2005; Varni, Burwinkle, Seid, & Skarr, 2003; Varni et al., 2007a; Varni et al., 2001). It is important to remark, that this result was only found with the PedsQL and not with the life satisfaction thermometer. Another
important observation, is that the difference in quality of life between the chronically ill and the healthy control group was observed using the combination of all five illness groups. However, by comparing every illness group to the healthy control group individually, it was found that only children with juvenile rheumatic disease had significantly lower quality of life than the healthy control group (both on the PedsQL and the life satisfaction thermometer). This finding regarding juvenile rheumatic disease was in line with previous research (Bomba et al., 2013; Gutiérrez-Suárez et al., 2007). The finding that children with diabetes, a kidney or liver transplant, IBD and renal disease had similar quality of life as healthy controls, was expected for diabetes (De Wit et al., 2007; Laffel et al., 2003; Upton et al., 2005) and not that surprising with regard to transplant patients (Sundaram et al., 2007; Taylor et al., 2005). However, most studies regarding IBD (De Boer et al., 2005; Haapamäki et al., 2001; Kunz et al., 2010) and renal disease (Gerson et al., 2010; Goldstein et al., 2006; McKenna et al., 2006) report lower quality of life than a healthy control group. It is important to take into account the fact that the five illness groups only consisted of a small number of participants (range 21-60). Especially the IBD (n = 21), transplant (n = 27) and renal disease group (n = 34) had small sample sizes, while the control group comprised 190 participants. It is possible that the sample sizes were too small to find significant differences between the five illness groups. On the other hand, the small sample size in the juvenile rheumatic disease group (n = 48) did result in a significant difference and some studies (though a minority) agree with the finding that children with IBD and renal disease have similar quality of life as healthy children (Eijsermans et al., 2004; Heath et al., 2011; Loonen et al., 2002).

The second hypothesis was not supported by the present study, as the results did not indicate that children with diabetes had better quality of life than all the other chronic illnesses (only juvenile rheumatic disease). This finding was not expected based on the research of Wagner et al. (2005) and Upton et al. (2005). It is however in line with the studies of Ingerski et al. (2010) and Taylor et al. (2009), who respectively found no significant difference in self-reported HRQOL across IBD, type 1 diabetes and kidney transplant and no significant difference in HRQOL between liver transplant and diabetes. It is important to keep in mind that almost no studies have explicitly compared chronic illnesses to each other. Most studies compare one chronic illness to a control group or compare one chronic illness to a group of other chronic illnesses (not separately) and in that way conclude that chronic illnesses have different quality of life. To our knowledge, only a handful of studies have statistically compared one or more chronic illnesses with each other (Ingerski et al., 2010; Kunz et al., 2010; Limbers et al., 2011; Taylor et al., 2009; Wagner et al., 2005).
Different than our expectations, children and adolescents with juvenile rheumatic disease had lower quality of life than children with diabetes, inflammatory bowel disease and renal disease (using the PedsQL). This result is in accordance with the previous finding that juvenile rheumatic disease was the only chronic illness with lower quality of life in comparison with the healthy control group. In the specific sample investigated in the present study, namely, Flemish children and adolescents with a chronic illness who are treated in the University Hospital of Ghent, it seems that most children with a chronic illness do generally well on quality of life. The present study found no difference in quality of life between healthy children and children with diabetes, IBD, renal disease or a transplant, as well as no significant differences across these chronic illnesses. These findings seem to suggest that having a chronic illness does not automatically result in lower quality of life. Furthermore, in agreement with Varni et al. (2007a), the results also suggest that chronic illnesses have differential effects on quality of life, as it was found that children with juvenile rheumatic disease had lower quality of life than the healthy group. A possible reason for the lower quality of life could be that this specific illness has a lot of serious consequences for the child. The clinical practice shows that children with juvenile rheumatic disease should avoid certain physical activities, which puts a strain on their social life. They also have periods of intense pain which sometimes results in missing school, which again puts a strain on their social life and academic career as well. This has also been put forward by Garnefski et al. (2009). These are factors that are not that prominent in the other chronic illnesses.

