Consequences of success in pediatrics: young adults with disability benefits as a result of chronic conditions since childhood
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Consequences of success in pediatrics

With the increased rates of successful treatment in pediatrics and its positive effect on life expectancy, new questions emerge. What happened to those with a chronic condition since childhood while growing up? And how do they function in adult life? What help do they need? What are the building blocks for an independent, happy and successful life?

This thesis describes the psychosocial functioning, the emotional well-being and the factors affecting the vocational success and well-being of young adults with disability benefits as a result of a chronic somatic condition since childhood.
Consequences of success in pediatrics
young adults with disability benefits as a result of chronic conditions since childhood

Eefje Verhoof
Consequences of success in pediatrics
young adults with disability benefits as a result of chronic conditions since childhood

This study was conducted within the Psychosocial Department and the Department of Pediatrics of the Emma Children’s Hospital, Academic Medical Center, University of Amsterdam.

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General introduction and outline of the thesis
This thesis is about the psychosocial functioning, the emotional well-being and the factors affecting the vocational success and well-being of young adults with disability benefits as a result of a chronic somatic condition since childhood. The following paragraphs explain the process of growing up with a chronic somatic condition and the additional challenges it entails. The added value of work participation in general, the work situation of people with chronic conditions and an explanation of the disability benefits are described below. This introduction continues with the research questions, the research model and gives an elaboration of the research topics.

CONSEQUENCES OF SUCCESS IN PEDIATRICS

In the past, most childhood diseases were fatal for the majority of children. As a result of improved medical knowledge, technology and practices, including the development of pediatric surgical interventions, pediatric cardiac surgery and pediatric anesthesiology, pediatricians were able to change the natural course of numerous diseases. This resulted on the one hand in higher survival rates for many diseases, including cancer, metabolic diseases, congenital heart disease and cystic fibrosis, but on the other, in an increased number of children growing up with chronic health problems and morbidities since these children have been treated but have not been cured. In addition, the prevalence of some diseases like obesity, asthma and attention deficit hyperactivity disorder has increased as well.

Consequently, the number of children growing up with a chronic illness has increased enormously in recent decades. Although numbers vary depending on methods and definitions, by any estimate the scope of the problem is huge. The number of chronically ill children approximates 7 to 20 percent of all children and will likely further increase because of medical advancements. In the Netherlands there are about 500,000 children (14%) with a chronic disorder. The prevalence of specific disease and conditions range widely. In the Netherlands, the most common diagnosed illnesses in childhood are asthma (10%) and eczema (6%). Other moderately prevalent illnesses (<1%) are diabetes mellitus type 1, epilepsy, juvenile idiopathic arthritis (JIA), sickle cell anemia, cystic fibrosis, hemophilia, and inflammatory bowel diseases (CBS statistics Netherlands, 2013).

With the increased rates of successful treatment and its positive effect on life expectancy, new questions emerge. Now survival is no longer the major challenge, additional challenges are added. The focus has shifted to the influence of growing up with a chronic condition and to how pediatric illness affects adult life. What happened to those with a childhood onset illness or disability while growing up? And how do they function in adult life? Are they independent and
successful? Are they happy? What help do they need? They live longer, they mature, but what does it mean to grow up with a chronic illness for later societal participation as an adult in our society?

GROWING UP

Growing up and learning to be an adult is for everyone a complicated process wherein people during childhood, adolescence and young adulthood experience multiple transitions. These transitions are processes during which youth develop attitudes, behaviors, and skills to successfully move to adulthood. The transitions to adulthood comprise different developmental tasks, e.g., the consolidation of their identity, the transition from family life to independent living, and from education to employment. Some transitions are determined by age or development, while others are dictated by ‘systems’, for example, the educational system or healthcare system. This journey from childhood to adulthood is characterized by starts and stops, anxiety and anger, and hope and despair, coupled with an ever-increasing mastery of an essential set of life skills necessary for independence in adulthood. Youth development is much more complex than biological growth and maturation. There are patterns of physical, cognitive, social and emotional changes that youth go through, but these changes often occur simultaneously or in rapid succession. In the 21st century, youth development and transition into adulthood have become less straightforward.

Arnett has described a new phase of development called ‘emerging adulthood’, a period that exists only in highly industrialized or post-industrial cultures that postpone the entry into adult roles and responsibilities until well past the late teens. Such countries require a high level of education and training for entry into the information-based professions that are the most prestigious and lucrative, so many of their young people remain in school into their mid-20s. Marriage and parenthood are typically postponed until well after schooling is completed, permitting a period of exploration of various relationships before marriage and for exploration of various jobs before taking on the responsibility of supporting a family. These young people between the ages of 18 and 30 are on the threshold of adulthood. Emerging adulthood is also notable for its heterogeneity. It is the time when people’s lives are least likely to be structured by social institutions. Children’s and adolescents’ lives are structured by family and school, and adults live (in young adulthood and thereafter) by family and work. However, emerging adults typically move away from their families, and their school and work patterns tend to be formed, but are relatively unstructured and unstable. The characteristics of this developmental stage include the following: identity explorations – trying out various possibilities in love, work, living situations and world views; instability; being self-focused and feeling in-between—neither adolescent nor adult; and possibilities — when hopes flourish and young people have unparalleled opportunities to transform their lives. These are not features that exist only in emerging adulthood, but they are more pronounced in emerging adulthood than at other ages.

GROWING UP INTO ADULTHOOD WITH A CHRONIC DISEASE OR DISABILITY (1)

Children and adolescents with chronic conditions are expected to pass through similar developmental stages as their nondisabled peers, to leave home, develop psychosocially, and define a role for themselves in the community through employment or other activities. A chronic condition can have a profound influence on aspects of development during the transition into adulthood. Children and adolescents with chronic conditions face many additional challenges during this process. Most children experience several consequences of their health care needs; they depend on medical care or medical aids to some extent, varying from medication use to medical interventions or medical aids (e.g., daily inhalation of corticosteroids, intravenous alimentation, and wheelchair). Some of them also have to deal with (late) treatment effects. Further, transition into adulthood may be more difficult as there will be less exposure to everyday events and therefore to opportunities to learn and explore. Social opportunity is lessened by ill health including frequent hospitalizations, and exclusion from the opportunities afforded by mainstream schooling or unsupervised play with in the age-appropriate peer group. The adolescent process of exploring limits, reality testing, and self-image development may be severely delayed. Enhanced vulnerability owing to physical or psychological stress may also complicate the transition to adulthood.

Concern has risen about the implications of growing up with a chronic condition. The condition and late treatment effects may affect the physical functioning and emotional functioning. Children with chronic diseases are somewhat more likely than healthy children to show maladjustment. They tend to suffer more than average from behavior problems, especially internalizing problems such as depression, anxiety, and social withdrawal. A meta-analysis of Pinquart and Teubert found children and adolescents with chronic physical illness to have, on average, lower levels of academic, physical, and social functioning than their healthy peers. Impairments were largest for physical function-

(1) International consensus about the conceptual definition of chronic health conditions in childhood is needed. Essential components of a definition are that the disease can be diagnosed according to professional standards, a basic requirement to ensure validity, as well as an expected duration of at least 3 months or the impossibility of cure. Disability is the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, developmental, or some combination of these. A disability may be present from birth, or occur during a person’s lifetime.
ing and smallest for social functioning. In line with this, evidence suggests that school-aged children with chronic conditions, regardless of their diagnosis, are at risk for lower participation in everyday activities than their peers; they participate less frequently in almost all activities compared with children without a physical disability. Furthermore, it is known that youth who have grown up with a disease are at risk for a delay in age-specific developmental tasks compared with peers, resulting in a delayed course of life. In summary, a part of the children with chronic conditions may have difficulties while growing up.

Exception for survivors of childhood cancer and those with end-stage renal disease, little research exists about whether the challenges and gaps between youth with chronic conditions and those without, persist into adulthood. Will they finish education, get jobs, and live independently? Can they become autonomous in a society where self-sufficiency and independence receive widespread recognition and social endorsement? And most important, how do they fulfill their lives in a meaningful and satisfying way? Given that the majority of research on emerging adulthood focuses on typically developing, college-attending healthy youth, little is known about the impact of growing up with a chronic condition on the milestones of emerging adulthood including work participation and the adaption to adult life.

**WORK**

An important way to participate in social life is work. Work generates material and immaterial benefits. The material purpose of work is earning an income to be able to support oneself. Besides money, employment offers a lot of other additional immaterial benefits like the possibility for further self-development, social relationships, development of skills, daily rhythms, and often, self-esteem and meaning in life. Having a paying job at some time during high school has become a near-universal adolescent experience. At first, paid work is episodic and generally quite limited. Many youth start to work informally even earlier, at about the age of twelve, most often in their own neighbourhoods, babysitting, cutting grass, or doing various odd jobs. By the age of 16, adolescent workers are more likely to have formal jobs, working in the retail and service sectors of the economy, for example in fast food restaurants, or retail stores. Employment becomes more regular and more time-consuming during the latter years of high school, with many teens working 20 or more hours per week. During and after their study this process continues; most young adults start a working career which continues in adulthood.

**Somatic conditions and work participation**

Having a chronic disease or disability often negatively affects the capacity to participate in gainful employment. A poor health condition, however, does not necessarily imply exclusion from the labour market. Yet, in various studies, the labour market position of people with a chronic disease or disability is found to be problematic, with regard to getting a job as well as job continuation. This, in turn, leads to a variety of economic, social and quality of life problems. The consequences of work disability for patients with chronic diseases include financial difficulties, increased social isolation, decreased confidence and self-esteem and stress. Besides, several studies among people with chronic somatic diseases show lower Health Related Quality of Life (HRQoL), worse mental health and more anxiety and depression in non-workers than in those who are participating in the workforce.

**Adolescents and young adults with somatic conditions and work participation**

Most of the research on the work experiences of people with disabilities has focused on adults while much less attention has been paid to younger people just entering the workforce. However, employment and its skill-building opportunities are essential elements for a successful transition to adulthood for young people. Adolescents want to work to earn their own spending money to be able to buy the accoutrements of adolescent life and take part in the leisure activities among their peers. Working enriches young people’s life experiences, thereby enhancing self-confidence, self-discipline, self-esteem, and independence. Furthermore, working experiences help young people think about their possible career trajectories and develop work attitudes. The shift out of school into education and occupation is a developmental stage in which young people gain increasing sense of control over their lives, experience a greater responsibility, and form an identity which they can use to shape their sense of self that will likely endure throughout adulthood. Avoiding unemployment in early adulthood is particularly important, because the decisions and actions that occur during this time, can affect income levels and occupational achievement across the lifespan.

