

‘On Your Own Feet’ Adaptive tasks of adolescents with chronic illness or disability: A content analysis



Master Thesis Health Economics, Policy & Law
Erasmus University Rotterdam
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Preface

In front of you lies my Master thesis. The final task to fulfil a valuable study period of two years at the Erasmus University of Rotterdam. Looking back, this period was not the easiest one in my life. Due to illness it was sometimes difficult to enjoy studying in combination with work and social activities. Nevertheless, it was a valuable time, in which I have learned a lot, had a lot of fun with my study-mates, and overall, I enjoyed it.

Because my connectedness with the subject, the choice for this topic was in the end an easy one. The adaptive tasks adolescents with chronic illness and disability are faced with, were very recognisable for me and made this research special, sometimes difficult, but especially very interesting.

I would like to thank my supervisor for her valuable feedback during the different phases of this project. Due to your enthusiasm I became more and more motivated during the process. In addition, I would like to thank my co-evaluators for their time and shown interest in this topic. Finally, I would like to thank my boyfriend, family and friends, who supported me during these two years of hard work. Especially I would like to thank my parents who were always there for me during a difficult period of my life. This gave me the strength to go on, with as a result, 'just' graduating in time.

Summary

With the improvements in health care, the majority of children born with a chronic illness or disability (CID) are now surviving into adulthood. To design successful strategies for adjustment to CID, the need to understand the lived experience of adolescents with CID increased. In relation to this need, the research project 'On Your Own Feet' was started to map the preferences and competencies for health care of adolescents with CID in the transitional period. Lacking research about the lived experience of Dutch adolescents with CID in combination with the findings of this project formed the motivation to start this study.

This study was performed as part of the Master HEPL and aimed to find out in which way the adaptive tasks of the model of Moos and Holahan were applicable to the situation of chronically ill Dutch adolescents, participating in the 'On Your Own Feet' research project. Furthermore, it was intended to identify the potential benefits and pitfalls by using secondary data and applying deductive analysis.

Qualitative secondary data analysis using content analysis has been applied. Because different health care problems encompass many comparable adaptive tasks a general approach was chosen. First, an extensive literature review was performed to strengthen the background and theoretical framework. Next, 31 interviews with adolescents with CID (12-19 years), collected in the research project 'On Your Own Feet', were analysed using the program Atlas.ti. Data have been coded deductively in correspondence with the adaptive tasks of the model. Detailed codes were derived inductively. Four 'respondent families' were distinguished: boys, girls, 12-15 years, and 16-19 years.

Four adaptive tasks are found most influential: maintaining a positive self-image, managing emotions, relating to family members and friends and managing treatment. School and fellow patients were not covered by the adaptive tasks from the model, but were important for Dutch adolescents. It became clear that the relationships with family members and friends are quite different, and therefore may influence coping skills in a different manner. Girls were more concerned and had more worries in relation to their CID than boys. Older adolescents emphasize the importance of living a normal life more often, and were more independent with respect to treatment than their younger fellow patients. 'Being normal' is found the most important theme for Dutch adolescents with CID.

While deductive analysis with secondary data is not a commonly applied method, this study demonstrates that this type of analysis may add value, by building on existing theories and improve applicability in practice. Furthermore, the material already available gave the opportunity to analyse a high quantity of material in a short amount of time. Theoretical conservatism and insufficiently highlighted aspects due to the approximation from a different perspective, were found the most important pitfalls that should be taken into account.

It may be concluded that the model of Moos and Holahan formed a good starting point to clarify the lived experience of Dutch adolescents with CID. Hereby, the optimism of Dutch adolescents was remarkable. The model may be adjusted by adding the tasks school/work and fellow patients, to make it more applicable in the Netherlands. Furthermore, it has been shown that deductive analysis with secondary data may be valuable in further development of theory and its applicability in practice, as long as the researcher takes the limitations into account. Further research of the complete model is needed to find out the applicability of the other panels in practice.

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1. Chronically ill, the road ahead

With the improvements in health care, the majority of children born with a chronic illness or disability (CID) are now surviving into adulthood. The increased survival of children with CID has resulted in a major increase in the prevalence of CID in adolescence (Blum, 1992). Therefore, the need to understand how they manage and think about their illness or disability in context with their daily life becomes more important. To design successful strategies for adjustment to CID it is important to understand the ideas and motivations of adolescents faced with the major change in their lives caused by this CID (Christian and D'Auria, 1997). In the literature, several definitions of CID can be found. In this study, CID is defined conform the comprehensive definition of a study of Mokkink et al. (2008). In the Netherlands consensus about this definition was attained.

A disease or condition is considered to be a chronic condition in childhood if: (1) it occurs in children aged 0 up to 18 years; (2) the diagnosis is based on medical scientific knowledge and can be established using reproducible and valid methods or instruments according to professional standards; (3) it is not (yet) curable or, for mental health conditions, if it is highly resistant to treatment and (4) it has been present for longer than three months or it will, very probably, last longer than three months, or it has occurred three times or more during the past year and will probably reoccur (Mokkink et al. 2008).

This chapter discusses the lived experience of adolescents with CID, and the context of the research project 'On Your Own Feet', studying the preferences and competencies of Dutch adolescents with CID for health care in preparation for transitioning to adult care, that formed the reason to start this study. Finally the research problem is clarified, by which the research questions are defined, and an outline of the thesis is given.

1.1 Adolescence

Adolescence is a stage of human development in which individuals experience dramatic physical, psychological and social changes. It is known as a unique and influential development stage in terms of life adjustment and well-being (Woodgate, 1998). During this period, adolescents become concerned about their own image, form their own ideas and preferences and are assumed to become more and more independent (Kim and Kang, 2003; van Staa, 2012). For young individuals with CID the step to independency may be more difficult, because their disease or disability can form an obstacle in this process. It therefore may be considered a time of dual stress. Besides their everyday worries related to friends, family, and school, adolescents may have concerns about their health and the consequences of having CID (Woodgate, 1998; van Staa 2012).

In this study, adolescence is defined as a period of rapid physical, emotional and social development during which young individuals develop a sense of an independent identity, focus on peer acceptance, plan for the future and develop romantic and intimate relationships. It describes the teenage years between 12 and 19 years (Suris et al. 2004).

1.2 'On Your Own Feet'

The research project 'On Your Own Feet' was started to improve the process of preparation of young adolescents on the road to independency, and thereby improve their transition from paediatric to adult care (van Staa, 2012). The overall aim of the project was to map the preferences for health care delivery and the competencies needed to enable young individuals with CID to independently direct their own treatment. The research project intended to answer the following questions (van Staa, 2012):

- What are the health care preferences of young individuals of 12-19 years with CID?
- Which competencies of young individuals and health care providers are important in the transition of young individuals to adult care / adulthood?
- To what extent are those competencies present in health care practice, and how can they systematically be developed, so young individuals are optimally prepared to health care transition?

The results showed that adolescents prefer providers who are honest and trustworthy, technically competent and attend to their needs. When they grow older they prefer to be treated as equal partners in care (van Staa et al. 2011a). Adolescents did not act in communication during consultations when they were not considered as main partners (Van Staa, 2011).

Because not all adolescents share common ideas about their illness, there is no 'one size fits all' approach to adolescent health care. Four distinct preference profiles were identified: 'Conscious and Compliant', 'Backseat Patient', 'Self-confident and Autonomous' and 'Worried and Insecure'. Most characteristic for 'Conscious and Compliant' patients is the high involvement with their disease management; 'Backseat Patients' are less mature and lean more on their parents; 'Self-confident and Autonomous' patients have a strong need to be upfront about their condition; and the 'Worried and Insecure' patients are most of all worried and insecure about their illness (Jedeloo et al. 2010).

The attitude of adolescents to health care transition and their level of self-efficacy seem to be the keystones to transition readiness. Strengthening their independence and self-management competencies, combined with early preparation and repeated discussions on transition, seem to be useful strategies to increase the readiness of adolescents to transition to adult care. Hereby, parental involvement should not be undermined (van Staa et al. 2011b; van Staa et al. 2011c).

Although the research project 'On Your Own Feet' focused on adolescents' preferences and competencies according to health care communication, aspects that influence the experience of life of young adolescents with CID were also present. However, this data was not systematically analysed yet. This study focused on the lived experience of CID during adolescence, by using the available data and interviews from the research project 'On Your Own Feet'.

1.3 Lived experience of adolescents with chronic illness or disability

Adolescents with CID share the same developmental issues as their healthy peers. While the physical consequences of CID on this development have been established, less is known about the subjective personal experience (Taylor et al. 2008).

Taylor et al. (2008) intended to identify and critique literature on this lived experience of adolescents with CID. The aim of their literature review was to identify literature focusing on the lived experience of CID during adolescence; critique the quality of the methodology; describe young people's experience of living with CID; and make recommendations for future research and clinical practice.

Research on young people's experience of living with CID, published between January 1990 and September 2007, was included through a search on the keywords 'quality of life', 'satisfaction', 'well-being', 'lived experience' and 'chronic illness'. Furthermore, cross-referencing was used. Studies were included in the review when they involved adolescents aged 10-19 years and used qualitative research methods. Studies that included children and adults were only included when the data was presented separately. By the use of these criteria the final sample consisted of 20 studies (Taylor et al. 2008).

Study quality was evaluated by the use of criteria outlined by Cesario et al. (2002). Each study was scored 0-3 points in each of the following categories: descriptive vividness; methodological congruence; analytical preciseness; theoretical connectedness; and heuristic relevance. The scoring was done by two independent researchers (Taylor et al. 2008). The outcomes of this assessment can be found in Appendix I. The table has been used to determine which articles might be useful for this study.

Taylor et al. (2008) concluded that the different research projects described seven common themes related to the lived experience of adolescents with CID: developing and maintaining friendships; being normal/getting on with life; the importance of family; attitude to treatment; experience of school; relationship with the health care professionals; and the future. These seven themes are further elaborated below, by using examples from the existing literature. The presence of the different categories in the literature can be found in table 1, including 3 articles not mentioned in the literature review of Taylor et al. (2008). These articles were added after the literature review was repeated, whereby new articles were found. Furthermore, some general literature studies per theme were added to further clarify those themes.

1.3.1 Developing and maintaining friendships

The most important theme found in the different studies was being with friends and gaining their acceptance (Taylor et al. 2008).

For adolescents with asthma, the involvement in physical activities or sports was often less than their healthy peers and required extra effort on their part. They often felt that this was unrecognised and underappreciated by others. Besides, their belief that others lacked understanding of their illness made it more difficult to keep up with them (Rhee et al. 2007).

Adolescents with Cystic Fibrosis (CF) experienced to be unprepared for the intensity of negative peer responses to their CF. Keeping secrets created a distance and undermined their attempts for intimacy, rather than becoming closer with peers / create friendships (Christian and D'Auria, 1997).

For adolescents with cancer it was difficult to develop and maintain friendships. They felt isolated from their age peers when receiving treatment, and some lost old friends because of this. Nevertheless, some adolescents met new friends that felt compassion to their illness, and some friends even

became closer to them. Despite the difficulties, friends played a very important role in their lives (Hokkanen et al. 2004; Nicholas et al. 2007).

This dichotomy is also highlighted in studies of adolescents with epilepsy. These adolescents also experienced bullying and social isolation, but friends were also seen as a supportive factor (McEwan et al. 2004; Elliott et al. 2005).

For adolescents with thalassemia or sickle cell disorder, absences from school caused by hospital appointments or admissions contributed to a sense of isolation, because it disrupted social relationships (Atkin and Ahmad, 2001).

The above outcomes showed that friends were important for adolescents with CID, especially in promoting the feeling of joy and affirmation as an equal teenager. Being with friends helped to experience a feeling of liberty and spontaneity (Berntsson et al. 2007).

In general, studies that compared friendships of adolescents with and without CID showed some differences between diseases. Adolescents with diabetes mellitus (DM) did not suffer much negative consequences on their friendships because of their disease. Their friendships were similar to those of healthy adolescents. Nevertheless, they may experience a greater need for support from their friends compared to their healthy peers (Helgeson et al. 2006). Studies of adolescents with juvenile fibromyalgia syndrome and cancer survivors showed the opposite. These adolescents reported to have fewer friends, be more isolated, and less popular. They were more often a subject of peer victimization (Forgeron et al. 2010; Kashikar-Zuck et al. 2007). As a result, the way friendships are developed and maintained differed and may be influenced by the nature of disease.

1.3.2 Being normal/getting on with life

Getting on with life is the next most reported theme of living with CID (Taylor et al. 2008). The approach persons with CID use to continue what that person perceives to be a normal life is called normalisation. The general idea of people about normal life is the ability to work, participate in social activities and have the capacity to perform a variety of physical tasks, including self-care activities. With CID, a person's capacity to perform these tasks may be limited or restricted. Normalisation refers to attempts of persons with CID to establish, maintain or pretend to be living as normal and existing as possible, despite their illness symptoms, handicaps and complicated treatment regimens. This is a complicated process involving both behavioural and cognitive components (Royer, 1998).

Being normal and getting on with life became clear in a study about adolescents with a physical disability in Korea. These adolescents experienced the meaning of life when they achieved their goals, lived as a normal citizen, became productive members of society and improved their daily activities (Kim and Kang, 2003).

Adolescents with thalassemia and sickle cell disorder placed a high value on 'being like any other'. Doing well at school, getting a job and being accepted by their peers was seen as very important. They were aware of 'being different', but tried to work with it instead of against it (Atkin and Ahmad, 2001).