In conclusion, while investigating the first research question, the present study found support for the statement that children and adolescents with specific chronic illnesses have better quality of life than peers with other chronic illnesses. Children with diabetes, inflammatory bowel disease and renal disease had better quality of life than children with juvenile rheumatic disease. It is important to keep in mind that the results of the present study were obtained in a Flemish sample of children and adolescents with a chronic illness, all recruited in the University Hospital in Ghent. It is probable that different countries provide different care for chronically ill children and adolescents. This, together with the fact that there are many different conceptualisations and measures for quality of life, could attribute to the fact that a lot of conflicting results regarding quality of life in chronically ill samples have been reported.

**Emotion Regulation as a Correlate of Quality of Life**
The present study did not provide support for the hypothesis that chronically ill children who use more adaptive emotion regulation strategies have better quality of life than those who use less adaptive strategies. Before discussing the results further, it is important to realize that it is possible for children and adolescents to use both adaptive and maladaptive strategies. Therefore, it is not as easy as to make a distinction between children who use adaptive emotion regulation versus children who use maladaptive emotion regulation. Instead, on an individual level, it is more the ratio of adaptive to maladaptive emotion regulation that is important. However, on a group level (as investigated in the present study), the contribution of adaptive emotion regulation in the explanation of quality of life, can be investigated independently from the contribution of maladaptive emotion regulation and vice versa.

Different than our expectations, the present study found that children who use a lot of maladaptive emotion regulation strategies, have lower quality of life than children who use less maladaptive strategies. However, using little maladaptive emotion regulation does not automatically mean that you use more adaptive emotion regulation. The results in the present study seem to suggest that maladaptive emotion regulation could be a risk factor for quality of life, instead of adaptive emotion regulation being a protective factor. However, no definitive conclusions can be made about this, due to the cross-sectional nature of the study. Longitudinal research is needed to explore the direction of the relationship between maladaptive emotion regulation and quality of life. If maladaptive emotion regulation turns out to be a risk factor for quality of life in longitudinal research, caregivers in the clinical practice could focus on teaching chronically ill children and adolescents better alternatives for maladaptive emotion strategies, which could ameliorate their quality of life.

The present study had expected adaptive emotion regulation to be positively related to quality of life. However, it was found that adaptive emotion regulation was unrelated to quality of life and maladaptive emotion regulation was negatively related to quality of life. A first possible explanation for this finding, is that maladaptive emotion regulation is simply more important in the explanation of quality of life than adaptive emotion regulation. It is possible that maladaptive emotion regulation is a risk factor for quality of life, but adaptive emotion regulation is not a protective factor. Previous studies have shown that it is possible to find an effect for only maladaptive or adaptive emotion regulation, without also reporting the other strategy to be significant (Miklósi et al., 2013; Vanderhasselt et al., 2014). Furthermore, a meta-analysis by Aldao, Nolen-Hoeksema, and Schweizer (2010) has concluded that maladaptive
emotion regulation strategies have a stronger association with psychopathology than adaptive emotion regulation strategies. This statement is in line with what was found in the present study.