In general, youth with disabilities are much less likely to be employed than their peers during high school and often encounter barriers when striving for independence. This trend of unemployment during adolescence appears to be continuing in young adulthood. Young adults with disabilities experience considerably lower employment rates compared to their non-disabled peers and their unemployment periods often last longer and they face higher risks of losing their jobs than non-disabled people (www.edf-feph.org).
YOUNG ADULTS WITH SOMATIC CONDITIONS AND DISABILITY BENEFITS IN THE NETHERLANDS

In the second half of the 1970s the Netherlands government made a crucial decision to support that young people with chronic conditions or disabilities can participate in society with a personal income, independent from parents and others. This was effected through the General Disability Act (AAW), a national insurance against disability, which in principle all residents of Netherlands were insured for. There have been a number of developments and changes in this insurance for young people over time. The following Act was effective during this study:

The Disablement Assistance (Young Persons) Act; ‘old’ Wajong (2)

The General Disablement Act was abolished in 1997, and on 1 January 1998 a new Act came into force for young people and students who have become disabled at an early age and therefore do not qualify for wage-related benefits: the Disablement Assistance (Young Persons) Act, known as ‘Wajong’ in Dutch. This Act provides (supplementary) income support as well as support to find employment and if necessary support at the work place. The benefit is not obligatory or automatically including all young adults with disabilities: the initiative for application lies with the individual and his/her social environment. A Wajong benefit is payable not earlier than the 18th birthday, for as long as the inability to work lasts and ends when the recipient reaches the age of 65. The Employee Insurance Agency (UWV) implements the Act and is also responsible for determining the level of benefit paid. The level of benefit received under the terms of the Act depends on age and the amount someone can earn from a job; Wajong income support is a supplementary payment on top of what a young person with a chronic disease or handicap is able to earn from work. The UWV insurance physicians assess the work ability of the claimant considering the medical history and prognosis and describe the limitations for work. Based on the limitations assessed by the insurance physician, employment specialists investigate what jobs the claimant could perform on the labour market despite these limitations and what work opportunities are available. Depending upon the question whether or not the young disabled can theoretically earn a minimum wage with a job, a disability pension will be refused or awarded. A part of those who receive a Wajong benefit is potentially (partially) capable to work. The other part is declared fully unfit for work.

Numbers of Wajong applicants

The numbers claiming benefits under the Wajong scheme rose from 40,000 in 1976 to 127,400 in 2000 and 238,700 in 2013 (table 1). This meant that one out of every 20 people aged 18 (4.8%) was claiming and receiving this disability benefit. This increase contrasted with the numbers of claims made under the WAO/WIA Act – which caters for people who develop a disability at some stage during adulthood – which has seen modest falls in recent years. A number of studies have examined the possible causes of this take-up of the scheme. The reasons behind the increase in claimants of this disability benefit are complex and likely to be multi-factorial. For example, the eligibility rules for entry into benefits systems are likely to have changed, diagnostic criteria may also have changed, and systems may have become more efficient at recognising health problems. At a personal level, there may have been a real increase in health problems or there may have been a decline in employment prospects which has pushed people to register as disabled. Social reasons, especially those relating to the level of family support, may also play a role. Also, statistical or administrative aspects, the maturation of the scheme, and greater awareness of the scheme amongst potential claimants can have influence. In addition, the current economic climate could affect attitudes towards the employment of young people with health problems. It is not known what proportion of children and young people who grow up with a chronic somatic disease or disability eventually ends up in the Wajong.

<table>
<thead>
<tr>
<th>Year</th>
<th>Influx Wajong benefit</th>
<th>Outflux Wajong benefit</th>
<th>Current benefits end of year</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>8,200</td>
<td>4,400</td>
<td>158,500</td>
</tr>
<tr>
<td>2004</td>
<td>9,400</td>
<td>4,900</td>
<td>142,600</td>
</tr>
<tr>
<td>2005</td>
<td>10,400</td>
<td>5,600</td>
<td>147,200</td>
</tr>
<tr>
<td>2006</td>
<td>13,600</td>
<td>4,900</td>
<td>155,900</td>
</tr>
<tr>
<td>2007</td>
<td>15,300</td>
<td>4,400</td>
<td>166,800</td>
</tr>
<tr>
<td>2008</td>
<td>16,100</td>
<td>4,300</td>
<td>178,600</td>
</tr>
<tr>
<td>2009</td>
<td>17,600</td>
<td>4,300</td>
<td>192,000</td>
</tr>
<tr>
<td>2010</td>
<td>17,800</td>
<td>4,600</td>
<td>205,500</td>
</tr>
<tr>
<td>2011</td>
<td>16,300</td>
<td>5,200</td>
<td>216,200</td>
</tr>
<tr>
<td>2012</td>
<td>15,300</td>
<td>5,100</td>
<td>226,500</td>
</tr>
<tr>
<td>2013</td>
<td>17,700</td>
<td>5,500</td>
<td>238,700</td>
</tr>
</tbody>
</table>

(2) The new Wajong Act was introduced on 1 January 2010. See appendix for further details.
Gender, age and diagnoses of applicants at Wajong influx

Table 2 shows the gender, age and diagnoses of new Wajong applicants. There are slightly more men than women applying for a Wajong benefit. Most applicants enter the Wajong at an early age. The Wajong influx contains for the most part of youngsters having developmental disorders. Another large group of young people have been diagnosed with psychiatric disorders (25%, for instance schizophrenia or personality disorder). These statistics only partly reflect the reality because 42% have multiple conditions diagnosed 53. About 14% is having a disability benefit because of somatic (physical) malfunctions or disorders.

TABLE 2: Gender, age and diagnoses of Wajong applicants at influx in 2008, 2010 and 2013

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2010</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>58</td>
<td>57</td>
<td>58</td>
</tr>
<tr>
<td>Women</td>
<td>42</td>
<td>43</td>
<td>42</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 and 19 year</td>
<td>58</td>
<td>62</td>
<td>62</td>
</tr>
<tr>
<td>20 t/m 24 year</td>
<td>20</td>
<td>22</td>
<td>24</td>
</tr>
<tr>
<td>25 t/m 34 year</td>
<td>13</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>35 year and older</td>
<td>9</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Diagnosis group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Development disorders</td>
<td>60</td>
<td>66</td>
<td>67</td>
</tr>
<tr>
<td>Mental retardation (intellectual impairments, learning problems)</td>
<td>38</td>
<td>37</td>
<td>35</td>
</tr>
<tr>
<td>Autistic spectrum impairments</td>
<td>11</td>
<td>15</td>
<td>18</td>
</tr>
<tr>
<td>Attention deficit (ADHD, ADD)</td>
<td>4</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Other development disorders</td>
<td>6</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Psychiatric diseases</td>
<td>26</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>Somatic diseases</td>
<td>15</td>
<td>13</td>
<td>14</td>
</tr>
</tbody>
</table>

Annual report Employee Insurance Agency (UWV jaarverslag 2013)

Work participation of Wajong applicants

Although some of the young adults with Wajong benefits were unable to work in any way because of their limitations, others could and were willing to work. However, those young adults with a Wajong benefit who were able to work remain under-represented in the labour market. Data from the Social and Economic Council of the Netherlands (SER) indicated that around 60% of people on Wajong benefit were able to work (at least 12 hours a week). In reality, around 25% did so (table 3) 51, 51, 53. The greatest part of the young adults with Wajong benefits has difficulty participating in employment. The problem of the low employment rate among people on Wajong benefit is in finding employment, as well as in holding on to it. A high proportion of those who find employment lose their jobs within a short time 53. Around 20% of the people who are not working when they get the Wajong disability benefit find a job within a year. Almost half of those who find a job, lose their job again within one year 53.

TABLE 3: Number of working people with a Wajong benefit

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people with a Wajong benefit</th>
<th>Number of working people with a Wajong benefit</th>
<th>Percentage working people with a Wajong benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>147,161</td>
<td>38,735</td>
<td>26,3%</td>
</tr>
<tr>
<td>2006</td>
<td>155,860</td>
<td>39,814</td>
<td>25,5%</td>
</tr>
<tr>
<td>2007</td>
<td>166,805</td>
<td>45,613</td>
<td>27,3%</td>
</tr>
<tr>
<td>2008</td>
<td>178,590</td>
<td>45,900</td>
<td>25,7%</td>
</tr>
<tr>
<td>2009</td>
<td>191,956</td>
<td>47,598</td>
<td>24,8%</td>
</tr>
<tr>
<td>2010</td>
<td>205,154</td>
<td>49,700</td>
<td>24,2%</td>
</tr>
<tr>
<td>2011</td>
<td>216,240</td>
<td>53,844</td>
<td>24,9%</td>
</tr>
<tr>
<td>2012</td>
<td>226,481</td>
<td>53,749</td>
<td>23,7%</td>
</tr>
<tr>
<td>2013</td>
<td>238,708</td>
<td>53,890</td>
<td>22,6%</td>
</tr>
</tbody>
</table>

Employee Insurance Agency Wajong monitor 2008 en 2010; key data Wajong 2013

THE EMWAJONG STUDY

Among the young adults with Wajong benefits as a result of a chronic illness or disability, some have a congenital disease or disability, some are survivors of a severe disease in childhood, some have a long-standing yet less severe condition and some have been ill or disabled since adolescence only. Health status and functional limitations, however, do not tell us everything about the impact of growing up with a chronic condition on well-being and participation in society. The major question is that of their well-being, independence and future. Since the Wajong population can be considered as the most vulnerable young adults with chronic conditions – those who have to apply for disability benefits as a result of their conditions – it is essential to gain insight into the challenges they may be encountering in dealing with their condition while becoming an adult. All in all, the (often hidden) psychosocial consequences of the pediatric success story on growing up and social integration deserves attention. If we can gain insight into the adjustment and process of growing up of the Wajong population, their emotional well-being and factors affecting their vocational careers, we may be able to develop strategies to support this vulnerable population towards adulthood independence and economic participation. It is crucial that these young adults in our society are able to find their place in the adult world.
Aim and research questions
The purpose of this study was to evaluate the psychosocial functioning, the emotional well-being and the factors affecting the vocational success and well-being in young adults with a Wajong benefit for a childhood-onset chronic somatic condition while growing up. The study was aimed at young adults with a disability benefit as a result of a somatic illness or condition. The primary research questions of this study are as follows:

1. How does the psychosocial developmental trajectory (course of life) of young adults with disability benefits as a result of a somatic condition compare to that of a reference group?
2. How does the Health Related Quality of Life (HRQoL) and anxiety and depression of young adults with disability benefits as a result of a somatic condition compare to that of reference groups?
3. What are the Illness Cognitions (IC) of young adults with disability benefits as a result of a somatic condition? Is there an association of IC with HRQoL, anxiety and depression in this study population?
4. Is there a difference in the psychosocial development trajectory of young adults with and without a disability benefit?
5. What are the disease characteristics, work characteristics, and work motivation of young adults with disability benefits as a result of chronic conditions and the association of those factors and IC with the likelihood of being employed?