Adolescents with CF felt the need to reduce the aspect of being different by keeping secrets about their disease, hiding visible differences, and discovering a new baseline for their lives. They chose, for

example, not to tell teachers and coaches about their disease, so they could compete on an equal basis with peers (Christian and D'Auria, 1997).

Being together with friends and not always solely focusing on the illness, but more on other things was considered helpful for a lot of adolescents with CID. In general, it was important for them to accept the CID as a natural part of their life (Woodgate, 1998; Berntsson et al. 2007). Getting on with life and acting like anyone else was important.

1.3.3 The importance of family

The family has both a positive and negative impact on adolescents' life, which is shown by the examples below.

The study of Atkin and Ahmad (2001) found that parental support offered protection to the adolescents from practical problems of illness, but also to negative views and actions of others. However, this became more difficult when they grew older, because then they became more aware of their personal and social differences to others. Nevertheless, most of the children were aware of the impact of their illness on other family members (Atkin and Ahmad, 2001). Adolescents with DM also knew that their diagnosis had impact on their family, but noted that their family relationships were good. They had their own position in the family and claimed not being treated differently (Damião and Pinto, 2007).

Family (and friends) showed to be important for adolescents with depression. They could help them to feel connected by trying to understand them and checking in on them during difficult periods (Woodgate, 2006; Nicholas et al. 2007).

In brief, support from family has shown to be essential. A good relationship with parents contributed to 'feeling good'. Adolescents wanted their parents to be near when there is need, but trust and independency was also seen as important (Berntsson et al. 2007). Although family support is important, some studies found the overprotectiveness of parents to be an obstruction to the independency of the adolescents (Hokkanen et al. 2004; McEwan et al. 2003; Elliott et al. 2005).

From a literature review about social support and adolescent cancer survivors of Decker (2007) it became clear that support from parents (especially the mother) and friends was equally important. However, the support of family seemed to be much more satisfactory than that of friends. The importance of parents in the support network of adolescents with CID is supported by findings of Kyngäs (2004).

Although family is seen as the most important factor of support, there are some differences between family members. The importance of parents is highlighted several times, but the relation with siblings of adolescents with CID may be different. Charmaz (1980) refers in her review that chronically ill young people often did not have the feeling they could call upon their siblings, as these were involved with their own lives. Nevertheless, it appeared they shared their problems more often with their siblings than their healthy peers do. This may be related with difficulties in their peer relationships. When not receiving support from friends, this is sought by their siblings (Orr et al. 1984).

Table 1 Reviewed articles

Articles mentioned in literature review referred to in paragraph 1.3

Literature / Category	Rhee et al. 2007	Damião and Pinto, 2007	Hokkanen et al. 2004	McEwan et al. 2004	Kim and Kang, 2003	Atkin and Ahmad, 2001	Christian and D'Auria, 1997	Woodgate, 2006	Woodgate, 1998
Developing and maintaining friendships	X		X	X	X	X	X		X
Being normal / getting on with life			X	X	X	X	X		
The importance of family		X		X		X	X	(X)	
Attitude to treatment	X	X					(X)		X
Experience of school	X		X	X			X		
Relationship with the health care professional			(X)					X	(X)
Future			(X)	X		(X)			X

X Mentioned by Taylor et al.

(X) Not clearly mentioned by Taylor et al.

Table 1 Reviewed articles (continued)

Articles mentioned in literature review not referred to in paragraph 1.3

Literature / Category	Edwards et al. 2002	Rechner, 1990	Gallo et al. 1992	Kyngäs and Barlow, 1995	Admi, 1996	Horne, 1999	Snethen et al. 2001	Eklund and Sivberg, 2003	Beaune et al. 2004	Woodgate, 2005	Huus and Enskar, 2007
Developing and maintaining friendships	(X)		X					X	X		X
Being normal / getting on with life			X		X	X	X				X
The importance of family	(X)		X	X	X		X				
Attitude to treatment					X		X	X			
Experience of school	(X)			X							X
Relationship with the health care professional		X		X							
Future			X		X		X			X	

X Mentioned by Taylor et al.

(X) Not clearly mentioned by Taylor et al.

Table 1 Reviewed articles (continued)

Articles not mentioned in the literature review, referred to in paragraph 1.3

Literature / Category	Elliott et al. 2005	Berntsson et al. 2007	Nicholas et al. 2007
Developing and maintaining friendships	(X)	(X)	
Being normal / getting on with life		(X)	(X)
The importance of family	(X)	(X)	(X)
Attitude to treatment			
Experience of school			
Relationship with the health care professional		(X)	
Future			(X)

X Mentioned by Taylor et al.

(X) Not clearly mentioned by Taylor et al.

On the other hand, having a brother or sister with CID also has its impact on siblings. They may be positively and negatively affected by their brother's/sister's CID, related to receiving attention from parents, worries, and uncertainty (Derouin and Jessee, 1996).

1.3.4 Attitude to treatment

Adolescents often refer to the treatment of their illness, but only in a few studies the impact of treatment was mentioned and further elaborated (Taylor et al. 2008). Adolescents with DM noticed that DM care may be part of their daily life. They have to deal with it the rest of their lives (Damião and Pinto, 2007). Some adolescents found it hard to incorporate treatment into their lives and thought life would be much easier when they did not have the disease (Rhee et al. 2007).

Adolescents with CF were worried about others seeing them taking medications. Peer interactions influenced treatment adherence, specifically during adolescence (Christian and D'Auria, 1997).

When adolescents became older, they started to understand their illness better and started to develop a routine, which may give them more control in relation to their treatment (Atkin and Ahmad, 2001).

Kyngäs et al. (2000) found that compliance with treatment in CID was affected mostly by psychosocial factors, like the positive personal meaning of illness and treatment, therapeutic motivation and well-being. Besides, family, peer and health care provider support were essential to the promotion of compliance to treatment. This shows there is a relation between the different themes distinguished by Taylor et al. (2008). The factors that influenced compliance with treatment differed between individuals, which made it hard to universally understand the factors that affect the way persons with CID feel about their treatment (Kyngäs et al. 2000).

1.3.5 Experience of school

Adolescents may experience difficulties in daily school life. Adolescents with cancer experienced being bullied at school, which mainly was caused by physical changes due to their illness. Their illness made it harder to keep up with school, because of absence and treatments (Hokkanen et al. 2004).

The biggest issue for adolescents with epilepsy was the reaction of teachers to their illness, rather than their academic performance. Most of them overreacted in case of a seizure. Besides, sometimes adolescents were restricted from school grounds during breaks because of safety reasons. This segregated them from their peer groups. Teachers were mostly seen as not knowing enough about the health condition and imposing unnecessary actions (McEwan et al. 2004; Taylor et al. 2008).

In general, it is found that adolescents with CID were more vulnerable than their healthy peers, when going to school. A study among Icelandic schoolchildren between 10-12 years showed children with CID reported lower connection and lower positive feelings about their school than children without CID. This was highest among children with mental illness. As positive school connectedness is seen as an important contribution to health development of young people, this can slow down the development of these adolescents (Svavarsdottir, 2007). Another study found adolescents with CID more likely to be victims of bullying compared to their healthy peers. This was especially experienced by adolescents with mental illnesses, which may be caused by the fact that it is socially not that accepted to bully those with physical problems, who are less capable to defend themselves. The

greatest difference between adolescents with CID and their healthy peers was found in social exclusion (Pittet et al. 2010). This form of exclusion may lead to fewer friends and lower levels of support, which shows a relation with paragraph 1.3.1.

1.3.6 Relationship with the health care professionals

Not many studies explored the relationship with health care professionals, but there were some studies found by Taylor et al. (2008) that describe important aspects of this theme.

For adolescents with depression, health care professionals who valued them as human being seemed to be very important. They derived much comfort and strength from the health care professionals that showed respect and really tried to understand them (Woodgate, 2006).

Adolescents with cancer added more value to the time doctors spent with them and the use of 'language' they could understand. They found it important that their life outside the hospital was also included (Hokkanen et al. 2004).

In addition, Woodgate (1998) found that most adolescents felt that talking to family or friends was more helpful compared to talking with health care professionals. This was especially the case when the health care professionals did not (try to) understand how living with CID is for them. This underlines again that understanding of health care professionals was very important for adolescents with CID.

Adolescence studied by Berntsson et al. (2007) highlighted the importance of the competence of the nurses and doctors. When there was a need for medical help, they found it important health care professionals knew what to do and what not.

In general, adolescents preferred providers who were honest and trustworthy, technically competent and attending to their needs. Adolescents wanted to participate in their care and desired health care providers to take them seriously and to focus on them instead of on their parents (Van Staa et al. 2011a; Britto et al. 2004).

1.3.7 The future

The way adolescents looked at the future depended on the type and state of their illness. It also differed per person.

Some adolescents with cancer mainly concentrated on living here and now. They also had fears of the illness recurring. Others made plans for the future, regardless of the illness or bearing it in mind. Despite the fact that the adolescents received a lot of information about their illnesses, treatments etc. they felt that they did not know much about their future perspectives (Hokkanen et al. 2004).

Adolescents with epilepsy were mostly concerned about being alone when having a seizure. Besides, when they became older, they had worries about having children and the chance to transmit the disease (McEwan et al. 2004; Elliot et al. 2005).

Even when their condition was stable, adolescents with thalassemia or sickle cell disorder worried about what the future would bring (Atkin and Ahmad, 2001). This shows that uncertainty played a role in the way adolescents with CID looked at the future.

Adolescents with inflammatory bowel disease (IBD) experienced a lot of uncertainties about their disease. They never knew when a period of disease exacerbation took place. This brought a lot of worries for the future, mainly about having children and employment (Nicholas et al. 2007).

In her study, Woodgate (1998) found that the worry related to developing complications was of particular concern. This was especially the case for adolescents with DM or Crohns' disease. Furthermore, some adolescents with CID were also worried about dying, isolation as a result of their disease, and future employment.

The fact that adolescents with different CID experienced similar thoughts and feelings about above themes supports the assumption that regardless of the CID, adolescents share similar concerns and challenges (Taylor et al. 2008; Woodgate, 1998). Different health care problems encompass many comparable adaptive tasks. These tasks are encountered in all chronic conditions, but their relative importance varies, depending on the person, specific health problem and other unique circumstances (van Staa, 2012). Therefore, a general approach seemed most appropriate for this study, because I did not focus on the medical aspects, but on the psycho social processes of the adolescents. Nevertheless, it should be held in mind that there are also differences and not all aspects are generalizable. These differences are already highlighted in the themes above: some diseases seem to have more influence on friendships than others; individual differences in attitude to treatment; differences in vulnerability of adolescents with physical and mental problems in relation to bullying at school; and different perceptions of the future.

1.4 Reasons for research

The literature described above shows that different international studies of lived experience of adolescents with CID are performed and seven common themes of interest were found. These themes may lead to interesting insights for the development in health care and the understanding of adolescents' experiences with CID. Nevertheless, studies of lived experience of Dutch adolescents with CID have received little attention in the Netherlands. To find out if these seven common themes are also of importance for Dutch adolescents' with CID, further research was needed.

To understand the way adolescents with CID experience and cope with their illness or disability, different conceptual models were developed. The conceptual framework: 'the determinants of health-related outcomes of chronic illness and disability' of Moos and Holahan (2007) offers a way of 'conceptualizing coping skills and integrates coping in a broader predictive model'. With the model, Moos and Holahan (2007) wanted to contribute to the development of a broad understanding of people's adaptive strengths and capacity for personal growth, in the context of a wide spectrum of health crisis. Because the model of Moos and Holahan (2007) shows a lot of similarities with previous findings, this framework formed the starting point of this study. The model is based on theory, so the applicability in practice needed to be examined. The model is further explained in chapter 2.

1.5 Research objective and relevance

The objective of this study was twofold. The applicability of the model of Moos and Holahan (2007) was tested by analysing the interviews of the research project 'On Your Own Feet'. Insights drawn from this study may aid to understand the ideas and motivations of Dutch adolescents growing up with CID. These insights may also be useful to facilitate the transition from paediatric to adult care and hence contribute to the follow-up of the 'On Your Own Feet' research project.

Secondary analysis on existing interviews was applied by using an existing conceptual framework. The study also focused on the added value of deductive analysis. Despite growing interest in the re-use of qualitative data, secondary analysis is still an under developed approach (Heaton, 1998). It has not been widely accepted, because of concerns about the appropriateness of reanalysis of data from a different perspective, which is not central to the original research question (Hind et al. 1997). With this study it was intended to identify the potential benefits and pitfalls by using secondary data and applying deductive analysis.

1.6 Research question

The following research question formed the main aim of this study:

In what way are the adaptive tasks from the integrative conceptual framework of Moos and Holahan applicable to the situation of chronically ill Dutch adolescents participating in the 'On Your Own Feet' research project?

Related research questions:

1. Which elements of the conceptual framework are recognisable/applicable in the interviews of the 'On Your Own Feet' research?
2. What are the observed differences between boys and girls?
3. What are the observed differences between age categories (12-15 years / 16-19 years)?
4. What are the strengths and limitations of deductive analysis with secondary data found in this particular study?

1.7 Outline of the thesis

In the second chapter the theoretical framework of Moos and Holahan (2007) is described. The third chapter outlines the methodology used in this research. In chapter four, the results of the analysis of the interviews of the 'On Your Own Feet' research project are given, followed by a discussion of the results in chapter five. Finally, chapter six provides the conclusions and recommendations.