A second possible explanation for the findings, is that the measure for adaptive emotion regulation is not adequate. A possible indication for this statement is that a positive correlation was found between adaptive and maladaptive emotion regulation, while a negative correlation was expected. In addition, Miklóse et al. (2013) state, that the adaptive strategies of the CERQ are quite heterogeneous and not all strategies have consistently been found to be adaptive. It is possible that a strategy can be adaptive or maladaptive, depending on the situation, which has been proposed before (Compas, 1987). It is important to note, however, that other research has used the same distinction between adaptive and maladaptive emotion regulation based on the CERQ. Most of these studies have not reported problems with the used measure for adaptive emotion regulation (Besharat & Shahidi, 2014; Hoorelbeke et al., 2016; Vanderhasselt et al., 2014), only Miklóse et al. (2013) made the same remark as in the present study. It is important to keep in mind that the four above mentioned studies are all carried out using adult samples. The sample used in the present study consists of children and adolescents with a chronic illness. It is possible that this positive correlation between adaptive and maladaptive emotion regulation is specific for the sample being investigated. The children and adolescents in the present study experience a lot of stress in their everyday lives, because of their chronic illness. As a consequence, it is probable that they have to use more emotion regulation to deal with the stress related to their chronic illness than healthy children (and adolescents). Keeping this in mind, it is not unlikely that they show more adaptive and maladaptive emotion regulation, which could be the reason for this correlation. Future research is needed to clarify this question.

The second hypothesis was not supported by the present study, as the results indicated that chronic illness was not a moderator in the association between emotion regulation and quality of life. This means that the relation between emotion regulation and quality of life is similar for all five chronic illnesses. However, it seems important to mention that this analysis was marginally significant. Because of the clinical relevance of this hypothesis and because the number of participants in each illness group was rather low (which reduces the chance of finding a significant result), it seems relevant to briefly consider these results. The present study seemed to suggest that children with juvenile rheumatic disease and IBD who use a lot of maladaptive emotion regulation strategies, have lower quality of life than children with diabetes, a transplant or renal disease who use the same level of maladaptive emotion regulation. Future research should further investigate this hypothesis in larger samples and with different chronic
illnesses, because if this finding turns out to be significant, extra attention should be given to maladaptive emotion regulation strategies in children with juvenile rheumatic disease and IBD. Especially because the present study has already shown that children with juvenile rheumatic disease have lower quality of life than healthy controls. On the other hand, the present study used a cross-sectional design, which means that it is not known which direction the association is in. It is still possible that lower quality of life leads to more use of maladaptive emotion regulation strategies instead of the other way around.

In conclusion, emotion regulation is related to quality of life. However, it was found that only maladaptive emotion regulation was relevant, while adaptive emotion regulation was not. Therefore, instead of saying that emotion regulation is a correlate of quality of life, it is better to say that maladaptive emotion regulation is a correlate of quality of life. As stated before, not a lot of studies have investigated the role of emotion regulation in quality of life in pediatric chronically ill samples. The findings in the present study are in line with Garnefski et al. (2009), but it is not exactly clear whether the findings by Graue et al. (2004) are completely similar to the present study. This study mainly found negative associations between quality of life and emotion regulation strategies. However, because they used different measures for emotion regulation, it is not always clear if the reported strategies would fall under adaptive or maladaptive emotion regulation in the present study. This difficulty has been acknowledged by Compas et al. (2001) as well. For instance, active coping, mental disengagement and behavioral disengagement (Graue et al., 2004) cannot be categorized as adaptive or maladaptive emotion regulation that easily. Contrary to our findings, Jaser and White (2010) and Edgar and Skinner (2003) did find adaptive emotion regulation to be associated with better quality of life (or well-being). However, the same remark can be made as with the previous study. To our knowledge, no previous studies have investigated chronic illness as a moderator in the relationship between emotion regulation and quality of life. A final remark, is that it is important to note that no significant results were obtained using the life satisfaction thermometer.

**Parental Distress as a Correlate of Quality of Life**

Parents in the present study, experienced less parental stress than parents of chronically ill children described in a different study (Vrijmoet-Wiersma, 2010). However, this comparison study contained parents of children with cancer, so it is possible that they experience more stress than parents of children with other chronic illnesses. Studies by Fredericks et al (2007) and Guilfoyle, Denson, Baldassano and Hommel (2012) supported this statement, they reported different levels of parental stress for different chronic illnesses. The same remark can be made
for emotional distress in parents of chronically ill children. It seems plausible that some chronic illnesses in children will lead to more emotional distress in parents than other illnesses, this could depend on the severity of the chronic illness, the impact on the family and child, the effects of the disease on the long term and so on. This idea is in line with the findings of van Oers et al. (2014). They reported different levels of emotional distress for every chronic illness. To conclude, it might not be that relevant to compare mean scores with previous studies, unless the sample of chronic illnesses is quite similar.