Research model
The guiding framework (figure 1) for this thesis is the International Classification of Function, Disability and Health (ICF) (World Health Organisation, 2001). This model integrates the major models of disability – the medical model and the social model – as a bio-psycho-social synthesis and measures health and disability at both individual and population level and covers the entire life span. The ICF classification does not classify people according to a diagnosis but describes different ways of functioning. The model identifies three levels of human function: body functions and structures (perspective of the body), activities (perspective of the individual), and participation (perspective of society). The functioning (both the capacity and the performance) of the individual can be influenced by the disease or disorder, but also by personal factors (e.g. age, gender, self-esteem and motivation) and by environmental factors (e.g. the social environment). ‘Disability’ is the ICF umbrella term for impairments (a problem in bodily functioning), activity limitations (like walking or personal care) and participation restrictions (a restriction an individual may experience in involvement in life situations, like labour, going to museums, going on holidays and meeting friends), influenced by personal and environmental factors.

The ICF model conceptualises functioning and disability as a dynamic interaction: disability can lead to loss in abilities, which in turn can lead to problems in participation in society. Young adults with disability benefits because of chronic conditions may experience problems in every day life. They may have participation restrictions while growing up because of difficulties in performing desired activities, which can influence their functioning and health condition. Outlined below are the topics in this study that could influence the interrelation between the functioning and disability of young adults with Wajong benefits.
for little of the variability in psychosocial adjustment compared to psychosocial factors. Less is known about medical and socio-demographic parameters and adjustment in emerging adulthood. A meta-analysis of Pinquart indicated that stronger differences in the achievement of developmental milestones - finishing advanced education, finding employment, leaving the parental home, marrying, and becoming parents - were found for respondents with neurological illnesses and sensory impairment than in individuals with other chronic diseases. Lower success rates were also observed if the illness/disability is highly visible to others and in the case of longer illness duration.

Chapter 1

The course of life has been investigated in several disease specific groups. From a developmental psychological point of view, risk behaviour is also relevant. To a certain extent, displaying risk behaviour – in terms of trying out – is part of the development from being a teenager to becoming an adult. Adolescents grown up with a chronic condition may display less risk behaviour than do their nondisabled peers. For patients with impairments, reaching these developmental stages can be challenging. They face many additional challenges to negotiate and obtain normative developmental milestones and maintain adaptive functioning. The burden of the disease or disability, treatment, hospitalization and long-term medical sequelae, and decrease in social and school-based participation could be a threat to the accomplishment of developmental tasks, resulting in a delayed course of life.

From a developmental psychological point of view, risk behaviour is also relevant. To a certain extent, displaying risk behaviour – in terms of trying out – is part of the development from being a teenager to becoming an adult. Adolescents grown up with a chronic condition may display less risk behaviour than do their healthy peers, because they are keenly aware of the vulnerability of their health. Moreover, increased parental involvement as a result of the paediatric condition experience may limit children’s opportunities to have unsupervised time with peers, which may decrease their opportunities to engage in risk activities with peers. On the other hand, we could possibly expect to observe more risk behaviour among adolescents with a childhood-onset, in compensation for the limitations that were imposed upon them by disease in their youth. The course of life has been investigated in several disease specific groups. We already know that young adults who have grown up with a disease are at risk for a delayed CoL compared with the peer group. Particularly the CoL of patients with end-stage renal disease and survivors of childhood cancer was found to be hampered. So far, little is known about the CoL of young adults with somatic chronic diseases or disabilities with disability benefits.

Course of Life

The developmental consequences of growing up with a childhood chronic condition may have consequences in adulthood. The fulfilling of age-specific developmental tasks in youth is of great importance to the adjustment in adult life. The developmental tasks and the resulting developmental milestones that are necessary in the development of a child are referred to as ‘the course of life’ (CoL). The normal developmental tasks of childhood and adolescence involve the attainment of social and academic competence, the development of peer relationships and increasing independence from parents. Children and adolescents with chronic diseases are expected to pass similar developmental stages as their nondisabled peers. For patients with impairments, reaching these developmental stages can be challenging. They face many additional challenges to negotiate and obtain normative developmental milestones and maintain adaptive functioning. The burden of the disease or disability, treatment, hospitalization and long-term medical sequelae, and decrease in social and school-based participation could be a threat to the accomplishment of developmental tasks, resulting in a delayed course of life.

Health Related Quality of Life

WHO defines Quality of Life (QoL) as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment. Health-related quality of life (HRQoL) refers to how health impacts on an individual’s ability to function and his or her perceived well-being in physical, psychological and social domains of life. Physical functioning refers to activities of daily living, as well as to physical symptoms resulting from disease or treatment. This physical functioning part of HRQoL includes basic activities, such as self-care (eg, bathing, dressing), as well as work-related activities (whether paid or not) such as housework and career. Social functioning refers to social relationships and interactions, and to societal integration. The psychological well-being part of HRQoL is somewhat more subjective than the functioning part, because it relies almost exclusively on the internal, subjective perceptions of the respondent. Psychological functioning ranges from severe psychological distress to a positive sense of well-being, and it may encompass cognitive functioning. Included is whether the person feels happy, sad, depressed, or anxious (emotional well-being), whether they are in severe pain or have no pain at all, and whether they are energetic or lethargic. Beyond this core set of HRQoL domains, additional issues may be relevant. In the case of young people with chronic illness, developmental changes should be taken into consideration. Definitions of HRQoL therefore should include goals and aspirations as well as the constraints imposed through ill-health and treatment.

The past 20 years has seen an explosion of studies of HRQoL in chronic conditions, reflecting a widening of focus from biomedical outcomes to include psychological and social dimensions of health. This expansion in the field of HRQoL studies is mainly focussed on children and adults. Overall, children with a chronic disease are at a greater risk of HRQoL problems than their healthy peers, but not in all cases, and not on all domains. A lot of studies describe the HRQoL of adolescents with a chronic childhood condition, but less studies report the HRQoL of young adults with a chronic childhood condition. Most studies on HRQoL on young adults with a chronic condition have been...
illness specific and show affected HRQoL scores. For example, survivors of childhood cancer reported a lower HRQoL than their peers and specific chronic health problems had a negative impact on survivors’ HRQoL. The literature on adults with chronic illness since childhood found a lower HRQoL and more emotional problems compared to the general population. Socio-demographic characteristics such as gender, age and education are generally of little significance for the general health perception of adults with a chronic illness or disability. The severity of the condition seems to have more impact on their HRQoL than the nature of the condition itself.

Having a paid job can have positive effects on the wellbeing and QoL of people of working age. Several studies among people with chronic somatic diseases show lower Health Related Quality of Life in non-workers than in those who are participating in the workforce. Nevertheless, there are also studies indicating only small differences in the HRQoL between working and non-working people with a chronic somatic disease. Particularly, the severity of the physical disability carries weight in the evaluation of someone’s HRQoL. Participation in work and well-being appears to be less associated when adjusted for the severity of physical disability. However, few studies have focused on the emotional well-being of young adults with childhood onset chronic conditions who encounter barriers when pursuing employment, as compared to young adults without chronic conditions. Also, the HRQoL and emotional functioning of young adult beneficiaries with a childhood-onset somatic condition as a group has never been studied.

Anxiety and Depression

In the general adult population, having a chronic illness is a significant risk factor for the development of mental health disorders such as anxiety and depression. Internalizing problems, such as anxiety and depression are also described as potential concerns for children with chronic illness. Several meta-analyses on children with chronic illness have found elevated levels of anxiety and depression in children with chronic physical illness. Two meta-analyses of Pinquart and Shen compared levels of anxiety and depression of children and adolescents suffering from chronic illnesses with their healthy peers across a large number of diseases. Strongest elevations were found for chronic fatigue syndrome, migraine/tension headache, sensory impairment and epilepsy in relation to anxiety, and in chronic fatigue syndrome, fibromyalgia, cleft lip and palate, migraine/tension headache, and epilepsy in the case of depression. Most research on mental health and chronic conditions concern children or adult populations. Less is known about anxiety and depression on those in the period of emerging adulthood.

Illness cognitions

There is increasing evidence that psychological factors play an important role in the adaption to living with a chronic disease. Studies on adaptation to chronic illness have shown that there often is a considerable discrepancy between the level of illness-related dysfunction as reported by patients and the underlying pathology of their disease. The magnitude of the physical, mental, and social problems that patients with chronic diseases present can vary greatly from patient to patient, even in patients with the same medical condition or the same severity of disease. The weak relationship between biomedical parameters and wellbeing has given rise to the hypothesis that other, psychosocial, factors contribute to health outcomes in patients with chronic diseases.

In recent years, the role of illness perceptions and coping responses of patients have especially been highlighted. Health psychologists have shown that, to make sense and respond to the problems caused by a chronic illness, patients create their own explanations or “beliefs” on their illness. When patients are diagnosed with an illness they generally develop an organised pattern of beliefs about their condition. These illness perceptions or cognitive representations directly influence the individual’s emotional response to the inherently aversive character of a chronic condition, to maintain a sense of balance and to achieve a satisfying quality of life. This in turn determines how patients respond to the chronic condition; in their coping behaviour such as adherence to treatment. It has been commonly assumed that the way adult patients perceive and think about their illness accounts for much of the individual differences in their physical and psychological health status. Specifically, patients who report high levels of helplessness and low levels of acceptance with regard to their illness, emphasize the negative aspects of their condition. They generalize their cognitions to all facets of daily life and consequently experience worse physical and psychological functioning. In this view, illness cognitions (IC) can be considered as prognostic factors predicting physical functioning, psychological distress and therefore possibly adaption to society.

In addition, there is increasing evidence that illness cognitions could play a role in work participation. A review study of Hoving et al. exploring the relationship between illness perceptions and work participation in patients with somatic diseases and complaints found promising evidence. Even though the number of studies in the review was limited, all included studies report significant findings between one or more illness perception dimensions and measures of work participation. In particular, all studies found that non-working people perceive more negative consequences of their disease. This suggests that illness perceptions play a role in the work participation of patients with somatic diseases or complaints. Most of the research on IC has focused on adults while...
much less attention has been paid to younger people who grew up with a chronic condition. Also, the IC of young adult beneficiaries as a group has never been studied.