2. Managing a health crisis

The moment an individual is confronted with having CID is a turning point in his/her life. The confrontation with a severe illness or disability, treatments and uncertainty may have an enormous impact on an individuals' life. Most individuals cope reasonably well with such a crisis and are able to achieve a new equilibrium, but others are demoralized and suffer large psychological problems (Moos and Holahan, 2007).

To address the different issues that determine the individuals' psychosocial adaptation to CID, Moos and Holahan (2007) offer a framework that considers CID as an extended life crisis, describes relevant adaptive tasks and coping skills and identifies the primary determinants and outcomes of adaptive coping. They have based their framework on different psychological perspectives of coping with CID: crisis theory; a biopsychosocial orientation; and diverse models of coping processes and resources.

Crisis theory focuses on how individuals confront and manage major life crises and disturbances to their patterns of personal and social identity. According to this theory an individual is more sensitive to outside influences at a time of disequilibrium (Roberts, 2000).

The biopsychosocial orientation grew out of psychosomatic and behavioural medicine and integrated these two directions. The psychosomatic orientation focuses on the influence of personal and social factors in the onset and course of CID. It tends to neglect the role of adaptive coping skills in recovery, whereas behavioural medicine emphasizes problem-solving coping skills and focuses on the active role of the individual in managing and controlling the consequences of CID (Moos and Holahan, 2007).

A basis of diverse models of coping processes and resources lies in the stress and coping model of Lazarus and Folkman (1984). Their focus lies on a transactional approach to the stress and coping process. A stressful experience starts with primary appraisal, where the individual becomes aware of the actual and threatened change. This includes an evaluation of the potential significance ('am I in trouble or benefited?'). This is followed by the evaluation of the options for coping and the extent to which the individual may be able to control or change the situation, which is called secondary appraisal. The ways an individual approaches the situation (e.g. belief in a desired outcome) are important determinants of coping (Moos and Holahan, 2007; Lazarus and Folkman, 1984).

By integrating above theories, Moos and Holahan (2007) constructed a framework of seven panels to guide the understanding of the process of coping with CID. The different panels and their relations are outlined in figure 1.

Because this study focused on the lived experience of adolescents with CID, the emphasis lies on panel V: 'What adaptive tasks do individuals confront'? The other panels are briefly described to clarify the background of the model.

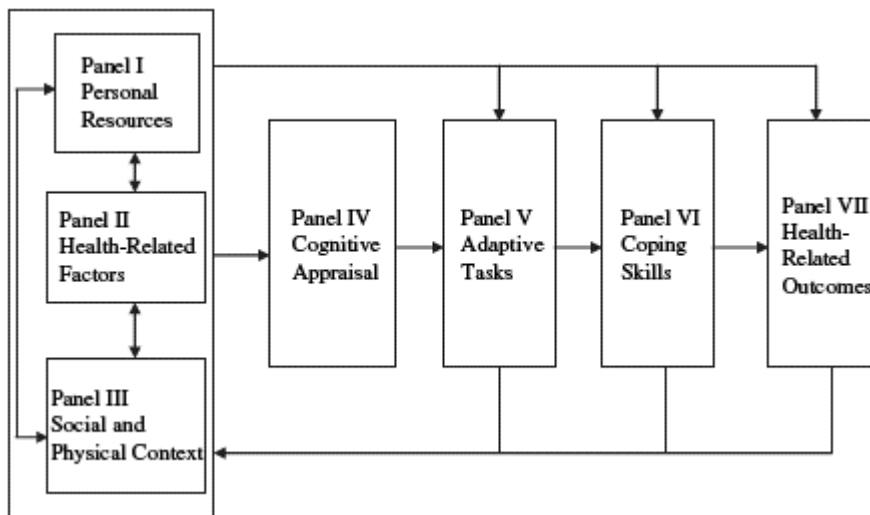


Figure 1 Conceptual model of the determinants of health-related outcomes of chronic illness and disability (Moos and Holahan, 2007)

In their model, Moos and Holahan (2007) distinguish five sets of factors associated with the selection and choice of coping skills (panel I – V).

2.1 Panel I: Personal resources

Personal resources include aspects as intellectual ability, self-image, religious beliefs and prior health-related and coping experiences. Besides, demographic characteristics like age, gender and education play a role. The personal characteristics influence the way individuals cope with their CID (Moos and Holahan, 2007).

2.2 Panel II: Health-related factors

The health-related factors include the severity of a condition, the location of symptoms and the rapidity of onset and progression of a condition. Further the health care environment and treatment procedures may influence the situation (Moos and Holahan, 2007). Moos and Holahan (2007) suggest that the way individuals cope with their illness probably varies more in relation to stage than type of illness. This is supported by findings of Heijmans et al. (2004) who identified differences in the amount and type of stressors experienced between diseases. However, these differences could not solely be explained by type of disease. Personal characteristics as, age, gender and illness duration were also important in determining the type of stress experienced.

2.3 Panel III: Social and physical context

The social context focuses more on the relationships individuals with CID have with their family and friends and on the support they get from these individuals and other members of their social network. The physical context includes the features of a home and workplace. It includes the accessibility and the influence on mobility and autonomy of the individual (Moos and Holahan, 2007).

2.4 Panel IV: Cognitive appraisal

The first three panels describe the personal factors and the context that can influence the way in which individuals appraise a crisis. The way in which they appraise their situation is the first step in construing adaptive tasks and choosing potential coping strategies (Moos and Holahan, 2007). The key aspects of this appraisal are twofold. First it questions if the individual was able to prepare for the situation. What was the context of the stressor; and does the individual see the situation as a challenge or a threat? The way in which an individual reacts on this situation can lead to approach (problem-focused) or avoidance (emotional-focused) coping. The more expected, controllable and changeable, the more an individual relies on approach coping. On the other hand, the more severe, the more individuals seem to rely on avoidance coping (Moos and Holahan, 2007; Lazarus and Folkman, 1984) (See also panel VI). Adaptation to the situation involves applying the form of coping that is considered most appropriate by the individual to the particular situation (Stewart et al. 2004). Every type of (emotional) reaction depends on this particular cognitive appraisal process and may differ between people. Even when the external conditions are identical, the outcome of the process may differ, because people differ in their sensitivity and vulnerability to certain events, as well as in their interpretations and reactions (Lazarus and Folkman, 1984).

2.5 Panel V: Adaptive tasks

Once confronted with the situation of CID, individuals have to deal with different aspects to adapt to the situation. Moos and Holahan (2007) divide these tasks into seven groups. The first three tasks are related to the health condition; the other tasks are more general and can also be applied to other (not health-related) life crises. Some additional findings are added to increase the understanding of the different tasks.

1. Managing symptoms

The task 'managing symptoms' is about managing the discomfort, incapacitation and other symptoms that appear when having CID. Individuals with CID must learn to recognise these symptoms and try to control them as good as possible.

2. Managing treatment

The second task distinguished in the model is 'managing the treatment'. When confronted with CID individuals are confronted with therapeutic measures like surgical procedures, radiotherapy and chemotherapy. Besides, hospital environments such as operating rooms, intensive care units and even waiting rooms can encompass significant stressors (Moos and Holahan, 2007).

3. Forming relationships with health care providers

The third task is about 'developing and maintaining relationships with health care providers'. When facing CID an individual is confronted with a complex set of tasks. They have to find out how to make their feelings clear and how to ask questions to the professionals. Besides, they may be confronted with a frequent turnover of providers and specialised caregivers (Moos and Holahan, 2007).

4. Managing emotions

The fourth set of tasks that is distinguished in the model is about 'managing emotions'. The confrontation with CID brings a lot of emotions. Individuals have to try to find a reasonable emotional balance when feeling upset and aroused by the health crisis. Moos and Holahan (2007) found that maintaining hope forms an important aspect of this task.

The way adolescents are able to find this balance is influenced by the condition characteristics (e.g. uncertain prognosis, complex therapies), personality (temperamental, intellectual), the family system and informal support networks (Patterson and Blum, 1996). Two main categories of emotion regulation can be distinguished: avoidance and inhibition of emotions, and expression and acknowledgement of emotions. The first category is associated with maladaptive outcomes like increase in disease occurrence, while increasing evidence shows the second category may promote good adjustment. Overall, it seems better to generally express, than to deny emotions (de Ridder et al. 2008).

5. Maintaining a positive self-image

'Maintaining a positive self-image' is the fifth adaptive task in the model. This task is about keeping a satisfactory self-image. Changes in physical functioning or appearance can make this hard to deal with. The ways individuals look at themselves, and are able to change one's own values to accept CID are included in this task (Moos and Holahan, 2007).

6. Relating to family members and friends

The sixth set of tasks focuses on sustaining positive relationships with family members and friends. Family and friends can give support, which may help an individual with CID to make decisions and deal with his / her emotions. However, because of serious illness episodes it may be hard to maintain these relationships and to accept comfort and support (Moos and Holahan, 2007).




7. Preparing for an uncertain future

The last task that is distinguished is about the uncertain future individuals with CID are confronted with. Individuals have to deal with uncertainty and the threat of significant losses like hearing or sight. While hope for new treatments can be beneficiary for coping with CID, new health care procedures, which raise hope for individuals with incurable illnesses can make this task more difficult, because the uncertainty increases (Moos and Holahan, 2007).

Interestingly, the seven tasks mentioned above are almost identical to the themes described in paragraph 1.3. Table 2 gives an overview of the similarities between this theoretically based framework and the seven themes found inductively by Taylor et al. (2008).

Table 2 Similarities theoretical framework Moos and Holahan (2007) and inductive theory Taylor et al. (2008)

Empirical / Theoretical	Developing and maintaining friendships	Being normal / getting on with life	The importance of family	Attitude to treatment	Experience of school	Relationship with health care professionals	The future
Managing symptoms							
Managing treatment				Similar			
Forming relationships with health care providers						Similar	
Managing emotions	Related, as well adaptive as maladaptive	Related, as well adaptive as maladaptive	Related, as well adaptive as maladaptive	Related, as well adaptive as maladaptive	Related, as well adaptive as maladaptive	Related, as well adaptive as maladaptive	Related, as well adaptive as maladaptive
Maintaining a positive self-image		Similar					
Relating to family members and friends	Similar		Similar				
Preparing for an uncertain future							Similar

-  Similar
-  Related, as well adaptive as maladaptive
-  No similarities

2.6 Panel VI: Coping skills

The five sets of factors mentioned above (panel I-V) shape the choice of coping skills. Moos and Holahan (2007) distinguish two different approaches in their model. The first approach is about the focus of coping. An individual can approach the problem and can actively try to resolve it and live with the situation (approach or problem-focused coping). On the other hand an individual can avoid dealing directly with the situation (avoidance or emotional-focused coping).

The second approach is about the method of coping, where the focus is on the differences in response on the situation. The response may be more cognitive or behavioural. Individuals do not rely on just one coping skill: 'An on-going health condition presents a variety of related tasks and requires a combination or sequence of coping skills' (Moos and Holahan, 2007).

2.7 Panel VII: Health-related outcomes

Coping skills in a certain way mediate between the influences in panels I to V and the health-related outcomes in panel VII. On the other hand, the health-related outcomes may have their influence on panels I to VI (Moos and Holahan, 2007).

In general, more reliance on approach coping tends to be associated with better outcomes. However, there are important exceptions due to the match or mismatch between specific adaptive tasks and particular coping responses. Individuals can temporary benefit from cognitive avoidance, for example denial can help regulate mood in the early stage after a traumatic event. Besides, it may be effective in dealing with unalterable health problems (Moos and Holahan, 2007). Nevertheless, the failure to acknowledge and express these emotions can leave the emotions unresolved, which may affect a patients' health in the future (de Ridder et al. 2008). Another exception can be found in the detrimental aspects of approach coping. An individual who for example tries to gain active control in a situation that cannot be changed can have feelings of blame and guilt (Moos and Holahan, 2007). In spite of the positive and active appraisal, the coping strategy can have adverse effects.

At large, to achieve psychological adjustment, adolescents with CID need to face the reality of being chronically ill and make efforts to change their lives to adjust to the changed circumstances (de Ridder et al. 2008).

Panel V of the model formed the starting point of this study. The interviews of the research project 'On Your Own Feet' are analysed to find out if these adaptive tasks are applicable in the situation of these adolescents with CID. Because the focus lied on these adaptive tasks, the coping skills are not further elaborated. Nevertheless, with the applicable findings of this study the model may be helpful in understanding the behaviour of adolescents confronted with CID. So, despite of the fact that this part of the model lied beyond the scope of this study, it should be held in mind when discussing the results.

3. Methods

In this chapter the research methods used to answer the research question are described. First, the research strategy is exposed whereby the strengths and limitations of the deductive analysis are included. Second, the design and setting of the research project 'On Your Own Feet' is described, followed by the strengths and limitations of secondary research. Furthermore, it is described how the review of the literature was done. Finally the different steps in the data analysis are described and steps to achieve trustworthiness are provided.

3.1 Research strategy

To gain insight in the lived experience of Dutch adolescents with CID, qualitative secondary data analysis using content analysis has been applied.

Because the conceptual framework of Moos and Holahan (2007) formed the starting point, a deductive approach was chosen. Deductive reasoning, in contrast to inductive reasoning, starts with a theory about the topic of interest. By narrowing down, from this theory specific hypotheses can be formed that can be tested. Observations are used to address this hypothesis. With the specific data out of the observations the original theory can be (dis)confirmed (Trochim and Donnelly, 2006; Elo and Kyngäs, 2008). The application in this study is showed below:

Theory → Hypothesis → Observation → Confirmation

Theory:	Adaptive tasks of coping with illness and disability.
Hypothesis:	The conceptual framework by Moos and Holahan is applicable in the situation of Dutch adolescents with CID.
Observation:	31 qualitative semi-structured interviews of the research project 'On Your Own Feet'.