The present study decided to analyze the relationship between parental distress and quality of life, using both parent proxy-report and self-report of child quality of life. The reasoning behind this, was that it would be interesting to see if the results were similar. It seemed plausible that the level of parental distress could influence the way parents view their child’s quality of life, for instance, parents who experience a lot of parental distress could report their child to have lower quality of life, while the child itself might not report a lower quality of life. The present study was not the first to put forward this notion, Davis, Mackinnon and Waters (2012) acknowledged this as well. It was expected that chronically ill children and adolescents in families with a lot of parental distress, would have worse quality of life than their chronically ill peers in families with less parental distress. The results supported this hypothesis, however, a few differences were found between parent-proxy and self-report of quality of life.

When parents rated their child’s quality of life, parental distress was found to be negatively related to quality of life using all measures (PIP, HADS, PedsQL and life satisfaction thermometer). Thus, it was found that parents with high levels of parental distress, reported their children to have lower quality of life than children of parents with lower levels of parental distress. This association was stronger when the PIP was used to measure parental distress, instead of the HADS. However, there were a couple of peculiar results as well. The results with the PedsQL showed that only the frequency of stressful events was related to quality of life, and not the difficulty associated with these events. The life satisfaction thermometer showed the opposite result and reported a negative relationship between age and quality of life as well, revealing that parents rated older children to have lower quality of life (using the PIP). When children rated their quality of life, parental distress was also found to be negatively related to quality of life, but only while using the PedsQL and the PIP. Again, only the frequency of stressful events was significantly related to quality of life. It is notable that a negative relationship between age and quality of life was found here as well, again only using the life satisfaction thermometer, but for both the PIP and the HADS. This means that older children
rated their quality of life to be lower than younger children, according to the life satisfaction thermometer. It has to be noted that the strength of the association between parental distress and quality of life was a lot lower with self-report of quality of life (only 8% of the variance in quality of life was explained by the PIP instead of 25% for parent report).

These results seem to suggest that parents who experience a lot of parental distress, do indeed rate their child’s quality of life to be lower than it actually is. Even so, it is important to note that parental distress is still associated with quality of life using child report. The results may be smaller, but are still significant. The findings regarding parent and child report taken together, suggest that parental distress could be a risk factor for quality of life. However, as stated before, a cross-sectional design cannot explore the direction of the association between parental distress and quality of life. It is still a possibility that worse quality of life leads to more parental distress, instead of the other way around. Yet there already is some support for the notion that parental distress is a risk factor. Wu et al (2014) found parenting stress to be a predictor of lower child quality of life in a prospective, longitudinal study. However, these results should be replicated in other longitudinal studies. If parental distress does turn out to be a risk factor for worse quality of life, reducing the level of stress in parents could ameliorate the quality of life in the chronically ill child or adolescent.

The finding that parental distress was negatively related to child quality of life in a pediatric chronically ill sample, was in line with previous findings (Herzer et al., 2011; Kazak & Barakat, 1997; Laffel et al., 2003; Wu et al., 2014). The finding that weaker results were found using the HADS as measure for parental distress, was in line with a study by Davis et al. (2012). This study found a negative association between parent proxy-report of quality of life and parental depression, but concluded that this result was quite weak. Regarding the association between age and quality of life, it is important to note that a couple of previous studies have reported a similar finding, both using parent proxy-report (Gerson et al., 2010; Varni et al., 2007a) and self-report of quality of life (Norrby et al., 2006; Varni et al., 2007a; Wagner et al., 2005). However, these studies used a questionnaire (PedSQL, KINDL-R or CHQ) instead of a single item question (life satisfaction thermometer). Yet the present study did not report an association between age and quality of life using the PedSQL, which is not in line with above mentioned research. On the other hand, this finding is similar to previous studies by Laffel et al. (2003) and Alonso et al. (2008) where no age difference was found. The fact that gender did not influence quality of life was in line with previous research (Alonso et al., 2008; Haapamäki et al., 2001; Laffel et al., 2003; Lundberg et al., 2012; Norrby et al., 2006; Varni et al., 2007a),
however, some studies did report an age difference in quality of life (De Boer et al., 2005; Gerson et al., 2010; Upton et al., 2005; Wagner et al., 2005).