Factors that influence participation in work

There is little detailed information about the employment patterns of young people with chronic conditions compared to their non-disabled peers. Although there are studies on (return-to-)work factors among adults with chronic conditions, the factors found for impaired adults may not be the same as those for young adults who are at the beginning of their career. Knowledge regarding factors that influence the work participation of young adults in practice is hardly available. Previous studies mentioned the following factors: socio-demographics (age, gender, education, geographic location and the number of people living in the household), psycho-social functioning, severity of disability, type and duration of disability, level of depression and dispositional optimism. A systematic review concerning factors that promote or hinder work participation in young adults with disability benefits found motor impairment, low physical ability, co-morbidity, epilepsy, IQ lower than 80, younger age at diagnosis and higher radiation grade in cancer survivors to be related to negative employment outcome. However, the abovementioned studies focussed on specific disease categories or examined both physical and mental conditions. So far, little is known about the early determinants of work integration of young adults with disability benefits because of a chronic somatic condition as a group.

Motivation

Young people’s motivation points out to be a critical ingredient in achievement in education and in occupational outcomes later in life. Those with a firmer work motivation are more likely to participate successfully on the labour market. Among the young adults with chronic conditions, motivation likely leads to greater initiative to search for employment. In addition, motivated people receive more guidance or support to find a job, and coaches and employers react positively to motivated individuals.

Also, lack of motivation has been found to be an internal barrier to employment for these young adults. It is hypothesised that motivation and early employment history are interrelated, such that early frequent job losses had an impact on the individual’s self-confidence and increased anxiety, which led to a likelihood of a pattern of job loss.

The work motivation of young adults with Wajong benefits as a result of somatic complaints has never been studied. What about their work motivation?

Are their aspirations associated with their illness cognitions and better employment outcomes in early adulthood?

STUDY DESIGN

The EMWAjong study is a large cross-sectional study. All young adults between 22 and 31 years of age who claimed a Wajong benefit (3) in the year 2003 or 2004 for a chronic somatic condition were invited to fill in an online questionnaire via a letter. The target group is a heterogeneous group with different types of health conditions and different abilities and limitations. Those with no sustainable work opportunities (classified as fully incapable for work) were excluded because the EMWAjong study aimed to identify factors that could help to improve vocational success. Those with serious cognitive impairment or psychiatric conditions were also excluded because the EMWAjong study was directed at young adults with childhood-onset somatic illness or disability.

In total, 2,046 persons were invited to take part in the study. To maintain the privacy of the beneficiaries, the invitation letter was sent by UWV, the Dutch benefits agency. The letter contained a personal log-in code, a password and a link to the online questionnaire. After two weeks, participants received a reminder letter. Participants who completed the entire questionnaire received a gift voucher. The sample was recruited at the end of 2009. The study was performed according to the regulations of the medical ethical committee; due to the once-only internet-based nature of the survey, no formal approval by the medical ethics committee was required.

The standardized and validated questionnaires that were used in the EMWAjong-study, related to the study questions, are presented in table 4. Due to privacy reasons, no information about the chronic conditions of the participants was provided by the benefits agency. This information was therefore derived through beneficiaries’ self reports. The questions concerning disease-characteristics were based on existing questionnaires and recommendations of experts in the field. Work participation was defined in conformity with Statistics Netherlands (CBS), as performance of paid work for at least 12 hours per week for an uninterrupted period of 6 months.

[During this study, people who were not able to earn as much as a healthy person with the same qualifications and experience were classified as being occupationally disabled under the terms of Wajong. Those eligible for Wajong benefit were at least 25 per cent occupationally disabled during the time as a student, as a result of which they were unable to work on a full-time basis after their studies.]
our study group with that of peers from the general Dutch population. Subsequently, the course of life and the HRQoL of young adult women with a Wajong benefit as a result of Juvenile Idiopathic Arthritis compared with the general Dutch population is described in chapter 4. We examined the illness cognitions (IC) of young adults with Wajong benefits because of chronic health conditions in chapter 5 and examined whether there is an association of IC with Health Related Quality of Life (HRQoL), anxiety and depression in this study population. In chapter 6 we investigate possible differences between the psychosocial development trajectory of young adults with childhood cancer with and without a disability benefit. Finally, we examined the disease characteristics, work characteristics, and work motivation of young adults with disability benefits as a result of chronic conditions and the association of those factors and IC with the likelihood of being employed in chapter 7. This thesis ends with the general discussion in chapter 8 of the main results, a reflection of the methodology, clinical and societal implications and key messages.

**TABLE 4: The standardized and validated questionnaires used in the EMWAjong-study**

<table>
<thead>
<tr>
<th>Research question</th>
<th>Purpose</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Chapter 2 and 4)</td>
<td>How does the course of life young adults with disability benefits as a result of a somatic condition compare to that of a reference group?</td>
<td>Course of life questionnaire (LVJV)</td>
</tr>
<tr>
<td>2 (Chapter 3 and 4)</td>
<td>How does the Health Related Quality of Life (HRQoL) and anxiety and depression of young adults with disability benefits as a result of a somatic condition compare to that of reference groups?</td>
<td>RAND-36, Hospital Anxiety and Depression Scale (HADS)</td>
</tr>
<tr>
<td>3 (Chapter 5)</td>
<td>What are the Illness Cognitions (IC) of young adults with disability benefits as a result of a somatic condition? And is there an association of IC with HRQoL, anxiety and depression in this study population?</td>
<td>Illness Cognition Questionnaire (ICQ), RAND-36, Hospital Anxiety and Depression Scale (HADS)</td>
</tr>
<tr>
<td>4 (Chapter 6)</td>
<td>Is there a difference in the psychosocial development trajectory of young adults with and without a disability benefit?</td>
<td>Course of life questionnaire (LVJV)</td>
</tr>
<tr>
<td>5 (Chapter 7)</td>
<td>What are the disease characteristics, work characteristics, and work motivation of young adults with disability benefits as a result of chronic conditions and the association of those factors and IC with the likelihood of being employed?</td>
<td>Illness Cognition Questionnaire (ICQ), Subscale of Work and Life Attitude Scale (WLAS)</td>
</tr>
</tbody>
</table>

**OUTLINE OF THE THESIS**

This thesis focuses on evaluating the psychosocial functioning, the emotional well-being and the factors affecting the vocational success and well-being in young adults with a Wajong benefit for a childhood-onset chronic somatic condition while growing up. The general introduction of this thesis is covered in the current chapter (Chapter 1). In chapter 2 we assessed the developmental trajectory (course of life) of young adults with a disability benefit as a result of chronic somatic conditions and compared this with that of peers from the general Dutch population. Chapter 3 compares the HRQoL, anxiety and depression of
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Toen ik net geboren was, was het nog niet duidelijk dat er iets met mijn nieren was. Later bleek dat ik cystenieren had. Dat was niet dusdanig erg dat er meteen iets aan moest gebeuren, ik ging heel langzaam achteruit. Ik was wel altijd snel moe. Ik moest heel vaak op controle en dan voelden de dokters aan mijn buik. Al die controles hoorden bij mijn leven, ik vond dat niet zo heel spannend. Ik begon op een gegeven moment zodanig achteruit te gaan, dat er iets moest gebeuren. Ik 2005 werd ik getransplanteerd, toen was ik 18. Niet echt een fijne leeftijd om getransplanteerd te worden. Je wordt niet zo mooi van alle medicatie die je moet slikken. Ik kreeg afstotingsverschijnselen, maar je wordt helemaal volgestampt met prednison enzo. Ik kreeg daar een heel groot hoofd van en ook veel haartjes. Ik heb nog steeds harigheid, maar het is al wel veel minder. Het duurde na de transplantatie echt wel een jaar voordat ik weer helemaal mezelf was, zowel fysiek als psychisch. Ik was weer gezond, maar dat voelde niet zo. Je voelt je juist in eerste instantie veel meer uit je leven gerukt. Het herstel ging op zich wel goed, maar ik kreeg suiker en dat vond ik toch wel moeilijk te verkroppen. Ik dacht dat ik niks meer mocht eten en bij elk broodje op moest letten. Ik kan vrij gemakkelijk wat negatiever denken en dat gebeurde toen ook. Dan was ik ineens heel boos en zag ik het allemaal niet meer zitten. Dan vond ik mezelf heel dik en harig en dan had ik ook nog suiker. Ik heb periods gehad dat ik me telkens afvroeg waarom dit mij moest overkomen. Ik vond de begeleiding door de artsen daarbij erg goed. En dat er meerdere mensen bij de tienerafdeling om je heen zijn, vond ik ook heel fijn. Ik lag op zaal, dat vond ik eigenlijk walgelijk, maar ik lag daar wel met hele leuke meiden. Iedereen had wat. Maar je wist ook dat iedereen weer beter zou worden. Maar op een keer lag er een meisje die wist dat ze niet ouder zou worden dan 30 jaar. Zij was haast verdrietig als ze jarig was. Toen dacht ik: “wow, ik moet echt niet zien, ik moet maar blij zijn dat ik dit heb en dat ik hier wegkom”. Ook al vind je jezelf soms echt de zieligste op aarde, dan ga je echt wel relativeren. Ik heb dat moment gezien als een belangrijke ervaring. De overstap naar de volwassenzorg vond ik heel moeilijk en heftig. Je wordt gezien als een volwassene, terwijl je eigenlijk nog een kind bent. De zorg was hetzelfde, maar minder persoonlijk. Bij de volwassenen had ik het idee dat ik een dossier was. Nu ben ik weer zo goed als normaal. Het heeft wel altijd een plek in mijn leven, die pillen vooral. Dat blijft voor mij een drama. Voor de rest ben ik niet zo bezig met mijn ziekte. Ik ben stabiel, geen toestanden. Afstoting kan vrij acuut gebeuren, dus je bent altijd een levende tijdbom. Maar ik voel dat niet zo. Als je daarmee gaat leven, kun je maar beter thuisblijven, dan durf je niks. Zo heftig zal het ook wel niet zijn, dat geloof ik niet. Ook voordat ik ge-
Story 1