The choice for deductive analysis may not seem that obvious at first. Deductive analysis is usually associated with quantitative analysis and not very popular in qualitative research (Bryman, 2004; van Staa and Evers, 2010). Opponents of deductive analysis mention the risk of theoretical conservatism as the main limitation of this approach. The researcher may interpret the data in such a way that it will always confirm the empirical validity of the hypothesis (Bryman 2004). Applying an inductive strategy averts this pitfall, because all observations and categories are approximated with an open mind and none of them are in- or excluded in advance (Maso and Smaling, 2004).

On the other hand, advocates have argued that deductive analysis may be very effective in research when theories and concepts of the subject under research are already available (Evers and van Staa, 2010). From this starting point, the analysis can be systematically approximated and theory may be (dis)confirmed and further elaborated.

In response to this dissension, Evers and van Staa (2010) argued that it is best to perceive qualitative data analysis as a combination of both inductive and deductive analysis. Hereby, the data can be structured by the use of existing theoretical notions and frameworks (deductively), combined with the

flexibility of exploring the data with an open mind (inductively). Prior to their argument, other authors argued that a clear distinction between inductive and deductive analysis leads to oversimplification. Inductive and deductive approaches can be simultaneously found in virtually every research project (Bryman, 2004; Maso and Smaling, 2004).

3.2 Design and setting interviews of research project ‘On Your Own Feet’ (van Staa et al. 2011b)

The material from this research project used in this study was made available by my supervisor. Here, I used the qualitative interviews collected in 2004.

Sample

In 2004, the Medical Informatics Department identified all patients between 12 and 19 years of age who had visited Sophia Children’s Hospital at least once in the past six months and had been under continuous treatment for at least the past two years. Two thirds have been receiving treatment for over ten years. No specific disorders or conditions were selected, because the study aimed to obtain a general understanding of adolescents’ attitudes toward health care and self-management and to research common adaptive tasks faced by all adolescents coping with a chronic somatic disorder. Adolescents with psychiatric diagnoses, a history of life-threatening illnesses, such as cancer, and with known learning disabilities were excluded.

Two groups were distinguished: younger (12-15 yrs) and older adolescents (16-19 yrs). To facilitate the purposive sampling process, equal numbers of random cases were drawn from both groups. The research team aimed at equal numbers of participants from both age groups, and even distributions of sex, nature of the condition (i.e. congenital or acquired in past five years; progressive or not; physically disabling or not), and hospital experience within groups.

Setting

Semi-structured qualitative interviews were held with adolescents with chronic conditions treated in the departments of Paediatrics or Paediatric Surgery in the Sophia Children’s Hospital to explore their preferences, competencies and experiences with hospital care.

Data collection

Eligible adolescents and their parents received an invitation letter, a study information leaflet and a reply form from the research team. Upon written consent of both adolescent and parents, the primary researcher arranged a face-to-face interview alone with the adolescent at their home.

Twenty-seven interviews were conducted by pairs of purpose-trained nursing and paramedical students and four by a researcher. Interviews lasted between 45-90 minutes and were recorded. Participants were rewarded with a gift voucher of €20.

Ethics

All study procedures were approved by the Medical Ethics Review Board of the Erasmus Medical Centre Rotterdam. Participants were assured of confidentiality and data were processed anonymously.

The researchers had no access to participants' medical records. Eligible adolescents and their parents received written information about the study.

3.3 Secondary research

The interviews of the research project 'On Your Own Feet' were analysed with a new perspective / conceptual focus. This is a type of secondary research that analyses a data set from a different perspective, in order to examine concepts which were not central to the original research (Heaton, 1998). The analysis may result in useful findings that had not been made explicit in the primary research (Hinds et al. 1997). The major theoretical challenges of secondary research are associated with the nature of the data and problems in fitting the secondary question with the design of the primary research (Thorne, 1994). The ethical and practical considerations that were taken into account in this study are listed below (Heaton, 1998).

Compatibility of the data with secondary analysis

Tightly structured interviews may tend to limit the range of responses, while designs using semi-structured schedules may produce more and rich varied data. In the 'On Your Own Feet' research project semi-structured interview questions were used, increasing the chance of presence of usable information to answer the research question of this study (Hinds et al. 1997; Heaton, 1998).

Position of the secondary analyst

When not being part of the original research team, it may be more difficult to access the primary data. Nevertheless, because my supervisor participated in the research project 'On Your Own Feet', I have had access to the full transcriptions of the 31 interviews. Besides, the peer reviews with my supervisor were helpful in cross-checking the results of my secondary analysis (Heaton, 1998).

The fact that I did not take part in the original research, decreases my sensitivity to the context of the primary research, but it may have benefited the research purpose, because I had no firm or fixed ideas about the phenomena in the data set (Hinds et al. 1997).

Reporting of original and secondary data analysis

When performing a secondary analysis it is very important that the study design and methods of the primary research are reported as clear as possible. Besides, the way the secondary research has been applied should be clearly described (Thorne, 1994). Therefore, the link with the original research project 'On Your Own Feet' and the data collection procedure is incorporated in chapters 1 and 3 (Hinds et al. 1997; Heaton, 1997; Thorne, 1994).

Ethical issues

As described in paragraph 3.2, informed consent was obtained. Re-use of the data did not violate this agreement, because there was no access to any medical file and the interviews were anonymously processed (Hinds et al. 1997).

3.4 Review of the literature

The review of Taylor et al. (2008) is used as starting point to form the background of lived experience of adolescents with CID. All articles that scored 'I' (see Appendix I) in their literature review were used to explain and underpin the seven categories found. The articles of Admi (1996) and Eklund and Sivberg (2003) were not included, because the other articles gave enough background in strengthening the need of this research. The article of Edwards et al. was not included because it focused on a Quality of Life framework which added no value to the aim of this study.

The articles of the review used in chapter 1 were read several times to check the categories found by Taylor et al. (2008). During this re-analysis of the review in some of the articles more categories than in the original review were identified (see table 1). These findings were added to the review findings of Taylor et al. (2008) before the analysis was started. Furthermore, an additional search was performed to repeat the review. A search was repeated on PubMed, APA Psychnet and Google Scholar using the same keywords as Taylor et al. (2008), adding the keyword 'adolescents'. Three new useful articles were found and added. In contrast to the review of Taylor et al. (2008), two of these articles included children and adolescents in the age of 7-19 years, instead of 10-19 years. Nevertheless, it was decided to include the outcomes of these two studies, because the majority of this group fell into the category chosen by Taylor et al. The difference in age categories may explain why Taylor et al. (2008) did not incorporate these studies.

In addition to the review, a more extensive search per distinguished category was performed to add some specified information per category. A search was made on Pubmed and Google Scholar using the category names, 'chronic illness', 'lived experience' and 'adolescents' as keywords. This search was not exhaustive, but intended to give more background information about the findings of these specific categories. A systematic review of the available literature was beyond the scope of this study. The article of Rudolf H. Moos and Charles J. Holahan (2007): 'Adaptive Tasks and Methods of Coping with Illness and Disability' is used as the basis of the theoretical framework. To strengthen the importance of this framework as a basis for this study, the outcomes of the various literature studies about lived experience with CID were compared with this theoretical framework (see table 2).

A fourth sub question focused on the strengths and limitations of deductive analysis and secondary research respectively. To gain more insight into these two aspects a literature search was performed by the use of PubMed and Google scholar. Hereby the keywords 'deductive', 'inductive', 'approach', 'qualitative', and 'analysis' were used. From this search it became clear that the use of a deductive approach in qualitative analysis is not very common. Therefore, it was decided to include the experiences from this research in the discussion section, which gave the ability to discuss the added value of this kind of research strategy.

3.5 Content Analysis

To answer the first three sub questions, 31 interviews of the research project 'On Your Own Feet' were analysed using the program ATLAS.ti.

The interview transcripts were analysed using deductive content analysis, also referred to as directed content analysis (Hsieh and Shannon, 2005). Content analysis is a method of systematically analysing

written, verbal or visual communication messages (Elo and Kyngäs, 2008). Hsieh and Shannon (2005) define content analysis as 'a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns'.

Content analysis was chosen, because it is a research method that has come into wide use in health and nursing studies in recent years and has showed that it is well-suited to analyse the multifaceted, sensitive phenomena characteristic of nursing (Elo and Kyngäs, 2008; Hsieh and Shannon, 2005). 'The main strength of the directed approach to content analysis is that existing theory can be supported and extended' (Hsieh and Shannon, 2005). The main intention of content analysis is to classify the many words of the interview text into much smaller content categories (Elo and Kyngäs, 2008).

Despite the fact that deductive content analysis has been used less than the inductive analysis in nursing studies, it may be useful, because inductively built models can be complemented, tested and developed further with the aid of deductive analysis (Elo and Kyngäs, 2008). The findings of the applicability of the conceptual model on the situation of the chronically ill and disabled that were interviewed in the research project 'On Your Own Feet' may be useful in the development of the transition of care for adolescents.

In the analytic process, three phases could be classified: the preparation phase; the organizing phase; and the reporting phase (Elo and Kyngäs, 2008).

Preparation phase

The preparation phase started with selecting the unit of analysis. The unit of analysis in this study were the interview texts of the research project 'On Your Own Feet'. Hereby the idea of Graneheim and Lundman (2004) was followed who suggested that a unit of analysis should be large enough to be considered as a whole, and small enough to be kept in mind as a context for a meaning unit during the analysis process. They considered a meaning unit as words, sentences or paragraphs containing aspects related to each other through their content and context.

Because secondary analysis on existing qualitative material was applied it was only possible to study the text. The latent content, which also notices silence, sighs, laughter, posture etc. could not be analysed (Elo and Kyngäs, 2008).

Before starting the analysis, the interviews were read through several times to make sense of the data, and become immersed and familiar with it. After making sense of the data, the interview text was uploaded in Atlas.ti. Hereby, the 'old' codes and fragments were deleted and the analysis was conducted using a deductive approach (Elo and Kyngäs, 2008).

Organizing phase

In the organizing phase, a categorisation matrix was developed (see table 3). The categorisation matrix was used to review the data. To keep a good overview of the data, the seven categories (main codes) were divided into more detailed codes. The data has been coded in correspondence with the identified categories (adaptive tasks conceptual model). While the detailed codes were derived inductively, the analysis was mainly deductive, because the seven pre-defined 'code families' formed

the starting point of the analysis and the newly identified codes were clustered within these codes. During the coding process, the concepts school and fellow patients were added, because they could not be placed under the pre-defined categories (Elo and Kyngäs, 2008; Zhang and Wildemuth, 2009; Hsieh and Shannon, 2005). No other categories were added.

After all interviews were coded, the code manager of Atlas.ti was used to screen the quotations of the codes to find out if the coding process was done structurally. When this was not the case, the interviews were screened on keywords using the search tool in Atlas.ti. and codes were linked to the quotations when necessary. This process has been performed for the words: 'school', 'dokter', 'specialist', 'arts', 'ongevraagd advies', 'ziekenhuis', and 'opname'.

After finishing this coding process in Atlas.ti the coded quotations were printed, whereby four 'respondent families' were distinguished: boys, girls, 12-15 years, and 16-19 years. In this way the quotations may be analysed per group to detect the differences and similarities. Furthermore, the analysis focused on the relation between the different categories to estimate in which way they might influence each other. Hereby, 'network view' of Atlas.ti was used.

Table 3: Categorisation matrix (Elo and Kyngäs, 2008)

	Managing symptoms	Managing treatment	Forming relationships with Health care providers	Managing Emotions	Maintaining a positive self-image	Relating to family members and friends	Preparing for an uncertain future
What are the aspects individuals have to deal with to adapt to the situation?							

Reporting phase

The outcomes of the categorisation and coding process are further discussed in chapters 4 and 5.

3.6 Trustworthiness

In this paragraph the steps taken during the research process to achieve trustworthiness are described (Hamberg et al. 1994).

Credibility

The credibility of the data collection depended on the accurateness of the researchers of the 'On Your Own Feet' research project. There was a clear description of the context, selection and characteristics

of participants available, before this study was started. To demonstrate the link between the results and the data, tables and quotes are included (Hamberg et. al. 1994; Elo and Kyngäs, 2008).

Dependability

Because secondary research was applied, the context wherein the research took place did not change. No new data inputs were included during the study period (Hamberg et. al. 1994).

Confirmability

To enhance confirmability, a detailed description of the analytic steps is included in this method section. Peer review with the main researcher of the 'On Your Own Feet' research project was helpful in questioning the findings, rethinking and critically reviewing the material (Hamberg et. al. 1994; Zhang and Wildemuth, 2009).

Transferability

The context wherein the study took place is described and a clear description of the selection and characteristics of participants is included, to make transferability of the results possible. With this information other researchers will be able to decide whether the findings are relevant in other situations (Hamberg et. al. 1994). Authentic citations are added to describe from what data categories are formulated (Elo and Kyngäs, 2008).

4. The Dutch lived experience

In this chapter the results of the analysis are provided. First the research sample is described. Second, the way the adaptive tasks of the model of Moos and Holahan (2007) were experienced by the participants of the 'On Your Own Feet' research project is described. Finally, some additional findings are provided. An overview of the actual implementation of coding the data, as explained in paragraph 3.5, can be found in Appendix II.