In conclusion, it can be said that parental distress is a correlate of quality of life. However, a few comments have to be made. First, this association is stronger when parents rate their child’s quality of life. Future research should focus on child measures, because parent proxy-report of quality of life seems to be (at least partly) influenced by the level of parental distress. Second, the results show a stronger association between quality of life and parental distress while using the PIP. Moreover, using child report, no significant results were found for the HADS at all. A possible explanation for the difference between those two measures, is that the PIP is a better measure for parental distress than the HADS. An alternative explanation is that the HADS measures a specific component of parental distress that is not that strongly related to quality of life. Future research is needed to clear out this issue. Third, the frequency of stressful events seems to be more important in the association with quality of life than the perceived difficulty associated with those events. Thus, the more stressful events that occur in a family, the lower the quality of life of the child is. Finally, it seems that the PedsQL obtains stronger results than the life satisfaction thermometer. This has been found with all three research questions, which suggests that this single item measure might not be the best measure for quality of life. Furthermore, most researchers prefer to use a multiple item questionnaire, which makes it difficult to compare the results of the present study to previous research. The life satisfaction thermometer may be of better use in the clinical practice, where a quick assessment of quality of life is useful.

**Implications of the Present Study**

In terms of theoretical implications, the present study adds to the existing literature by comparing quality of life in a Flemish sample across five chronic illnesses. In addition, maladaptive emotion regulation and parental distress were found to be correlates of quality of life in this chronically ill sample. Furthermore, the results suggest that it is better to use self-report of quality of life while investigating possible correlates of quality of life. The present study has clinical implications as well. First, it was shown that the juvenile rheumatic disease group had lower quality of life than the other chronic illness. These results suggest that children with juvenile rheumatic disease experience more difficulties regarding their illness, which could then lead to lower quality of life. The clinical practice should be more attentive to this illness group and perhaps children and adolescents with this chronic illness could be monitored more closely. Second, the present study suggests that maladaptive emotion regulation and parental
distress might be risk factors for worse quality of life. These suggestions have to be proven in longitudinal research, although one prospective study already found evidence for parental distress to be a risk factor of quality of life (Wu et al., 2014). If future research establishes that these two correlates are risk factors for quality of life, then these results have important clinical implications. Caregivers in the clinical practice could develop interventions that focus on teaching chronically ill children and adolescents better alternatives for maladaptive emotion regulation strategies. Interventions specifically targeting parents could be developed as well, these interventions could focus on reducing the stress levels in parents of children and adolescents with a chronic illness. These interventions could ameliorate the quality of life in the chronically ill child or adolescent (but only if these correlates turn out to be predictors of quality of life in longitudinal research).