Kan worden, of dat er misschien wel dat ik weer een keer getransplanteerd moeten er ook rekening mee houden… Ze het serieus is en dat ik misschien wel tje confronteren. Je moet aangeven dat woон meer over uitleggen en ze een bé-

ze het moeilijk vinden, moet je er ge-
noot maken dat je je voelt, omdat je geen werk hebt. Het is heel mooi als je het wel hebt, maar ik wil me er niet rot over gaan voelen als ik het niet heb. Wat ik wel lastig vind, is dat ik nog nooit zelf een baan heb geregeld. Ik ben straks af-
gestudeerd en dan moet ik zelf een baan gaan vinden. Dat durf ik eigenlijk niet. Daar worstel ik heel erg mee. Ik ben bang dat ze zullen zeggen: “Oh, je hebt geen werkervaring, ga maar weg”. Ik heb ook moeite gehad om mijn eerste stageplek te vinden. Ik durfte gewoon niet naar binnen te stappen om te zeggen: “Hallo, ik ben die en die, en ik wil graag stage lopen”. Ik miste ervaring om zelf-verzekerd over te komen. Uiteindelijk heeft een leraar het voor me gedaan. En mijn ouders zijn echt van die hamster-
tjes die bovenop hun kinderen zaten en goed voor ons wilden zorgen. Ze heb-
en werken nooit echt gestimuleerd. Misschien omdat ze dachten: “Dat kan ze niet, dan gaan we het ook niet voor

haar regelen”. Ik heb het overigens heel goed ervaren met mijn ouders. Ze heb-
en ook veel zorgen wegenomen. Maar ik denk dat het misschien beter was ge-

weest als ze me toch een schopje onder mijn kont hadden gegeven. Zo van: “Oké, misschien heb je niet zoveel fut, maar misschien zou je toch eens kunnen kijken naar iets kleins om een beetje er-

varing op te doen”. Eigenlijk kwam ik in aanraking met een Wajong-uitkering via mijn zus. Die is twee jaar ouder, zij had ook een Wajong uitkering nodig. Dan is het voor haar door mijn ouders hele-

maal uitgedokterd en een paar jaar later ben ik aan de beurt. Ik weet niet precies hoe dat in zijn werk is gegaan. Ik moest naar UWV om te kijken in hoeverre ik ar-

beitsongeschikt ben. Geen idee voor welk percentage ik ben afgekeurd, vrij groot denk ik. Een in de zoveel tijd krijg ik een herkeuring. Ik vind dat ik het nu vrij goed doe. Dus als ik geen school had, zou ik nu gewoon gaan werken. Als ik ga werken mag de Wajong eruit. Ik vind het fantastisch dat ik die nu tijdens mijn opleiding heb, maar daarna wil ik het zelf gaan doen. Ik vind het heel fijn dat de uitkering er is, maar het is ook wel erg gemakkelijk. Wat je eraan houdt, kun je gaan uitgeven. Dat vind ik ook wel weer slecht van mezelf. Maar ik heb die Wajong niet voor niets, in ieder geval niet voor mijn zweetsoeken. Ande-

ren zullen daar misschien anders over denken, maar je wilt niet weten wat ik ervoor heb moeten laten. Dus voor nu vind ik het ook wel goed. Ik zou max-
immaal 4 dagen kunnen werken, anders trek ik het niet. En ik wil bij het sollicite-

ren eerlijk zeggen dat ik iets mankeer. Ik ga het niet direct zeggen, maar ik zou het opgooien; “Ik heb wel iets waar je rekening mee moet houden…”. Ik wil heel graag dat mensen normaal tegen me blijven doen. Ik ben toch bang dat mensen gauw denken dat je zielig bent. Laat me gewoon doen wat ik kan doen. Dus wel rekening met me houden, maar graag niet teveel nadruk leggen op mijn beperkingen.
Growing into disability benefits?

Psychosocial course of life of young adults with a chronic somatic disease or disability

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ABSTRACT

AIM: A growing number of young adults with somatic diseases/disabilities since childhood apply for disability benefits. The achievement of psychosocial milestones while growing up (course of life) is assumed to be related to job participation. This study assessed the course of life of young adult beneficiaries with somatic limitations compared to peers from the general Dutch population.

METHODS: Young adult beneficiaries (22 to 31 years, N = 415) completed the Course of Life Questionnaire assessing the achievement of milestones on autonomy, psycho-sexual and social development and risk behaviour. Differences between respondents and peers were tested using analysis of variance and logistic regression analysis by group, age and gender. Associations were expressed as Odds Ratios (OR) with confidence intervals.

RESULTS: The beneficiaries achieved fewer milestones, or achieved the milestones at a later age than peers. The differences were substantial: most effect sizes were moderate to large and most of the ORs lower than 0.5.

CONCLUSIONS: Young adult beneficiaries with somatic limitations since childhood are at risk of a delayed course of life. Health care providers should pay systematic attention to the psychosocial developmental trajectory of their patients in order to optimise their development to adulthood, and, consequently, create conditions for an optimal labour market position.

INTRODUCTION

As the treatment of children with chronic or life threatening disease has improved over recent decades, more and more paediatric patients reach adulthood. In the Netherlands, at least 14% (500,000 children) of all children grow up with a chronic disease. As a result more young adult patients with a childhood-onset reach the age to enter the labour market. However, the labour market position of people with a chronic disease can be characterized as problematic, with regard to getting a job as well as job continuation. So far, little is known about the influence of having a chronic disease or disability since childhood and job prospects in later life.

In the Netherlands, young people who are (partially) unable to work because of a chronic disease or disability may be eligible for benefit under the scheme for young disabled persons: Wajong (act Work and labour support Young Disabled Persons). A person may apply for Wajong benefit if he/she is at least 25% occupationally disabled before the 17th birthday or during study (but before the 30th birthday if being a student for at least six months in the year prior to the occupational disability). A part of the Wajong recipients is declared fully unfit for work; the other part is partially capable of work. The Wajong scheme offers a supplementary benefit at a minimum level, amounting to the difference between actual income and the social minimum. The amount of the benefit provided depends on age and the degree of incapacity for work. Somatic diseases (including disabilities) account for 15% of the 203,700 young adults with Wajong-benefits and this number is growing strongly (UWV, June’10).

According to the sharp rise of young adults claiming Wajong benefits, there is growing attention to their labour market position. Data from the Social and Economic Council of the Netherlands (SER) indicate that around 60% of people on Wajong benefit are able to work. In reality, around 25% do so, though a much larger group is declared partially capable of work. If, however, causes of unemployment in young adults with Wajong benefits were known, tailored guidance could be offered and, thereby, reduce the number of young adults who apply for Wajong benefits and help those with this disability benefit successfully integrating in the workforce. So far, little is known about early psychosocial determinants of integration of young adults with somatic chronic diseases or disabilities into the workforce. If we can gain insight into these determinants of integration into the workforce, we may be able to develop interventions in paediatric healthcare that will be helpful in later life.

For adolescents transition into adulthood is a critical phase, characterised by multiple transitions including from family life to independent living and from education to employment. Success is closely related to positive social and emo-
tional development earlier. Children and adolescents with chronic diseases or disabilities face many additional challenges to negotiate and obtain normative developmental milestones and maintain adaptive functioning. We assume that the achievement of psychosocial milestones while growing up (course of life: CoL) is related to participation in society including job participation.

The course of life of young adults claiming disability benefits because of chronic somatic disease or disability who are partially able to work has never been studied. Therefore, the aim of the present study was to assess their CoL and to compare with that of peers from the general Dutch population. The hypothesis was that the CoL of young adults claiming Wajong-benefits would be delayed.

METHODS

PROCEDURES
This study was conducted within the framework of a large cross-sectional study (EMWAjong) examining psychosocial factors affecting the employment of young adults with a Wajong-benefit because of a chronic somatic disease or disability since childhood. All young adults between 22 and 31 years of age, who claimed a Wajong-benefit in the year 2003 or 2004 because of a somatic disease or disability, were invited to participate in EMWAjong by completing an online questionnaire. Those with no sustainable work opportunities (declared totally unfit for work) or cognitive impairment were excluded. The nature of this once-only internet-based survey did not require formal medical ethical approval. Because of the privacy of the beneficiaries the invitation letter was send by UWV, the Employee Insurance Agency. The letter contained a personal log in code, a password and the link to the online questionnaire. After two weeks they received a reminder letter and after completing the whole questionnaire they received a gift voucher.

MEASURES
The Course of Life Questionnaire (CoLQ) was used to assess the achievement of psychosocial developmental milestones. This instrument was developed by the Psychosocial Department of the Emma Children’s hospital AMC to be able to investigate the psychosocial developmental trajectory (CoL) of young adults who have grown up with a chronic or life-threatening disease, and to facilitate comparison with peers without a history of disease. The items, based on the literature and on clinical experience, concern behavior characteristic of certain age stages, psychosocial developmental tasks, and the limitations children might face when they grow up with a chronic disease. Most questions ask retrospective whether the respondent had achieved certain psychosocial milestones or at what age the respondent achieved the milestones. The answers are dichotomized (1 = milestone not achieved, 2 = milestone achieved), if necessary, before being added up to the scale-score. The items are divided into five scales: autonomy development (6 items, autonomy at home and outside the home), psychosocial development (4 items, love and sexual relations), social development (12 items, contacts with peers), antisocial behavior (4 items, misbehavior at school and outside it), and substance use and gambling (12 items). A higher score on the first three scales indicates the accomplishment of more psychosocial developmental milestones. Higher scores on antisocial behavior and on substance use and gambling mean that the respondent displays more risk behavior. The psychometric characteristics of the CoL-scales are satisfactory, including reliability and validity. Normative data of young adults from the general Dutch population are available, recruited through general practitioners in a former study. For more details see Stam et al., 2005.

STATISTICAL ANALYSIS
The Statistical Package for Social Sciences (SPSS) Windows version 16.0 was used for all the analyses. Demographic characteristics of EMWAjong and norm group were compared by using Chi²-tests for categorical data and t-tests for continuous data. Because age and gender of EMWAjong differed significantly from that of the norm group, further analyses were corrected for age and gender. Firstly, variate analysis of variance (ANOVA) by group, age and gender were performed to test group differences on the course-of-life-scales. Effect sizes (d) were calculated by dividing the difference in mean scale scores of EMWAjong and the norm group by the standard deviation of the scores in the norm group. We considered effect sizes of up to 0.2 to be small, effect sizes of about 0.5 to be moderate and effect sizes of about 0.8 to be large (11). Secondly, in order to gain detailed insight into the CoL of EMWAjong, differences on item level (milestones) between EMWAjong and the norm group were also tested. Therefore, logistic regression analyses by group, age and gender were conducted at the frequency distributions of the individual (dichotomized) scale items, and odds ratio’s (OR for group) were calculated.

A significance level of 0.05 was used for the scale scores. To compensate for multiple testing we used a significance level of 0.001 (99.9%-CI) for the individual milestones.
RESULTS

In total 415 of the 2046 who were invited for the study (response rate 20.1%) participated. Col data from 382 participants could be used for the analyses in the present paper: 267 women (64.3 %) and 148 men (35.7%). The characteristics of the EMWAjong group and the norm group are listed in Table 1. Non-responders differed from responders with respect to gender: 51.4% women and 48.6% men.