4.1 Research sample

Of the purposive sample of 66 adolescents who were invited, 31 eventually participated. 24 refused (36%) and 11 (17%) could not be reached by phone for a reminder. Thus, 31 (47%) consented to an interview. Most of those who refused said they had no time; some said they were too ill or too occupied with family problems; while others were not interested to participate in the study. A non-response analysis based on the determinants used for the sample selection revealed no significant differences between participants and non-participants. Socio-demographic characteristics of the participants are summarized in Table 4. Mean age for the interviewees was 15.3 (SD 2.1), 16 (52%) were male.

4.2 Adaptive Tasks

This paragraph describes the lived experience of the adolescents that participated in the 'On Your Own Feet' research project.

4.2.1 Managing symptoms

Almost all adolescents interviewed could recognise their symptoms and knew what to do when these symptoms occurred. Most of them took medicines, rested or contacted a doctor. Mentioned symptoms were pain, fatigue, less condition and headache. Three boys indicated not to recognise their symptoms. They suffered from metabolic disorder, kidney problems, and epilepsy and were all in the age of 12-15 years. *It just happens, you do not notice it* (Zafir, 15 years, epilepsy).

Adolescents claimed to be able to indicate their limitations while undertaking activities. One boy clearly mentioned to exceed his limits, because he did not want to stop his activity. *I know when to stop, but sometimes I go on. For example when I play tennis and play a good game* (Jasper, 18 years, kidney failure). Both boys and girls were aware of the risks involved in ignoring their symptoms, but boys mentioned it more often. They spoke of the risks of dying or worsening condition. *When the blood glucose level becomes low, you can get into a coma and if it goes on, you die* (Evert, 16 years, metabolic disorder).

Furthermore, adolescents mentioned their daily life was not severely affected by the symptoms. They were aware of their limitations, but it was argued that these limitations had no large influence. This was underpinned by comments of boys like: *I can do the same as anybody else, I only have to stop earlier. They can go on playing tennis, I have to take a break* (Jasper, 18 years, kidney failure); *It does not influence my daily life that much, I only have to take medication* (Egbert, 13 years, IBD).

Table 4 Socio-demographic characteristics (van Staa et al. 2011a)

	<i>N</i>	<i>%</i>
	Interviews / Q-study n=31	
Gender		
Girls	15	48.4
Boys	16	51.6
Age		
12-15 yrs	17	54.8
16-19 yrs ¹	14	45.2
mean (SD)	15.3 (2.1)	
Ethnicity		
Dutch surname	26	83.9
Non-Dutch surname	5	16.1
No. of outpatient visits in past three years		
≤ 12	19	61.3
≥ 13	12	38.7
Hospital admissions in past three years		
Yes	12	38.7
No	19	61.3
Diagnosis after age of six¹		
yes	9	29.0
no (at birth & first 5 y)	22	71.0
Therapeutic regimen (i.e. medication, diet or exercise)		
yes	24	77.4
no	7	22.6
Presence of physical limitations		
Yes	11	35.5
No	20	64.5

¹ Diagnoses represented in the interview study: scoliosis/kyphosis, facial schisis, benign intracranial hypertension, congenital bladder disorder, congenital heart disorders, rheumatoid arthritis, haemophilia, diabetes mellitus (DM), epilepsy, inflammatory bowel disease (IBD), cystic fibrosis (CF), various metabolic disorders, HIV, nephrotic syndrome, immune and hormone deficiencies, lung insufficiency, progressive kidney failure, congenital skin diseases, asthma, and neuromuscular diseases.

Girls had the same view: *I cannot do a few things, but a lot of nice things I can* (Esmee, 14 years, haemophilia, spasticity); *I am not allowed to eat that much, further I can do everything* (Cecilia, 14 years, DM).

There were also boys and girls who did feel limited due to their symptoms. A boy who noticed to be limited had a physical disability, limiting him in walking, and functioning in the house. Nevertheless, he also mentioned positive aspects. He needed help with everything, *but since living in a new house it goes much better* (Murat, 14 years, Duchenne). One girl mentioned her life was influenced, because she was worried about being rejected because of her symptoms (Sandra, 13 years, skin disease). Two

other girls were worried about difficulties in getting a driver's license due to their symptoms (Maria, 15 years, scoliosis; Sheila, 18 years, brain tumor, DM).

In general, there were no big differences between boys, girls and the age groups. Nevertheless, differences between disorders were present. Adolescents with physical and/or visible disabilities had more difficulties in managing their symptoms. Moreover, adolescents seemed to have difficulties when they were totally unable to undertake certain activities, while they did feel less hampered if they were able to undertake the activity in a lesser extent than their healthy peers.

4.2.2 Managing treatment

When looking at treatment, adolescents seemed to have a 'love-hate relationship' with it. For all adolescents, adherence to treatment and following regimen was sometimes difficult. They mostly forgot to take medication when they performed activities, were with friends, or at a party. *When I go out with friends, it is difficult to follow my regimen* (Annika, 17 years, hormone deficiency); *When there is a party, or when I am busy, I sometimes forget to follow my diet* (Evert, 16 years, metabolic disorder).

Adolescents seemed to be quite independent in relation to their treatment. They were able to inject themselves, and to take their medications and claimed to make appointments in the hospital. Adolescents acknowledged they wanted to be independent in relation to their treatment, but some of them mentioned that they only wanted to become more independent in the future. *When my medication is in the closet, I get them myself, but my mother orders them for me* (Anita, 16 years, epilepsy).

Few adolescents spoke about recent experiences with hospitalisation. Most had been too young to remember. When they remembered, they were positive about the treatment, but they did not really like hospitalisation. One girl mentioned not to like the admissions, because it happened too many times. *For me it is normal to be admitted in the hospital twice a year, but this year it already happened four times* (Daphne, 19 years, CF).

Boys as well as girls found it important to know what the effect of their treatment was and knew what the consequences of non-adherence were. When non-adhering they recognised some (negative) effects of it. *I follow my regimen, otherwise I will have more pain* (Vince, 12 years, haemophilia). *Yes of course I know the consequences, you become tired, grow slower [...] everything gets less* (Jasper, 18 years, kidney failure).

With respect to attitude to treatment, two groups could be determined: One group that valued the importance of adherence, while the other stressed the importance of 'living a good life'. The adolescents that felt it was no problem for them to sometimes skip treatment or ignore their regimen were mostly older (16-19 years). *You just have to accept what you have and follow your regimen* (Anton, 18 years, lung insufficiency). *Every 'CF-er' skips treatment sometimes, I do not think anybody follows the treatment exactly* (Daphne, 19 years, CF). The type of disorder did not seem to influence this attitude. Both groups have had difficulties with adhering to treatment. In the beginning they needed to get used to it, did not like the pain, and found the treatment sometimes annoying. In the end many mentioned that having to stick to a therapeutic regimen was not that bad. *It is annoying to miss*

things because of appointments in the hospital, but it is not the end of the world (Maria, 17 years, scoliosis). *You follow your diet and get used to it* (Ricco, 14 years, metabolic disorder). Girls more often commented on their ambivalent feelings in relation to treatment than boys. No large differences in attitude to treatment between the younger and older age group were apparent. However, adolescents whose treatment took more time, and those who needed to think about their medication more often during the day, were more aware of the negative influence of their treatment. *Actually, I have to salve twice a day [...] I only do that when my symptoms get worse [...] it is annoying* (Sandra, 13 years, skin disease).

4.2.3 Forming relationships with health care providers

Because the research project 'On Your Own Feet' mainly focused on this adaptive task, a more detailed description can be found in the study of van Staa et al. (2011a).

Before a consultation with their health care provider, only three older adolescents (Daphne, 19 years, CF; Sheila, 18 years, brain tumor, DM; Arnaud, 19 years, facial schisis) mentioned to prepare themselves. Others just waited till their physician or parents asked questions.

While adolescents stated that they would like to participate in the consultation, they all appreciated the presence and support of their parents. Furthermore, most admitted they found it okay when their parents asked and answered the questions. *I could have done it myself, but I did it together with my mother* (Maria, 17 years, scoliosis); *When the doctor asks my parents, they just answer. But when I do not get it they also answer* (David, 12 years, epilepsy). Adolescents especially appreciated the support of their parents in relation to the explanation of difficult questions and answers from their health care providers. *I do not need them to talk to me with difficult words, I am not that good with difficult words and sentences* (Mileen, 15 years, hormone deficiency, back problems). Older boys (16-19 years) mentioned more often to visit their physician on their own, but sometimes they were still supported by their parents, especially when difficulties around their CID were discussed.

All adolescents made decisions in relation to their CID in consultation with their parents. However, the older group (16-19 years) seemed to have more influence on these decisions. *I do the talking, but I like my mother to be present* (Daphne, 19 years, CF). *I am allowed to participate in decisions, but not in all yet* (Sandra, 13 years, skin disease).

In addition, adolescents had the feeling they could discuss everything with their physician. They were satisfied about the clarity of the communication and claimed they could make themselves clear. *Mostly he uses a computer program and explains the virus [...] I like that* (Charles, 15 years, HIV).

Differences between boys and girls in relation to their role during consultations with their health care provider could be observed. Girls mentioned more often they wanted to have more influence and a less childish approximation. *Why do I have to come anyway, they do not talk with me* (Carla, 12 years, epilepsy). One girl felt really hampered by her mother's interference. *Probably my mother will start talking about it, she is always faster than me [...] I would have started talking about it myself* (Annika, 17 years, hormone deficiency). Boys also mentioned they wanted to become more independent, but were still satisfied with the way it went. *I prefer my mother answers the questions, because she can better explain what is going on* (Zafir, 15 years, epilepsy).

Adolescents had a good relationship with their physician. They appreciated having the same physician during their treatment periods. They found it important to trust their physician and they had the feeling their physician had enough knowledge to help them. Therefore, there was not much need for extra support from a nurse. *Yes, the doctor knows more than the nurse (Zafir, 15 years, epilepsy).* Nevertheless, three boys mentioned they liked the contact with a nurse, because they had more time for a conversation. These boys spend more time into the hospital. *When you are in day care for 5 hours reading a book [...] it is fine to have a nurse who wants to talk to you (Arjo, 17 years, immune deficiency).* When there was contact with a nurse this was especially for the treatment for certain diseases, for example to support the self-injection of haemophilia patients.

Furthermore, adolescents claimed they received enough information about their disease from their health care provider. Besides, their parents knew and explained a lot. Therefore there was no need to use internet to search for information. *Well, I never asked for it, it just has been told to me (Kasper, 17 years, haemophilia).* However, two girls mentioned they would like to know more about their disease *I am able to know more about it (Cecilia, 14 years, DM).* These girls also did not find their physicians explanation about their disease clear enough.

In general, it was observed that adolescents were satisfied with the relationship with their health care provider. They still received a lot of support from their parents in making themselves clear during the consultation, but most expressed a desire for a more active role in the future. Furthermore, parents seemed to be the main providers of information.

4.2.4 Managing emotions

All adolescents accepted their CID to a certain extend and claimed they got used to it. Most had difficulties with accepting their CID in the beginning, but after a while all expressed a certain degree of acceptance. *I grew up with it. You learn how to handle it. At the beginning of puberty, it was hard, but after that it became easier (Arnaud, 19 years, facial schisis); If you asked this question 2 years ago I did not know what to say [...] now I try to accept it (Sheila, 18 years, brain tumor, DM).*

Girls had much more concerns about their CID than boys. They mentioned to be afraid that new problems would occur in the future. One girl mentioned to be afraid of dying or getting cardiovascular disease (Cecilia, 14 years, DM). Both groups mentioned not having any concerns when it went well, but that this might change when it would become worse. *When it becomes worse, okay, than I will be concerned about it, but now, no (Anita, 16 years, epilepsy).*

Some never thought about their disease, and a few boys and girls mentioned they only had some moments of concern. *I never think about it (Anton, 18 years, lung insufficiency); Some moments you are concerned, but that is one moment, then it is over (Jasper, 18 years, kidney failure).*

Boys did not express much about their feelings in relation to the consequences of their disease. Those who did, felt that remembering to take medication and having pain were difficult to handle sometimes. *Sometimes it is a weird feeling, it hurts [...] that is annoying (David, 12 years, epilepsy).* Nevertheless, they claimed not having many problems with it. Girls, on the other hand, mentioned their emotions in relationship to the consequences more. Most of them had problems with the disability of participating in (sport) activities.

Girls also mentioned more often they disliked 'being different' from people without CID. Differences in capabilities in relation to sports were mentioned most often. Furthermore, they disliked people who were staring at them and the inability to do things on their own. *Just go outside with my friends on my own. I never play outside ...* (Carla, 12 years, epilepsy); *Yes, young people without a handicap [...] if they fall it is no problem [...] they are not staring at them* (Esmee, 14 years, haemophilia, spasticity). The younger group (12-15 years) mentioned difficulties with gymnastics more often than the older ones (16-19 years).

In relation to reactions of the environment, adolescents mentioned they did not like it to get unasked advice, even when it was given with good intentions. *Yes, I decide how to life for myself* (Daphne, 19 years, CF). *Yes, when you do not ask for advice, I think you do not have to get it* (Esmee, 14 years, haemophilia, spasticity). Further they disliked people joking about their condition. They tried to ignore this. It was clear that people who were not used to their CID changed their behaviour when the adolescents explained how it was to live with it.