Limits and Strengths of the Present Study

There are some limitations in the present study that must be considered. First, it is not known how many participants chose not to participate in the present study. Furthermore, there is no information about drop-out. Many participants agreed to participate but never filled in the questionnaires, the reason is not known. Second, due to the cross-sectional nature of the present study, no definitive conclusions can be made about the direction of the relationship between quality of life and parental distress or emotion regulation. Longitudinal research is needed to explore the causality of these associations. Third, more mothers than fathers participated in the present study (69% mothers) and the present study did not differentiate between them. However, it is possible that mothers and fathers experience different levels of parental distress and/or that the association with quality of life could be different depending on the parental respondent. Future research is needed to further explore this. Fourth, the number of participants in each illness group was rather small (range 21-60) and only patients from Ghent University Hospital were included. In addition, mainly parents with high socioeconomic status participated in the present study; most parents reported having high to very high education and being a clerk, an assistant, self employed or working at senior management. Furthermore, the generalization of the findings are limited to the five chronic illnesses used in the present study. Fifth, the present study used questionnaires and a possible problem with questionnaire studies is that the participants could be inclined to give socially desirable answers. The present study tried to minimize this possible problem by making all answers fully anonymous. Another remark, is that there might be some shortcomings with the measures used in the present study. For instance, the HADS obtained weaker results than the PIP, it is a possibility that the measure for adaptive emotion regulation could be inadequate and the life satisfaction thermometer seems to be less
useful in scientific research than expected. These findings have been discussed in the paragraphs above. Sixth, the mean adaptive and maladaptive emotion regulation scores in the present study were a lot lower than a healthy control sample and a Dutch sample consisting of children with juvenile rheumatic disease. Future research should investigate adaptive and maladaptive emotion regulation scores in different illness samples.

Despite these limitations, the present study has several strengths as well. First, the present study adds to the existing literature in several ways. Not a lot of studies had compared quality of life scores across different chronic illnesses. The present study investigated and compared quality of life in a Flemish sample containing children and adolescents with juvenile rheumatic disease, diabetes, inflammatory bowel disease, a liver or kidney transplant and renal disease. In addition, only a couple of studies have investigated possible correlates of quality of life in pediatric chronically ill samples. The present study added to the literature by investigating whether emotion regulation and parental distress were correlates of quality of life in a Flemish sample consisting of chronically ill children. Second, the present study had access to a control group that was matched to the present study by gender and age. Third, the present study combined child and parent report, which made it possible to compare certain results (for instance, the analysis regarding parental distress as a correlate of quality of life). This led to important insights regarding parent proxy-report of quality of life. Fourth, the total chronically ill group consisted of 190 children and adolescents and the total parental group consisted of 118 parents, which can be considered to be moderate sample sizes.

**Future Research**

Different suggestions can be made for future research. First, future studies should confirm the results found in the present study, while focusing on other chronic illnesses, different countries and participants with diverse socioeconomic backgrounds. Moreover, the association between adaptive emotion regulation and quality of life should be clarified in future studies. Furthermore, the moderator hypothesis from the present study should be reinvestigated in larger samples. It would be relevant to the clinical practice to learn if chronic illness turns out to be a moderator in the relationship between emotion regulation and quality of life. Second, future research should confirm the results while using a longitudinal design. This way, conclusions can be made about the direction of the associations that were found in the present study. Third, more correlates (or predictors when longitudinal research is being used) of quality of life should be investigated. Not all variance in quality of life can be explained by the correlates investigated in the present study, which suggests that emotion regulation and parental
distress are probably not the only correlates relevant for quality of life. Fourth, future studies should make a distinction between maternal and paternal distress scores and investigate whether different conclusions can be made using different respondents. Fifth, future research should split up children and adolescents and investigate whether age is related to quality of life. Sixth, future research should use different measures to assess the three variables in the present study to see if the results are robust. In addition, future studies should investigate whether the adaptive emotion regulation scale from the CERQ is adequate for measuring adaptive emotion regulation.

Conclusion

The results of this cross-sectional study extend our knowledge about quality of life in chronically ill children and adolescents in Belgium. First, children and adolescents with juvenile rheumatic disease obtained significantly lower quality of life than children with diabetes, inflammatory bowel disease, renal disease and a healthy control group. No significant difference was found with the transplant group. Second, maladaptive emotion regulation was found to be negatively related to quality of life, however, chronic illness was not a moderator in this association. Finally, parental distress was found to be negatively related to quality of life as well. This association turned out to be stronger using parent proxy-report of quality of life, suggesting that the parental distress score influenced the way parents view their child’s quality of life.
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