TABLE 1: Demographic and medical characteristics of the EMWAjong group and the peers from the general Dutch population

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>EMWAjong (N=415)</th>
<th>Peer group (N=508)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at study (years)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td></td>
<td>25.0 (2.1)</td>
<td>24.2 (3.8)</td>
</tr>
<tr>
<td>Gender*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>267 (64.3)</td>
<td>269 (53.0)</td>
</tr>
<tr>
<td>Male</td>
<td>148 (35.7)</td>
<td>239 (47.0)</td>
</tr>
<tr>
<td>Native country</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Netherlands</td>
<td>394 (94.9)</td>
<td>487 (96.1)</td>
</tr>
<tr>
<td>Other</td>
<td>21 (5.1)</td>
<td>21 (4.0)</td>
</tr>
<tr>
<td>Disease (EMWAjong)</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Visually impaired / blind</td>
<td>58 (14.3)</td>
<td>21 (5.2)</td>
</tr>
<tr>
<td>Intestinal complaints</td>
<td>24 (5.9)</td>
<td>15 (3.7)</td>
</tr>
<tr>
<td>Hearing impaired / deaf</td>
<td>34 (8.4)</td>
<td>46 (11.5)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>34 (8.4)</td>
<td>21 (5.2)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>17 (4.2)</td>
<td>31 (7.6)</td>
</tr>
<tr>
<td>Heart disease</td>
<td>7 (1.7)</td>
<td>49 (12.0)</td>
</tr>
<tr>
<td>Skin disease</td>
<td>9 (2.2)</td>
<td>17 (4.2)</td>
</tr>
<tr>
<td>Cancer</td>
<td>20 (4.9)</td>
<td>19 (4.7)</td>
</tr>
<tr>
<td>Liver disease</td>
<td>6 (1.5)</td>
<td>44 (10.8)</td>
</tr>
<tr>
<td>Disease characteristics (EMWAjong)</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Congenital disorder</td>
<td>211 (50.8)</td>
<td>209 (51.4)</td>
</tr>
<tr>
<td>Perceptible disability</td>
<td>171 (42.0)</td>
<td>195 (47.9)</td>
</tr>
<tr>
<td>Course of the disease</td>
<td>171 (42.0)</td>
<td>195 (47.9)</td>
</tr>
<tr>
<td>Better</td>
<td>71 (17.4)</td>
<td>96 (23.6)</td>
</tr>
<tr>
<td>Worse</td>
<td>73 (17.9)</td>
<td>35 (8.6)</td>
</tr>
<tr>
<td>Variable</td>
<td>93 (22.9)</td>
<td>577 (92.6)</td>
</tr>
<tr>
<td>Constant</td>
<td>170 (41.8)</td>
<td>241 (59.2)</td>
</tr>
</tbody>
</table>

* p < 0.001

Scales of the Course of Life Questionnaire

The ANOVA showed statistically significant main effects of group on all CoL-domains (p<0.001). EMWAjong scored lower than the norm group of peers from the general population: autonomy (8.7 versus 9.5), psychosexual (6.3 versus 7.1), social (19.0 versus 21.0), antisocial behaviour (4.3 versus 4.7) and substance use and gambling (13.5 versus 15.0). The differences between EMWAjong and their peers were small to moderate: effect sizes ranged from 0.40 (antisocial development) to 0.78 (social development).

COURSE OF LIFE ON ITEM LEVEL (MILESTONES)

Table 3 shows the individual (dichotomized) items of the CoL-scales. With respect to Autonomy development, we found statistically significant differences on four out of six items, with ORs ranging from 0.12 to 0.53. A lower percentage of the EMWAjong group than of the norm group of peers from the general population had had a paid job during elementary and middle and/or high school. A lower percentage of EMWAjong than of peers has been on holiday without adults before they were 18 years old and is living on their own. We found statistical significant differences between the EMWAjong group and the norm group on all items of the Psycho-sexual development scale; ORs 0.23-0.42. The EMWAjong group was older then the norm group when for the first time they: had a boyfriend or a girlfriend, fell in love, had sexual intimacy, and had sexual intercourse. With respect to the Social development scale, the EMWAjong group differed from the norm group on 10 out of 12 items (ORs 0.21-0.55). With respect to risk behaviour, we found that a lower percentage of the EMWAjong group than of the norm group had ever got trouble with the police or law (OR 0.32) and being refused admission to lessons, both during middle and/or high school (OR 0.55).

In addition, the prevalence of substance use was lower among EMWAjong than among the norm group: alcohol, softdrugs, smoking and gambling during and after finishing middle and/or high school (ORs 0.23-0.57).
### Table 3: Frequencies of the (dichotomised) items of the course-of-life-scales, EMWAjong versus peers from the general Dutch population (Odds Ratio; OR; Confidence Interval; CI).

#### Autonomy development

<table>
<thead>
<tr>
<th>Item</th>
<th>EMWAjong (N=380)</th>
<th>Peer group (N=500)</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>OR (99.9 – CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular chores/tasks in your family, elementary school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>47.4</td>
<td>180</td>
<td>46.0</td>
<td>253</td>
<td></td>
<td>0.66</td>
<td>(0.49,1.12)</td>
</tr>
<tr>
<td>no</td>
<td>52.6</td>
<td>200</td>
<td>54.0</td>
<td>247</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Paid jobs, elementary school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>21.1</td>
<td>80</td>
<td>55.6</td>
<td>170</td>
<td></td>
<td>0.63</td>
<td>(0.32,0.90)</td>
</tr>
<tr>
<td>no</td>
<td>78.9</td>
<td>300</td>
<td>44.4</td>
<td>326</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Regular chores/tasks in your family, middle and/or high school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>57.9</td>
<td>220</td>
<td>60.2</td>
<td>304</td>
<td></td>
<td>0.57</td>
<td>(0.57,1.42)</td>
</tr>
<tr>
<td>no</td>
<td>42.1</td>
<td>160</td>
<td>39.8</td>
<td>201</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Paid jobs, middle and/or high school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 18 or younger</td>
<td>46.1</td>
<td>175</td>
<td>87.4</td>
<td>445</td>
<td></td>
<td>0.38</td>
<td>(0.20,0.77)</td>
</tr>
<tr>
<td>at the age of 19 or older/never</td>
<td>53.9</td>
<td>205</td>
<td>12.6</td>
<td>64</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>For the first time vacation without adults</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 17 or younger</td>
<td>31.0</td>
<td>117</td>
<td>52.9</td>
<td>268</td>
<td></td>
<td>0.30</td>
<td>(0.17,0.71)</td>
</tr>
<tr>
<td>at the age of 18 or older/never</td>
<td>69.0</td>
<td>261</td>
<td>47.1</td>
<td>259</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Leaving your parents home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>62.7</td>
<td>237</td>
<td>64.6</td>
<td>328</td>
<td></td>
<td>0.47</td>
<td>(0.26,0.82)</td>
</tr>
<tr>
<td>no</td>
<td>37.3</td>
<td>141</td>
<td>35.4</td>
<td>180</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>for the first time playing with friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>friends</td>
<td>72.1</td>
<td>274</td>
<td>87.6</td>
<td>456</td>
<td></td>
<td>0.35</td>
<td>(0.19,0.65)</td>
</tr>
<tr>
<td>brothers and/or sisters, parents or your own</td>
<td>27.9</td>
<td>106</td>
<td>12.4</td>
<td>62</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>At least one year of competitive sports, middle and/or high school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>52.6</td>
<td>200</td>
<td>73.6</td>
<td>373</td>
<td></td>
<td>0.41</td>
<td>(0.26,0.67)</td>
</tr>
<tr>
<td>no</td>
<td>47.4</td>
<td>180</td>
<td>26.4</td>
<td>134</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>At least one year of competitive sports, after middle and/or high school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>30.1</td>
<td>114</td>
<td>48.9</td>
<td>245</td>
<td></td>
<td>0.46</td>
<td>(0.29,0.74)</td>
</tr>
<tr>
<td>no</td>
<td>69.9</td>
<td>265</td>
<td>51.1</td>
<td>254</td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

#### Psycho-sexual development

<table>
<thead>
<tr>
<th>Item</th>
<th>EMWAjong (N=380)</th>
<th>Peer group (N=500)</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>OR (99.9 – CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First girlfriend/boyfriend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 17 or younger</td>
<td>56.3</td>
<td>213</td>
<td>80.4</td>
<td>407</td>
<td></td>
<td>0.18</td>
<td>(0.18,0.50)</td>
</tr>
<tr>
<td>at the age of 18 or older/never</td>
<td>45.7</td>
<td>165</td>
<td>38.6</td>
<td>99</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>For the first time falling in love</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 18 or older/never</td>
<td>77.8</td>
<td>294</td>
<td>91.7</td>
<td>462</td>
<td></td>
<td>0.52</td>
<td>(0.16,0.62)</td>
</tr>
<tr>
<td>at the age of 18 or older/never</td>
<td>22.2</td>
<td>84</td>
<td>8.3</td>
<td>42</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>For the first time sexual intimacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 18 or older/never</td>
<td>38.4</td>
<td>145</td>
<td>83.4</td>
<td>421</td>
<td></td>
<td>0.23</td>
<td>(0.13,0.39)</td>
</tr>
<tr>
<td>at the age of 19 or older/never</td>
<td>61.6</td>
<td>233</td>
<td>16.6</td>
<td>84</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>For the first time sexual intercourse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 18 or older/never</td>
<td>38.4</td>
<td>145</td>
<td>58.5</td>
<td>296</td>
<td></td>
<td>0.23</td>
<td>(0.13,0.39)</td>
</tr>
<tr>
<td>at the age of 19 or older/never</td>
<td>61.6</td>
<td>233</td>
<td>41.5</td>
<td>201</td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

#### Social development

<table>
<thead>
<tr>
<th>Item</th>
<th>EMWAjong (N=380)</th>
<th>Peer group (N=500)</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>OR (99.9 – CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one year competitive sports, elementary school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>66.3</td>
<td>252</td>
<td>84.2</td>
<td>427</td>
<td></td>
<td>0.38</td>
<td>(0.22,0.66)</td>
</tr>
<tr>
<td>no</td>
<td>33.7</td>
<td>128</td>
<td>15.8</td>
<td>80</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Number of friends in kindergarten through third grade, elementary school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>less than 4</td>
<td>46.6</td>
<td>178</td>
<td>37.0</td>
<td>187</td>
<td></td>
<td>0.71</td>
<td>(0.44,1.13)</td>
</tr>
<tr>
<td>4 or more</td>
<td>53.4</td>
<td>222</td>
<td>63.0</td>
<td>319</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Number of friends in fourth-sixth grade, elementary school</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>less than 4</td>
<td>45.8</td>
<td>174</td>
<td>30.9</td>
<td>156</td>
<td></td>
<td>0.55</td>
<td>(0.34,0.87)</td>
</tr>
<tr>
<td>4 or more</td>
<td>54.2</td>
<td>206</td>
<td>69.1</td>
<td>349</td>
<td></td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

TABLE 3: Continued
In order to gain insight in the psychosocial developmental trajectory of young adults with disability benefits because of a chronic somatic disease or disability we assessed their course of life in comparison with age matched and sex matched peers from the general Dutch population. The course of life of our study group was found to be delayed since they proved to have achieved fewer milestones in all domains (social, autonomy and psychosexual development, substance use and gambling, anti-social behaviour), or to have achieved the milestones when they were older than their peers. The differences between EMWAjong and the peers were substantial: most effect sizes were moderate to large and most of the ORs lower than 0.5.