Not many adolescents felt socially excluded because of their CID. One boy was not included in certain games with friends and girls who mentioned exclusion where excluded during sports / gymnastics. *Yes, at elementary school. There were children playing with a tennis ball [...] I was not allowed to play, because they were afraid they would be blamed when they hit me* (Jason, 13 years, haemophilia). In general, they did not feel rejected, but some had experiences with exclusion in the past.

Most boys mentioned not to ignore their disease because it did not help them to feel better, it could have bad consequences and others could draw wrong conclusions about why they acted the way they did. *You have to say that you have something, otherwise it can end up wrong* (Evert, 16 years, metabolic disorder). Few boys mentioned that ignoring helped them to become less aware of their CID. *If you do not give it much attention, you recognise it less* (Egbert, 13 years, IBD).

Girls mentioned ignoring their CID more often than boys. Two girls did not want to know all information, because they were afraid to be confronted with negative aspects of their CID (Carla, 12 years, epilepsy; Annika, 17 years, hormone deficiency). However, there were also girls who did not ignore their CID, because that would not change anything. Girls were much more divided than boys in relation to ignoring. The type of disorder did not seem to play a role.

When looking at disclosure about their disease, boys were more open than girls, but they also did not want everybody to know about their CID. Adolescents who did not want to tell everybody informed family, good friends, and people who they trusted about their CID. Both boys and girls only told people about their CID when they were asked to. *I tell people whom I trust, like friends at school and teachers* (Janneke, 17 years, heart disorder); *If people ask I tell them, but I do not start to talk about it by myself* (Mona, 17 years, bladder deviation); *I am very open about it, that is better than when people have to find out themselves* (Kasper, 17 years, haemophilia).

In short, it became clear that in relation to managing emotions there were clearly more differences between gender than between the two age groups. Girls mentioned being more emotional in relation to their CID than boys. They expressed more concerns, and seemed to have more problems with accepting differences and consequences caused by it.

4.2.5 Maintaining a positive self-image

The participants of the 'On your Own Feet' research project mainly saw themselves as anyone else without CID. They claimed they felt 'normal, with only having something on top'. Girls noticed 'being different' more often than boys, but both groups were convinced they lived a normal life. Girls (except one that had depressive feelings (Annika, 17 years, hormone deficiency)) mentioned, that despite being different they did not feel hampered by it, they tried to ignore it and just did everything they wanted when possible. *I do a lot of things a healthy child does. It hurts, but I still do it* (Diana, 14 years, arthritis); *Just like all the other boys. Just very normal. I can do whatever I want* (Thomas, 15 years, nephrotic syndrome).

The reactions on the question if they felt like anyone else, were remarkable. As well boys as girls mentioned that their CID does not influence their lives, while it was followed by comments like: *A little bit different* (while sitting in a wheelchair) [...] *mentally I am okay, only physically a little less* (Katja, 14 years, muscle disorder); *I do everything I want, only I, yes I have to inject myself* (Kasper, 17 years, haemophilia). *I think there is no difference. I mean people can have pain sometimes. And sometimes I have inflammation, but I do not think that is a difference* (Jolanda, 13 years, arthritis). Adolescents were aware of the differences, but tried to normalise this.

When looking at the effects of bullying on their self-image, half of the adolescents said they had not experienced bullying. Six boys mentioned being bullied sometimes. Their strategy was first ignoring it, but when it continued they might become aggressive. Girls mentioned being bullied more often than boys, but their self-image did not seem to be affected, supported by reactions like: [...] *I think let them be afraid* (Katja, 14 years, muscle disorder); *Losers, because they do not know what they say* (Sandra, 13 years, skin disease). No differences in maintaining a positive self-image were observed between the different age groups. The type of disorder did not seem to influence the self-image of these adolescents. Nevertheless, adolescents with physical or visible disorders experienced more bullying.

4.2.6 Relating to family members and friends

Especially the parents play a large role in dealing with the CID of their child. All adolescents mentioned that their parents were concerned about their health situation. *Well it feels good. That your parents want to know how you feel* (Arnaud, 19 years, facial schisis); *I think it is nice they are concerned. Better than when they say: 'well I do not care what you have ...'* (Janneke, 16 years, heart disorder). Most of them understood these concerns, but sometimes they still found their parents' reactions annoying. However, they did not have problems with it as long as their parents did not become overanxious. Adolescents found the concerns unnecessary during periods of well-being. Especially older girls claimed more often that their parents 'had to let them go'. They wanted to become more independent. *My mother is still like [...] she says everything about me [...] she has to let me go* (Anita, 16 years, epilepsy).

Parents had an important role in managing the treatment. Especially the mother reminded their children about taking medication and following the right regimen. This was more often the case in the younger age group (12-15 years). *Sometimes I forget to take my medications, then my parents tell me to do so* (David, 12 years, epilepsy). In general, the adolescents found it very important that their

parents reminded them, but three girls found it annoying that their parents controlled them too often. *I do not want my parents to choose my sport, I want to do it myself* (Esmee, 14 years, haemophilia, spasticity). Carla (12 years, epilepsy) felt limited because her parents did not allow her to leave the house without company.

The role of the mother was mentioned much more than the role of the father when adolescents for example spoke about support during treatment. *Sometimes my mother still helps me. Then she gives me a note with things I have to ask* (Kasper, 17 years, haemophilia); *My mother helps me, together we know everything* (Katja, 14 years, muscle disorder).

The role of parents in relation to the treatment and appointments in the hospital was experienced as very important, while in general, boys and girls wanted to be independent and did not want their parents to interfere too much in their daily activities. They felt safe and supported by their parents, because they also had the experiences with the disease. Further, it was mentioned that the parents arranged a lot for them. *I just like her to be there. Just as support [...] I like it when I do not have to go there myself* (Janneke, 17 years, heart disorder).

Only a few boys and girls mentioned something about the relationship with their siblings. Those who did, stated that their disease did not influence their relationship with their siblings that much. Three had a brother or sister with the same disease (CF, muscle disorder, and haemophilia). Girls mentioned more often that they spoke about their disease with their siblings. *I talk with my siblings about how it goes and how I feel [...] mostly they understand me* (Carla, 12 years, epilepsy).

Both boys and girls mainly did 'normal' activities with their friends. They experienced differences, but the disease was not seen as the most important aspect. Boys as well as girls informed their friends, but after that it was not further discussed. They also said not everyone needed to know what was going on with them. *Well, not really actually [...] I told them once [...] when they asked* (Janneke, 17 years, heart disorder); *When you are friends, you talk about other things* (Jasper, 18 years, kidney failure). Still, they felt supported by their friends. They were helpful, supporting and knew what to do when something in relation to the disease happened. One boy mentioned his life would be much harder without his friends (Kasper, 17 years, haemophilia).

Only three older girls (16-19 years) mentioned something about the relationship with their boyfriends. All three mentioned their boyfriend accepted them the way they are. One girl mentioned some bad experiences in relationships, but now her current boyfriend accepted the consequences of her disease. *I have had problems with boys, actually [...] now I am very careful who, and when, I tell about my disease* (Daphne, 19 years, CF).

In general, parents seemed to play a larger role in the adolescents' life in relation to the CID than friends. While parents were more supportive in relation to the CID, the adolescents undertook more 'normal' activities with friends. This underlines the fact that the adolescents do not see the CID as the most central aspect of their life. They just want to be like their healthy peers.

4.2.7 Preparing for an uncertain future

In general, the adolescents had a positive view in relation to the future. Boys and girls claimed they thought they were able to do whatever they wanted in their future. In case there were concerns about

future possibilities, they still wanted to make the best of it. *Just as normal, normal people, that live without a disease* (Zafir, 15 years, epilepsy). There were also adolescents who did not find it important to think about the future. Mostly because they did not want to face the negative consequences of their progressive disease. *I do not make plans for the next half year [...] Every time I make plans I disappoint myself, when they are not fulfilled* (Daphne, 19 years, CF). *I do not want to know [...] I feel that good. I do not want to think about death* (Katja, 14 years, muscle disorder).

As well boys and girls talked with their parents about the future. They sometimes also talked about it with (good) friends or siblings. This was not related to their disease, but more about future education, job and holidays. *About what I would like to do in the future, where to go, together on a holiday. That kind of stories* (Annika, 17 years, hormone deficiency).

There was a clear distinction between boys and girls in relation to this adaptive task. Girls were more worried about their future than boys. Furthermore, more girls were thinking about heredity and pregnancy. Most of the boys did not speak about it yet. They did not have the need, because it is something that might happen in the far future. However, there was a clear difference between the age groups of boys. Older boys thought more about it and for them it was more important than for the younger group. *Yes, if I have plans to get children, I would like to know* (Egbert, 13 years, IBD). Girls of both age groups thought about heredity and pregnancy and to most of them it was very important and did lead to concerns. *I do want children so desperately, but that will be very hard* (Anita, 16 years, epilepsy).

With respect to age, older boys and girls (16-19 years) did mention their future ideas about education and job more often than their younger peers (12-15 years). Further, they also did think about the future more often. In general, they felt that they just have to live with it, they were interested in what may happen in their future, but it did not play an important role in their lives yet. *Well, you cannot change anything about it* (Ricco, 14 years, metabolic disorder).

Most boys knew what they wanted to achieve with their future education and job. They did not think their illness would limit their possibilities. Their ideas were very clear and positive. *Yes, I think just normal, just like anyone else* (Thomas, 15 years, nephrotic syndrome). Girls, on the other hand, were much more uncertain. Especially the older age group (16-19 years) did not really know what they expected of their future. Two were worried that their illness might have a negative influence on their possibilities. *I think it will be harder to find a job, because of my arthritis* (Diana, 14 years, arthritis).

Only the older group spoke about living independent. Few of the participants mentioned this aspect, but those who did thought it would go well. *I want to have a car when I become 18 and of course I want to live on my own* (Anita, 16 years, epilepsy).

Finally, there were some striking comments about having the same thoughts, uncertainties and sorrows about the future as anyone without CID. *Well, nobody knows what the future will bring, right?* (Diana, 14 years, arthritis). *But everyone has sad feelings about the future sometimes* (David, 12 years, epilepsy). There was a clear difference in the view of adolescents with different disorders. Adolescents with life threatening diseases did not (want to) think about their future that much.

4.3 Additional findings

In this paragraph some additional findings that were not covered by above adaptive tasks are described.

4.3.1 School

Almost all adolescents still went to school, and therefore it is an important time consuming activity in their lives. The opinions on absence from school were divided. Some boys and girls found their health more important than school, and mentioned their treatment was most important. Therefore, missing out on school was no problem for them. *It is about your own health, school and work may be forgotten for a while* (Arnaud, 19 years, facial schisis). Others, on the other hand, like to have their appointments scheduled outside school hours as much as possible. They felt that as school was very important for them, it was annoying to miss too much. *Yes, for me school and work are very important* (Kasper, 17 years, haemophilia). The type of disorder did not seem to influence this view.

Furthermore, it was mentioned that the school did take their CID into account and supported them as much as possible. Some went to special schools, where the program was adjusted to the well-being of the adolescent. *They take your disease into account. When you are ill, you can still follow the program, you work on your own level* (Diana, 14 years, arthritis); *Yes, and at school there are all children with a disease* (Murat, 14 years, Duchenne).

4.3.2 Fellow patients

In the adaptive task relating to family members and friends, the relation with fellow patients was not included in the model of Moos and Holahan (2007). Nevertheless, this relation was brought up by the interviewers and sometimes by the adolescents themselves. The opinions towards patient associations and contact with fellow patients were divided.

One part of the adolescents claimed there was no need, because they did not miss it in their daily life; had enough support from friends and family; had no idea what the added value was; or did not want to think too much about their disease. *Well, I think, if you do not think about it, that it is much more convenient* (Egbert, 13 years, IBD); *I do not think so, because I do not have problems with being ill* (Zafir, 15 years, epilepsy). One girl mentioned she had no need, because then she would feel different and she did not experience it that way (Anita, 16 years, epilepsy).

On the other hand there were also adolescents that enjoyed talking about their experiences with fellow patients. They found it interesting to know how others handled their disease. Furthermore they felt supported and understood by their fellow patients. Six boys and one girl participated in special camps for fellow patients. They felt more understood by their fellow patients than for example at school. Nevertheless, they mentioned to talk not that much about their disease during the camp. They just enjoyed the activities with others and became friends. *We can support each other [...] You need someone who totally understands you, with who you can talk about it [...] with friends you can talk, but that is different* (Daphne, 19 years, CF); *So actually, it is just normal, you do not talk about your disease, just like other people talk with each other* (Ricco, 14 years, metabolic disorder).

Adolescents who did not know much about the existence of patient associations claimed they may be interested in the future or wanted more information about it. *Well, I have heard of it. Seems funny, but [...] I do not know what to expect from it (Annika, 17 years, hormone deficiency).*

Gender, age categories and different disorders seemed not to influence the view towards contact with fellow patients, while the positive attitude of parents did positively influence this view.

5. Discussion

This study investigated in which way the adaptive tasks from the integrative conceptual framework of Moos and Holahan (2007) are applicable to the situation of chronically ill Dutch adolescents. This chapter compares the empirical data with the conceptual framework and the existing literature discussed in paragraph 1.3. Furthermore, the strengths and limitations of working with a deductive model and secondary data are discussed. Finally strengths and limitations of this study are provided.

5.1 Lived experience

This paragraph outlines the lived experience of Dutch adolescents with CID compared to previous findings, using the overview of table 2 as an outline.