This result is not very surprising, given that we already know that young adults who have grown up with a disease are also at risk for a delayed CoL compared with the peer group\textsuperscript{12}. Particularly the CoL of patients with end-stage renal disease and survivors of childhood cancer was found to be hampered\textsuperscript{9,12}. However, the present study concerns the part of these young adults who are not able to earn a full salary as an effect of their disease or disability and therefore applied for Wajong benefits. Therefore we consider young adults with a somatic disability as...
Growing into disability benefits?

Chapter 2

The delay in the psychosexual development is in accordance with other studies in the field. Children and adolescents with chronic diseases are expected to pass through similar developmental stages as their non-disabled peers, to leave home, develop psychologically, and define a role for themselves in the community through employment or other activities. For these patients with (complex) impairments, this is more difficult. Therefore, it is important to understand what types of delays are faced by chronically ill or handicapped youth in relation with workforce participation in order to develop strategies to ameliorate identified delays.

In relation to autonomy development, overprotection by parents with a chronically ill or handicapped child comes into focus. Parents who overprotect the child with a disease or disability will continue to over protect as the child enters adolescence and young adulthood (16). Lowered expectations and over-protection of a child with a disease or disability can cause lowered self esteem which can result in a life time of underachievement and failure to reach their full potential. This inhibits the child from developing the personal skills needed to cope with the extra challenge of the disease or disability. Adolescents may not be allowed work opportunities, because of imagined dangers. However, work experience in adolescents is an excellent way to discover interests and skills, but also limitations of the physical opportunities of the body. It is plausible that the present work participation rate of our study group is associated with their low rate of work experience during adolescence, because only 46.1% have had a paid job before the age of 18 compared to 87.4% in peers.

The results on the social development scale also indicate that it is important to encourage children with a somatic disease or disability to make friends and to participate in social events with peers, such as sport and going out to a disco. Close peer relationships are an important source of support for chronically ill or handicapped adolescents at a time when they have to tackle both developmental tasks and disease-related challenges.

The impact of reduced psycho-sexual development and risk behaviour that we found in our group remains speculative, but in this study it gives a clue to the developmental consequences of growing up with a chronic disease or disability. The delay in the psychosexual development is in accordance with other studies reporting that adolescents and young adults with a chronic disease or disability are at risk for psychosexual problems. Peer relationships are important for the development of social skills, self-esteem and self-image and have been associated with qualities of romantic relationships, especially in adolescents. Therefore, encouraging children with a somatic disease or disability to take part in peer activities is important for their social and psychosexual development, as well as their confidence in their ability. Risk behaviour seems also relevant, because, displaying risk behaviour - in terms of trying out - is, to a certain extent, part of the development of being a teenager to becoming an adult. On the one hand, we could expect more risk behaviour in our participants in order to compensate for the limitations in their youth caused by the disease or disability. On the other hand, it is imaginable that young adults with a chronic somatic disease since childhood display less risk behaviour than peers because they are aware of the vulnerability of their health. Given the low outcome on risk behaviour we assume the latter explanation suits with our group.

Survival rates for children who have a chronic disease have increased dramatically in the last 30 years and will likely further increase because of medical advancements. In the light of this enormous increase, the findings of the current study are clinically relevant. Developmental problems can be the result of the complex interactions between problems which are a direct result of the disease and its treatment and psychosocial problems which are an underlying reflection of life, social or economic status of these young adults. Systematic assessment of psychosocial development is not yet part of standard practice, though paediatricians and their teams know that a part of the population they treat is at risk for problems in later life. The impact of a somatic disease or disability on psychological well-being and social life can easily be overshadowed by consequences of the somatic disease and its treatment or the disability. However, the results of this study show that health care providers currently treating children with chronic conditions should pay systematic attention not only to their medical but also to their psychosocial development as well. To achieve optimal support for these young adults, paediatric health care workers should have knowledge about possible gaps in the course of life and look for them at follow-up. Therefore, periodically evaluation of their ongoing psychosocial, educational, and vocational needs during their developmental process should be an integral component of the comprehensive care of chronically ill or disabled children and adolescents. If possible, it is important to monitor the psychosocial development in an early stage, prior to adolescence when differences in for example autonomy behaviour may appear more salient. This would provide a chance to recruit patients with significant risks for an unfavourable psychosocial outcome for interventions, to help these children and adolescents to achieve optimal development. In addition, special attention should
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also be paid to the transfer to adult care, by assessing the transfer readiness 27. A good way to focus on medical as well developmental issues in clinical practice is flexible collaboration between paediatricians, nurses and psychosocial teams. Besides healthcare workers and parents, it is a political and social responsibility to support children, adolescents and young adults with somatic limitations in achieving academic and vocational success. This can only be addressed across systems. Cooperation between for example multidisciplinary rehabilitation teams and special education schools is necessary 28, in common with the development of programmes stimulating the children and adolescents in their development.

SAVTI (Successful Academic and Vocational Transition Initiative) of the Pediatric Oncology Group of Ontario (POGO) and Emma@work (job mediation for adolescents with a somatic disease) of the Emma Children Hospital Academic Medical Center in the Netherlands are examples of useful tools 29.

Some limitations of this study should be addressed. First, it should be realized that the act Wajong is a Dutch benefit. Most countries have no specific benefit for young disabled people. Therefore, it is advisable to be cautious and conservative while interpreting results of this study and extrapolating the findings to a larger population or other countries. Another limitation is the response rate of 20%, though this is a very average response rate among young adults with a disability 30, 31. Due to the growing interest in the labour market position of young adults with Wajong benefits, they are so often invited to participate in several studies that it is plausible that these young adults do not want to participate in all studies. Moreover, it is likely that respondents didn’t fill in the questionnaire because the invitation letter was sent by the benefits agency. Although the questionnaire was anonymous, most beneficiaries are afraid of losing their benefits. As a result of the privacy of the beneficiaries we have too little information regarding the non responders to be able to pronounce upon the selection bias. Furthermore, it is also unknown which part of all young adults with a chronic disease or disability apply for disability benefits. Therefore, we do not know whether the results are an underestimation or an overestimation of the problems of this group, so our results cannot be generalized. However, the problems found are substantial and therefore socially relevant and important to mention.

CONCLUSION

This study has set out the possible delay and challenges in the CoL faced by young adults with chronic somatic diseases or disabilities since childhood who have to apply for disability benefits. Although some of these young adults make a good adjustment to adult life, there are many others who may struggle reaching the psychosocial developmental milestones.

It is a political and social responsibility to support children, adolescents and young adults with somatic limitations in achieving academic and vocational success. With regard to medical practice, we believe that paediatric health care providers should pay systematic attention to the development of social and independent functioning of children and young adults with a chronic somatic disease or disability in order to optimise their adaptation to society at the time of transition to adulthood, and, consequently, to create conditions for an optimal labour market position. This study gives a point of departure for future research which might usefully focus on identifying those most likely to develop difficulties and who would benefit from psychosocial support, specific to workforce participation and quality of life.
Chapter 2
Growing into disability benefits?

REFERENCE LIST


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Ik was een te vroeg geboren baby met te weinig zuurstof in de hersenen. Ik heb daardoor een beperking aan mijn rechter been en ben spastisch. Mijn handicap heeft ook een naam maar die is voor mij altijd te moeilijk geweest om te onthouden dat ik altijd zei dat ik gewoon moeilijk te been was. In mijn jeugd was ik wel anders dan andere kinderen in de buurt. Ik droeg spalken aan mijn been en ik ging met een driewieler door de straat, omdat ik mijn evenwicht niet op een 2-wieler kon houden. Ook werd ik elke morgen opgehaald met een busje om naar school te gaan. Ik was altijd een vrolijk kind en toch had ik altijd vriendjes. Maar ik voelde me altijd wel anders en de drang mij voor alles te bewijzen was erg groot. Ik was altijd het zorgkindje wat ik erg irritant heb gevonden, want voor mijn gevoel was er niet veel aan de hand en was ik niet veel anders dan andere maar toch lieten mensen mij weten dat het wel zo was. Toen ik een jaar of zeven was brak ik mijn knie tijdens gym. De dokters zeiden dat het gekneust was en dat ik rust moest houden, maar het bleef maar zeer doen een jaar later bleek er toch wel wat op de fotos te zien te zijn en had ik een jaar lang op een gebroken knie gelopen. Natuurlijk had dat weer schade aangericht want ik probeerde in die jaar een manier te vinden om wel te kunnen blijven lopen waar door ik nu heel scheef loop. Waar ik me nog altijd voor schaam. Ik heb mijn handicap niet geaccepteerd, en dat merk ik door dat ik vaak doe alsof het er niet is maar ik er wel weer mee wordt geconfronteerd. Ik heb een eigen huis en doe alles zelf onderhouden en regelen. Ik werk nu sinds februari en fiets zelfs op een 2wieler wel lage instap maar dat is nu tegenwoordig hip. Van mijn spastischheid merk ik eigenlijk niks meer, want ik had ook een lichte vorm had geen spraak gebrek en moest ook niet overal van schrikken. Ik heb me helemaal nooit in het wereldje van gehandicapten thuis gevoeld terwijl ik er wel veel vrienden heb gekregen en ik wel een hele fijne jeugd heb gehad. Soms als ik in de stad loop en mensen staren mij aan dan realiseer ik mij dat het komt door mijn been, dat was ik dan zelf even vergeten. Of als mensen me vragen wat ik heb, denk ik eerst wat bedoel je en daarna oja. Ik ben er gelukkig goed uit gekomen nog wel wat onzeker maar dat gaat ook steeds beter.

‘Ik heb me helemaal nooit in het wereldje van gehandicapten thuis gevoeld’
Health-related quality of life, anxiety and depression in young adults with disability benefits due to childhood-onset somatic conditions
ABSTRACT

BACKGROUND: As the treatment of chronic or life-threatening diseased children has dramatically over recent decades, more and more paediatric patients reach adulthood. Some of these patients are successfully integrating into adult life; leaving home, developing psychosocially, and defining a role for themselves in the community through employment. However, despite careful guidance and support, many others do not succeed. A growing number of adolescents and young adults who have had a somatic disease or disability since childhood apply for disability benefits. The purpose of this study was to assess the health-related quality of life (HRQoL), anxiety and depression of young adults receiving disability benefits because of somatic conditions compared to reference groups from the general Dutch population and to explore factors related to their HRQoL, anxiety and depression.