Developing and maintaining friendships; Relating to family members and friends

Berntsson et al. (2007) stated that friends were especially important for adolescents with CID, in promoting the feeling of joy and affirmation as an equal teenager. This statement is confirmed by the Dutch adolescents. They informed their friends about their CID, but did not discuss it anymore. They 'just' wanted to do normal activities with their friends.

Previous studies that compared friendships of adolescents with and without CID, showed some differences between disorders (Christian and D'Auria, 1997; Atkin and Ahmad, 2001). These differences between disorders were not clearly observed in this study. Differences with healthy peers were present. Adolescents particularly felt supported by their friends, but treatment adherence was negatively influenced sometimes.

Being normal / getting on with life; Maintaining a positive self-image

The process of normalisation (Royer, 1998) was clearly present in this study. Most remarkable is the way adolescent see themselves. While the environment may see a lot of difficulties and differences they felt normal, 'with only having something on top'. This study confirms findings from Atkin and Ahmad (2001). The adolescents were aware of 'being different', but they claimed to live a normal life. According to Woodgate, (1998) and Berntsson et al. (2007) not always focusing on the illness, but more on other things, is considered helpful for a lot of adolescents with CID. This is experienced by the adolescents, who most of the time did 'normal' activities with friends and fellow patients and talked about other things than their CID.

The importance of family; Relating to family members and friends

Parents play an important role for adolescents in relation to managing their CID. However, like in previous studies (Hokkanen et al. 2004; McEwan et al. 2003; Elliott et al. 2005), these adolescents disliked the overprotectiveness of parents. For some this was an obstruction to their independency. As mentioned by Berntsson et al. (2007), adolescents in this study also did not want their parents to interfere in their daily lives too much, but with respect to their CID they appreciated and wanted their support.

Atkin and Ahmad (2001) stated that most of the children were aware of the impact of their illness on other family members. However, the influence of their CID on their family was not clearly mentioned by the adolescents in this study. Those differences may be caused by the fact that no clear question about the effects on their family was formulated. In addition, Charmaz (1980) referred in her review that chronically ill young people often did not have the feeling they could call upon their siblings. Adolescents who spoke about it, did not have the feeling the relationship was influenced that much. Moos and Holahan (2008) combined the adaptive tasks relating to family members and maintaining and developing friendships. However, in this study it becomes clear that the types of relationships are quite different, and therefore may influence the coping skills in a different manner. This may be caused by the importance of peer acceptance during adolescence as mentioned by Suris et al. (2004). Therefore, these tasks may better be divided, like Taylor et al. (2008) experienced in their review.

Attitude to treatment; Managing treatment

With respect to attitude to treatment, previous findings of Christian and D'Auria, (1997) can be confirmed. Peer interactions (negatively) influenced treatment adherence, especially during activities with friends or at a party.

As found by Atkin and Ahmad (2001) adolescents in this study also needed to get used to their illness, but eventually found a routine and had not much problems with sticking to a therapeutic regimen. Support of parents was most essential to the promotion of compliance. In contrast to earlier findings (Kyngäs et al. 2000), friends did not seem to have a large role in managing the treatment.

That factors that influenced compliance with treatment differed between individuals (Kyngäs et al. 2000), became clear in the appearance of two groups: one that valued the importance of adherence, while the other stressed the importance of a good life. This was not clearly linkable to gender or age.

Experience to school

The experiences of the adolescents with school were not in accordance to previous findings.

Svavarsdottir (2007) and Pittet et al. (2010) found that adolescents with CID were more vulnerable, and more likely to be victims of bullying than their healthy peers, when going to school. Pittet et al. (2010) also stated that the greatest difference between adolescents with CID and their healthy peers lies in social exclusion. However, adolescents in this study claimed not to experience much bullying and exclusion. Hereby, they did not feel rejected. Furthermore, in contrast to earlier findings of McEwan et al. (2004), the adolescents felt that their CID was taken into account at school and they were supported as much as possible.

The task experience of school was not included in the model of Moos and Holahan (2007). This may be explained by the fact that their model is not just focussing on adolescents with CID, but on persons with CID in general. Nevertheless, school or work are an important area of social participation and strongly related to well-being. Sinnema (1992) found that adolescents with CID view independent living and economic participation as the cornerstone of social integration. According to Royer (1998), in relation to normalisation, the general idea about normal life includes the ability to work. Furthermore,

Atkin and Ahmad (2001) found that doing well at school or getting a job was seen as very important. School / work should therefore be added as separate task to the model.

Relationship with the health care professionals; Forming relationships with health care providers

As found by Britto et al. (2004), Dutch adolescents claimed they wanted to participate in their care, and desired from health care providers to take them seriously. However, they received a lot of support by their parents to make themselves clear. They appreciated the input of their parents, and had a kind of 'wait and see' attitude. This confirms the analysis of van Staa et al. (2011a), who used the same interviews.

It also became clear that the use of understandable language during the consultation, already argued by Hokkanen et al. (2004), was important for the Dutch adolescents. Furthermore, they found it important to trust their physician and had the feeling their physician had enough knowledge to help them. This confirms the findings of Berntsson et al. (2007) who highlighted the importance of the competence of doctors.

The future; Preparing for an uncertain future

Previous studies found personality, and the type and state of illness of influence on the way adolescents looked at the future. In this study, especially the adolescents with a life threatening disease did not look much ahead. In agreement with findings of McEwan et al. (2004), Nicholas et al. (2007) and Elliot et al. (2005), adolescents had worries about having children and heredity when they become older. Nevertheless, only a few worried about the negative influence of illness on future employment.

Again the optimism of the Dutch adolescents was remarkable. Despite of their CID they claimed to be able to do whatever they want in the future. Hereby, the normalisation process (Royer, 1998) was present. Adolescents spoke about the future with families and friends, but did not focus on their CID, but rather on 'normal' aspects of life.

Managing symptoms

Managing symptoms did not emerge as a separate task in the literature review of Taylor et al. (2008). Moos and Holahan (2007) included it in their model, because they stated the importance for individuals with CID to learn to recognise their symptoms and to try to control these as good as possible.

In this study managing symptoms emerged as an important aspect in managing CID. Therefore, it should be included as a separate adaptive task.

Managing emotions

Managing emotions did not emerge as a separate task in the literature review of Taylor et al. (2008). The fact that emotions influence every adaptive task, may be the reason Taylor et al. (2008) did not added this aspect as a separate theme. When adolescents mentioned their emotions this was always related with other adaptive tasks. It became clear that girls had more concerns and more problems with accepting differences and consequences caused by their disease than boys.

Fellow patients

The task fellow patients was not included in the model of Moos and Holahan (2007) or literature review of Taylor et al. (2008). Nevertheless, it has shown to be important for half of the interviewees. Therefore it should be taken into account.

General approach

This study showed that different health care problems encompass many comparable adaptive tasks. While there are some differences observed, adolescents with different CIDs have to deal with the same challenges. The relative importance may vary, like for example showed by the differences in treatment experiences. However, all adolescents had to deal with the same adaptive tasks.

5.2 Differences and relations

Gender and age groups

In the literature there was no focus on the differences between gender or age groups. However, from this study it becomes clear there are some important differences that should be taken into account. The largest difference between boys and girls is the way they manage their emotions. Girls have more problems with 'being different' in relation to healthy peers, more worries about their future, and with accepting the consequences of their CID. Furthermore, girls are not that open as boys about their disease. Another clear difference is that girls more often mention they want to be more independent. The main differences between age groups occurs with respect to treatment and health care provider. Older adolescents have more influence on their treatment and act more independently than the younger group. Another difference is the attitude against treatment adherence. The older group mentions more often that it is no problem for them to sometimes skip treatment or regimen, because they just want to live. Finally, the older group mentions more about their future ideas in relation to job and education. This may be caused by the fact that they are close to, or at the point they have to make decisions about these aspects.

Relations between adaptive tasks

The different adaptive tasks cannot be viewed in isolation. In some way they are all related to each other. The relationship with the parents and the influence on treatment adherence is a clear example, also noted by Taylor et al. (2008). Furthermore, managing emotions, symptoms and friendships, in such a way that the adolescents feel themselves just like anyone else and maintain a positive self-image, also demonstrates how tasks may influence each other.

Four tasks that most influence the other tasks are: maintaining a positive self-image, managing emotions, relating to family members and friends, and managing treatment (see table 5). This is in accordance with the four tasks found most important by Taylor et al. (2008).

Table 5 Relationships tasks

	Managing symptoms	Managing treatment	Forming relationships with health care providers	Managing emotions	Maintaining a positive self-image	Relating to family members and friends	Preparing for an uncertain future	School	Fellow patients
Managing symptoms	X	Knowing what to do when symptoms occur.		Ignoring of symptoms, aware of the risks.	Most mentioned no influence daily life Some felt limited. One girl afraid to be rejected.	Indicate limitations while undertake activities with friends.	Less concerns. Some concerns about difficulties in finding a job.		Interesting to know how others handled symptoms.
Managing treatment		X		Needed to get used to the treatment. Takes time. Girls mentioned more about their feelings.	Non-adherence to live a normal life. Quite independent in relation to treatment.	More non - adherence when with friends. Reminded by parents to take medication.	Some only want to become more independent in the future.	More non-adherence when undertaking activities.	Fellow patients understand treatment.
Forming relationships with health care providers		Receive enough information about treatment.	X	Some girls were afraid for confrontation with negative aspects of disease.		Support of parents appreciated. A lot in consultation with parents.			
Managing emotions	Accepting CID at certain level. Sometimes symptoms like pain difficult to manage.	Difficult to always remembering to take medicines. Not wishing to think about regimen when with friends.		X	Girls had difficulties with differences. Not many were excluded. Ignoring bullying and to 'feel normal'. Do not want everyone to know about their CID.	No feelings of rejection or exclusion.	Afraid some new problems will occur in the future.	Felt not rejected or excluded.	Feeling more understood by fellow patients.
Maintaining a positive self-image	Ignoring, do normal activities.	Non-adherence, to live a normal life.		See themselves as anyone else.	X	Not much bullying.	Positive view.	Not much bullying.	

Table 5 Relationships tasks (continued)

	Managing symptoms	Managing treatment	Forming relationships with health care providers	Managing emotions	Maintaining a positive self-image	Relating to family members and friends	Preparing for an uncertain future	School	Fellow patients
Relating to family members and friends	Supported by parents.	Parents provide a lot of support. Reminding medications, regimen.	Parents influence position of adolescent to HC provider.	Some wanted to be more independent. Concerns sometimes annoying / overanxious.	'Normal' activities with friends. No big role for disease Disclosure: Not everyone needs to know.	X	Discuss the future with parents and friends, but not much about disease.		Positive attitude parents influences view patient associations.
Preparing for an uncertain future				Girls more worried e.g. heredity.	In general very positive view. Same uncertainties as anyone else without CID.	Talk about future with family and friends. Not much about disease.	X	Future education / job.	
School		Divided: Treatment more important than school; others found school more important.		School is part of 'being normal'			School is important.	X	
Fellow patients	Fellow patients understand symptoms.	Fellow patients understand treatment.		Felt more supported by fellow patients.	No need, because than you feel different. Most did normal activities with fellow patients.	Enough support from friends and family.			X

Improving the model of Moos and Holahan

The model of Moos and Holahan (2007) seems to be a good starting-point for understanding the lived experience of adolescents with CID. However, in contrast to the model of Moos and Holahan (2007) and the findings in previous studies, this study shows adolescents with CID may have to deal with 10, instead of 7 different adaptive tasks. The model may be adjusted by adding the task school/work and splitting up the task relating to family members and friends as found by Taylor et al. (2008). Furthermore, fellow patients may have an important role in the adolescents' life. Nevertheless, it may be questioned whether the task managing emotions should be seen as separate adaptive task, because emotions have shown to be a common theme running through the different adaptive tasks.

Panel V of the model of Moos and Holahan (2007) is explicitly described in this study, but some aspects of the other panels are also observed.

With respect to the first panel, personal resources, keeping a positive self-image has shown to be a strategy to feel normal and cope reasonably well with problems of CID. Hereby, gender had influence on the amount of worries and problems with 'being different'. The positivity of the adolescents may lead to better outcomes. However, it may also cause unrealistic expectations, especially for adolescents with life threatening diseases.

That health-related factors (panel II) influence coping also became apparent. The higher the quantity of treatment and medication, the more often adolescents mentioned having difficulties with it. All adolescents claimed they get used to their disease, but had difficulties at the onset. This is in accordance with the suggestion of Moos and Holahan (2007) and Heijmans et al. (2004) who suggested that differences in the amount and type of stressors experienced between diseases could not solely be explained by the type of disease, but also by the stage. Adolescents seemed to have more difficulties with dealing with their CID at the onset.

It became very clear that the relationship with family and friends (panel III social and physical context) has a large role in the way adolescents deal with their CID. Adolescents leaned a lot on their parents. Friends had a large influence in 'feeling normal' and forgetting the CID. The influence of autonomy and mobility mentioned by Moos and Holahan (2007) appeared to play a role. Adolescents who were less mobile or not able to undertake activities by themselves more often claimed to have difficulties in managing their disease.

The two types of coping, avoidance and approach, were both observed (panel IV cognitive appraisal). As argued by Moos and Holahan (2007), individuals with more severe disorders seem to rely more on avoidance coping. Adolescents with life threatening diseases, for example, did not want to think about their future.

Because this study focused on the fifth panel, it is beyond the scope of this study to determine how the appraisal process is influenced, which coping skills (panel VI) are chosen and how the health-related outcomes (Panel VII) are affected. Further research is needed to improve the model and find out the applicability in practice. However, the results show similarities with the different panels of the model, which makes the applicability of the model as a whole more likely.

'Being normal'

Taylor et al. (2008) found developing and maintaining friendships the most important theme. However, from the results it became clear that maintaining a positive self-image was the most important adaptive task. Therefore this adaptive tasks may be seen as the most important theme for Dutch adolescents with CID. The strong desire to 'be normal' was the most remarkable finding of this study. Even adolescents with severe life threatening, health conditions (e.g. Daphne, 19 years, CF; and Murat 14 years, Duchenne) saw themselves as 'normal, with only having something on top'.

This positive self-image is underlined by the differences in experiences at school and relationships with friends in contrast to previous studies. Dutch adolescents did not claim to experience much bullying and differences at school. Furthermore, their CID was not central in their lives and relationship with friends. They claimed to live a normal life, just as their healthy peers.

The positive attitude of Dutch adolescents may be related with their culture. The Dutch quote 'when you act normal, you act strange enough' may be applicable in this situation. Dutch people do not like to be different, and try to 'go with the flow'.

5.3 Added value methods

While deductive analysis is not a commonly applied method in qualitative research, it was not the most logical procedure to choose for a master student. Nevertheless, the challenges and the added value it might produce also made it attractive.

After finishing the literature review, a lot of similarities with the theoretical framework of Moos and Holahan (2007) were found. However, the seven categories found in the literature did not exactly fit the theoretical framework. It was possible to incorporate these categories in the model, but this may be seen as a disadvantage of deductive analysis, because the researcher may be pushed in a certain direction.

The risk of theoretical conservatism as the main limitation of this approach, as argued by Bryman, (2004), has therefore been present during the analysis. There were moments that I had the feeling that I tried to fit the material into the categories. To avert this pitfall, I read the material several times, and tried to look at the material with an open view. The seven categories formed the starting point of the analysis, but the different aspects in those categories were created inductively, like proposed by Maso and Smaling (2004). In the end I did not have the feeling that I missed important aspects. By including the two tasks 'school' and 'fellow patients' all aspects seemed covered.

Working with an existing framework also had some benefits. With the literature studies already available it was presumable that the model of Moos and Holahan (2007) was applicable to empirical data. By taking the model as starting point it was not necessary to develop a complete new model, leaving more time for a thorough analysis of the interview material. This is in line with the arguments of Evers and van Staa (2010), who argued that deductive analysis may be efficient in research when theories and concepts of the subject under research are already available.

This study showed, in accordance with findings of Bryman (2004), and Maso and Smaling (2004), that inductive and deductive approaches can be simultaneously used in a research project. The existing

theories are supported and where necessary extended, which supports the findings of Elo and Kyngäs (2008) and Hsieh and Shannon (2005) who reported that deductive content analysis has shown to be well-suited to analyse the multifaceted characteristics of nursing.

As stated by Thorne (1994), the major challenge of using secondary data was fitting the secondary question within the design of the primary research. Because the data set is analysed from a different perspective, some aspects were insufficiently highlighted. I would have preferred to talk with the adolescents about how they stay that positive during difficult situations. Additional research may fill this gap. Further, the quality of the research material depended on the interviewer. Therefore, not all of the interview material was useful. Finally, as advocated by Elo and Kyngäs, (2008), it was not possible to take the latent content into account, which made it impossible to judge the behaviour of the adolescents during the interview, which may lead to wrong interpretations of the material.

Working with existing interview material had a lot of benefits too. There were 31 interviews directly available which gave me the opportunity to analyse a lot of material. I would never have had the opportunity to collect this quantity of material in the short time available for this study. The quantity of the material made it possible to draw general conclusions about adolescents with different types of CID. Furthermore, the amount of data was sufficient to achieve saturation.

As argued in a previous study by Hinds et al. (1997) this analysis resulted in useful findings that have not been made explicit in the primary 'On Your Own Feet' research project. By applying existing theory on a subject that had not received a lot of attention in the Netherlands, this study has shown there may be added value by using deductive analysis with secondary data. This study has built on existing theories from studies applied in other countries and showed that these findings are at least partly applicable in the Netherlands. By adding some new aspects into the model, the model can be made useful in practice and may be helpful in understanding the lived experience of Dutch adolescents with CID.

It should be held in mind that the applicability of this kind of research depends on the kind of study and the material available. The accurate description of the 'On Your Own Feet' research project and the peer reviews increased the trustworthiness of this study. If there is a lot of material about the subject under study available, it seems unnecessary to start all over again. When the researcher realises the limitations of this kind of research it may be very helpful in the development of theories and the applicability of it in practice.

5.4 Strengths and Limitations

Within the scope of this study several strengths and limitations could be found. Because only patients from one university hospital in the Netherlands were included the results may not apply in other settings. Nevertheless, the international literature studies showed a lot of similarities with adolescents with CID in other countries. Furthermore, a heterogeneous sample with a wide range of chronic conditions was used, whereby only general conclusions about adolescents with CID could be drawn. Because of this wide range of CIDs, it was difficult to really detect differences between conditions.

In general, the participants of this study were very optimistic about their situation. This may be caused by the fact that only children who looked positively at their disease wanted to participate and therefore there could be a selection bias involved. Nevertheless, some adolescents also expressed worried and insecure feelings.

6. Conclusion and Recommendations

In what way are the adaptive tasks from the integrative conceptual framework of Moos and Holahan applicable to the situation of chronically ill Dutch adolescents participating in the 'On Your Own Feet' research project?

6.1 Conclusion

Which elements of the conceptual framework are recognisable/applicable in the interviews of the 'On Your Own Feet' research?

In the interviews of the 'On Your Own Feet' research project, the adaptive tasks of the conceptual framework were all applicable. Therefore, the adaptive tasks of the model of Moos and Holahan (2007) form a good starting point to clarify the lived experience of Dutch adolescents with CID. Nevertheless, to improve the model the adaptive tasks school / work and fellow patients should be included to adjust the model to the situation of (Dutch) adolescents with CID. Furthermore, it is recommended to separate friends and family to better estimate the influence of these groups.

Live a normal life, and keep a positive self-image is the most important adaptive task for Dutch adolescents with CID. Besides, managing emotions seems to be a common theme to anticipate at the different tasks. The main finding is the optimistic attitude of the adolescents in relation to having CID. They do not focus on their CID, and are convinced of living the same, normal life, as their healthy peers.

What are the observed differences between boys and girls?

The boys and girls in this study do not approach their CID in a similar way. The difference emerges in the adaptive task managing emotions. Girls are more concerned and have more worries related to their CID. They have more problems with 'being different', more worries about the future and with accepting the consequences of their CID. Furthermore, they are less open about their illness. Girls also mention more often that they want to be more independent with respect to managing their lives. The attitude of boys is more relaxed. They will see what the future will bring.

What are the observed differences between age categories (12-15 years / 16-19 years)?

With respect to age, older adolescents with CID (16-19 years) emphasize the importance of living a normal life more often than their younger fellow patients (12-15 years), and for them it is no problem to skip treatment and regimen sometimes. Furthermore, they are more independent with respect to their treatment and think more about future perspectives.

What are the strengths and limitations of deductive analysis with secondary data found in this particular study?

Applying deductive analysis on secondary data may add value to previous findings and theories. It gives the possibility to support and extend existing theories, and may add aspects that had not been made explicit in the primary research. Furthermore, the availability of secondary data gives the opportunity to analyse a high quantity of data in a short amount of time.

Theoretical conservatism and insufficiently highlighted aspects due to the approximation from a different perspective are the most important pitfalls that should be taken into account. A combination of deductive and inductive analysis is needed to prevent an approach too narrow.

The researcher should take into account that the applicability of this kind of research depends on the kind of study and the material available. Deductive analysis may be efficient in research when theories and concepts under study are already available and when it is possible to fit the secondary question with the design of the primary research.

From this study became apparent that a generic approach against adolescents with different types of CID is valuable. Adolescents with different health care problems encompass many comparable adaptive tasks. Despite some differences between disorders, a generic approach is helpful in understanding the lived experience of (Dutch) adolescents with CID in general.

6.2 Implications for practice

It is important to know how adolescents experience and approach their CID. By understanding the aspects that influence their lived experience, it may be easier to respond in the right direction and find the right way to treat them. The model of Moos and Holahan (2007) may be helpful to find out where to focus on.

A key aspect in adolescents' life is social participation. Peer acceptance is very important during these teenage years. The main finding of this study underlines the importance of this acceptance and the wish of adolescents with CID to 'be normal'. Health care providers should pay attention to these aspects in life. They should take the influence of social participation into account during the prescription of treatment and precepts, because for example, treatment adherence may be (negatively) influenced by peers /friends and school activities.

Because of differences between boys and girls a different approach with respect to gender may be needed to customize their support. In consultations with girls, health care providers should pay more attention to dealing with sorrows and emotions. With respect to age, a different approximation between age groups is needed. Health care providers should incrementally support the adolescents in their way to (treatment) independency when they grow older. Furthermore, more emphasis on treatment-adherence may be needed for older adolescents.

6.3 Recommendations for further research

This study provides a snapshot of the lived experience of Dutch adolescents with CID. Longitudinal studies would be worthwhile to find out their experiences over time. During the interviews the adolescents were very positive about future possibilities. Further research is needed to find out if the lived experience of these adolescents changed over time, and if they are still that optimistic.

Because there are very few qualitative studies with deductive analysis performed it is difficult to exactly estimate the differences in outcomes of inductive and deductive analysis. Let two researchers analyse the same material with the two different approaches, may be helpful in strengthening these findings.

Panel V of the model of Moos and Holahan (2007) is explicitly described in this study, and showed to be a good starting-point in understanding the lived experience of adolescents with CID. The results of this study show similarities with the other panels of the model, which makes the applicability of the whole model more likely. Further research of the other panels is needed to improve the model and find out the applicability in practice.

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List of abbreviations

CF Cystic Fibrosis

CID Chronic Illness or Disability

DM Diabetes Mellitus

IBD Inflammatory Bowel Disease

Appendix I Quality assessment

Assessment of methodological quality (Cesario et al. 2002)

Author	Methodological congruence						Heuristic relevance			Total score‡	Quality of evidence§	
	Descriptive vividness	Rigour in documentation	Procedural rigour	Ethical rigour	Confirmability	Analytical preciseness	Theoretical connectedness	Intuitive recognition	Existing knowledge†			Applicability
Rechner (1990)	2	2	1	0	0	1	NA	3	3	3	15	II
Gallo <i>et al.</i> (1992)	1	3	2	0	0	0	2	2	3	3	16	II
Kyngas and Barlow (1995)	2	3	2	2	3	2	NA	3	2	3	19	II
Admi (1996)	3	3	2	1	3	3	3	3	3	3	27	I
Christian and D'Auria (1997)	3	3	3	0	3	2	2	3	3	31	25	I
Woodgate (1998)	3	3	2	3	1	1	2	3	3	3	24	I
Horne (1999)	0	1	0	0	0	0	NA	0	2	0	3	III
Snehen <i>et al.</i> (2001)	3	2	1	1	3	0	NA	3	3	2	18	II
Atkin and Ahmad (2001)	3	3	2	0	2	2	2	3	2	3	20	II
Edwards <i>et al.</i> (2002)	3	2	3	0	3	3	3	3	2	3	25	I
Kim and Kang (2003)	2	2	2	3	2	2	2	2	3	3	24	I
Eklund & Sivberg (2003)	3	3	2	1	3	1	2	3	3	3	24	I
Holkanen <i>et al.</i> (2004)	2	3	2	1	3	2	1	3	3	3	23	I
McEwan <i>et al.</i> (2004)	3	2	2	1	2	3	3	3	3	3	25	I
Beaune <i>et al.</i> (2004)	3	3	2	0	3	2	NA	3	3	3	22	II
Woodgate (2005)	3	3	2	0	3	2	NA	3	3	3	22	II
Woodgate (2006)	3	3	2	0	3	3	2	3	3	3	24	I
Damiao and Pinto (2007)	3	3	1	3	3	1	1	3	3	3	24	I
Rhee <i>et al.</i> (2007)	3	3	2	3	3	1	NA	3	3	3	24	I
Huus and Enskar (2007)	2	2	1	0	1	1	NA	3	2	3	15	II

*Scored 0-3 depending upon the percentage criteria met.

†Relationship to existing body of knowledge.

‡Sum of scores of the 10 assessment criteria, maximum score = 30.

§QI = total score of 22.5-30; QII = 15-22.4; QIII = < 15.

¶NA, Not applicable as no theoretical basis or theory generated.

Appendix II: Coding

	Managing symptoms	Managing treatment	Forming relationships with health care providers	Managing Emotions
What are the aspects individuals have to deal with to adapt to the situation?	Actions Cause Consequences Effects daily life Ignoring Signals	Regimen Adherence Consequences Emotions Hospitalization Independency Medication	Clarity / Communication Information Nurse Physician Position Support	Adjustment Concerns Consequences Differences Environment Exclusion Ignoring Disclosure

	Maintaining a positive self-image	Relating to family members and friends	Preparing for an uncertain future	School	Fellow patients
What are the aspects individuals have to deal with to adapt to the situation?	Being normal Bullying	Classmates Friends Friends future Friends relationship Parents concerns/ independency Parents future Parents regimen / treatment Siblings	Activities / development Carefree /Avoidance Concerns Health care Heredity Independency Job/ Education Symptoms Uncertainty	(Not divided into 'sub' codes)	(Not divided into 'sub' codes)