METHODS: Young adults (N=377, 22-31 yrs, 64.3% female) claiming disability benefits completed the RAND-36 and an online version of the HADS. Differences between respondents and both reference groups were tested using analysis of variance and logistic regression analysis by group and age (and gender). Regression analyses were conducted to predict HRQoL (Mental and Physical Component Scale; RAND-36) and Anxiety and Depression (HADS) by demographic and disease-related variables.

RESULTS: The respondents reported worse HRQoL than the reference group (-1.76 Physical Component Scale; -0.48 Mental Component Scale), and a higher percentage were at risk for an anxiety (29.7%) and depressive (17.0%) disorder. Better HRQoL and lower levels of anxiety and depression were associated with a positive course of the illness and the use of medical devices.

CONCLUSIONS: This study has found worse HRQoL and feelings of anxiety and depression experienced by young adults claiming disability benefits. Healthcare providers, including paediatric healthcare providers, should pay systematic attention to the emotional functioning of patients growing up with a somatic condition in order to optimise their emotional well-being and adaptation to society during their transition to adulthood. Future research should focus on emotional functioning in more detail in order to identify those patients that are most likely to develop difficulties in emotional functioning and who would benefit from specific psychosocial support aimed at workforce participation.

BACKGROUND

Due to improved treatment possibilities and the positive consequences for life expectancy, the number of chronically ill children who live for longer is increasing, and more paediatric patients with somatic conditions are living into adulthood. 1 For these children, transition into adulthood is a critical phase. Children and adolescents with chronic illnesses are expected to go through similar developmental stages as their healthy peers; they will leave home, develop psychosocially, and define their role in the community through employment or other activities. 2 For patients with impairments, reaching these developmental stages can be challenging. Research findings indicate that school-aged children with chronic conditions, regardless of their diagnosis, are more limited in their participation in everyday life than their peers. 3-4. Also, research has showed that adolescents and young adults with disabilities often follow atypical developmental patterns when compared to their peers without a disability 5-7 and that they are at risk of poor educational, vocational and social outcomes in adulthood. 8-10

In the Netherlands, some 500,000 children (14%) are growing up with a chronic condition; 90% of them will reach adulthood. 1 As a result, many patients with a childhood-onset chronic condition will reach the age at which they enter the labour market. In the Netherlands, young people who are partially or fully incapacitated of working, due to a childhood-onset chronic condition, may be eligible for a benefit under the scheme for young disabled persons: Wajong (the Invalidity Insurance Act for Young Disabled Persons). The fact that young adults with Wajong benefits due to chronic conditions lag behind their peers in work experience is undesirable since employment is an important way to participate in social life. Besides money, employment offers many other additional immaterial advantages such as the possibility for self-development, social relationships, development of skills, daily routines, and, in many cases, meaning in life. 11 Consequently, employment has implications for the patients’ economic and social well-being in adulthood. 12 Furthermore, evidence shows that employment is often linked with higher levels of mental well-being in the general population. 13 However, few studies have focused on the emotional well-being of young adults with childhood onset chronic conditions who encounter barriers when pursuing employment, as compared to young adults without chronic conditions.

Also, the HRQoL and emotional functioning of young adult beneficiaries with a childhood-onset somatic condition as a group has never been studied. Since they can be considered as the most vulnerable young adults with chronic conditions - those who have to apply for disability benefits as a result of their conditions - it is important to know to what extent the chronic conditions are considered a
problem in daily life and affect their emotional well-being. Awareness for these problems is of utmost importance. Given the increase in the number of children and adolescents with a childhood-onset chronic condition and the growing number of them applying for disability benefits, it is essential to gain insight into their HRQoL and emotional functioning in order to be able to develop strategies to support this vulnerable population towards adulthood independence. Therefore, the purpose of this study was to assess the health-related quality of life (HRQoL), anxiety and depression of young adults claiming disability benefits because of somatic conditions compared to reference groups from the general Dutch population and to explore the relation of demographic and disease-related factors with their HRQoL, anxiety and depression. We hypothesized that young adults claiming disability benefits experience worse HRQoL and more anxiety and depression symptoms than reference groups from the general Dutch population.

**METHODS**

**PROCEDURES**

This study was conducted within the framework of a large cross-sectional study (EMWAjong), a study directed at investigating psychosocial functioning in young adults with a Wajong benefit for a childhood-onset chronic somatic condition and the factors affecting their vocational success. In this article we will refer to this group as ‘young adults claiming disability benefits’. All young adults between 22 and 31 years of age who claimed a Wajong benefit in the year 2003 or 2004 for a chronic somatic condition were invited to participate in EMWAjong via a letter. Participation meant completing an online questionnaire. Those with no sustainable work opportunities (classified as fully incapable for work) were excluded because the EMWAjong study aimed to identify factors that could help to improve vocational success. Those with serious cognitive impairment or psychiatric conditions were also excluded because the EMWAjong study was directed at young adults with childhood-onset somatic conditions.

In total, 2,046 persons were invited to take part in the study. To maintain the privacy of the beneficiaries, the invitation letter was sent by UWV, the Employee Insurance Agency. The letter contained a personal log in code, a password and a link to the online questionnaire. After two weeks, participants received a reminder letter. Participants who completed the entire questionnaire received a gift voucher. The study was performed according to the regulations of the medical ethical committee; due to the once-only internet-based nature of the survey, no formal approval by the medical ethics committee was required.

HRQoL was assessed using the RAND-36. The RAND-36 is a Dutch version of the MOS-SF-36 Health Survey and is almost identical to the Dutch SF-36 \(^4\). The RAND-36 is a multidimensional questionnaire consisting of 36 items with standardized response choices, clustered in 8 multi-item scales: Physical Functioning (PF), Social Functioning (SF), Role limitations owing to Physical health problems (RP), Role limitations owing to Emotional problems (RE), General Mental Health (MH), Vitality (VT), Bodily Pain (BP), and General Health perceptions (GH). All raw scale scores were converted to a 0-100 scale, with higher scores indicating higher levels of functioning or well-being. The validity and reliability of the RAND scales were satisfactory \(^8\). Among the EMWAjong group we found Cronbach’s alphas of 0.75 to 0.95. Overall physical and mental health was assessed by aggregating all scale scores according to the algorithm described by Ware and Kosinski \(^8\), yielding the so-called Physical Component Scale (PCS) and to the Mental Component Scale (MCS). The weights of the scales were derived from a Principal Components Analysis with the RAND-36 data of a Dutch reference group \(^9\), using a non-orthogonal rotation (Oblimin), based on the assumption that physical health and mental health are interdependent. A Dutch reference group was used comprising peers from the general population. This reference group was recruited through general practitioners for a previous study on late psychosocial consequences of cancer in childhood (see Stam et al. 2005 for details \(^7\)). The reference sample consisted of 508 respondents, 239 men (47.0%) and 269 women (53.0%). Mean age was 24.2 years (SD 3.8, range 18.0–30.9).

Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS). This 14-item scale describes a 7-item depression scale, a 7-item anxiety scale and a total scale. The 14 items are scored on a four-point scale (0–3), producing a total score ranging from 0 to 21. Higher scores indicate more anxiety or depression symptoms in the past week. A score of 8 or above is generally used as a cut-off score and is considered indicative of a possible presence of a depression or anxiety disorder; a score of 8 or above is called at risk \(^8\). The Dutch version of the HADS showed satisfactory validity and reliability \(^8\). In this study, the internal consistency (Cronbach’s alpha) of the anxiety scale was 0.83 and of the depression scale 0.75. The data of the Dutch HADS reference group are available, collected by a research institute that is specialized in online survey research \(^8\). The HADS reference group consisted of 182 respondents from the general Dutch population, 69 men (37.9%) and 113 women (62.1%). Mean age was 27.1 years (SD 2.5, range 22.0–30.0).

Due to privacy reasons, no information about the chronic conditions of the participants was provided by the benefits agency. This information was therefore derived through beneficiaries’ self reports. The questions concerning the
disease characteristics were chosen based on existing questionnaires and recommendations from experts in the field. The following dichotomous disease-related variables were used in the present study: congenital disorder (yes/no), visible disease/disability (yes/no), the nature of the disease process over time ("course of disease": stable or positive vs negative or variable), daily use of medication (yes/no), need for medical devices in daily life, e.g. hearing aid and wheelchair (yes/no), limitations in use of fingers/hands, sight, hearing, and not being able to sit/stand for half an hour (yes/no).

**STATISTICAL ANALYSIS**

The Statistical Package for Social Sciences (SPSS) Windows version 16.0 was used for all the analyses. Gender and age differences between EMWAjong and both reference groups were tested with Chi²-tests and t-tests respectively. Age and gender distribution in the EMWAjong group differed significantly from the RAND-36 reference group; further analyses concerning HRQoL were therefore corrected for age and gender. In the case of the HADS analyses, correction for age was required, but not for gender.

Univariate analysis of variance (ANOVA) by group, age and gender was performed to test differences in HRQoL (mean scale scores) between EMWAjong and the RAND-36 reference group. ANOVA by group and age was performed to test differences on Anxiety and Depression (mean scale scores) between EMWAjong and the HADS reference group. Effect sizes (d) were calculated by dividing the difference in mean scale scores of the EMWAjong group and the reference group by the standard deviation of the scores in the reference group. We considered effect sizes up to 0.2 to be small, effect sizes up to 0.5 to be moderate and effect sizes up to 0.8 to be large.

In addition, logistic regression analyses by group and age were conducted in order to test whether the proportion of young adults that were at risk of an anxiety or depression disorder in the EMWAjong group differed from the proportion in the HADS reference group, using the odds ratios (OR) for group.

Finally, regression analyses were performed to predict HRQoL, as expressed by the Mental and Physical Component Scale of the RAND-36 (MCS, PCS), and Anxiety and Depression of the HADS, by demographic (age and gender) and disease-related variables (congenital disorder, visible disease/disability, course of the disease and medical devices). In line with Cohen, binary-coded variables of 0.3 were considered small, 0.5 medium and 0.8 large. For continuous variables, regression coefficients of 0.1 were considered small, 0.3 medium and 0.5 large. A significance level of 0.05 was used for all analyses.

**RESULTS**

**EMWAjong GROUP**

A total of 415 young adults with a chronic somatic condition participated in the study (response rate 20.1%). Non-responders differed from responders with respect to gender; 51.4% vs. 64.3% women (p < 0.05). Thirty-nine respondents were removed from the analyses because of missing data on the RAND-36 questionnaire. In the case of the HADS, 38 respondents were removed. Consequently, the data of 376 and 377 participants respectively were used for the analyses of HRQoL and anxiety and depression: the group comprised 242 women (64.4%) and 134 men (35.6%). The characteristics of the EMWAjong group are listed in table 1.

There were significant differences with respect to age and gender between the EMWAjong group and the RAND-36 reference group (p < 0.001). The EMWAjong group and the HADS reference group were significantly different with respect to age (p < 0.001).

| TABLE 1: Demographic and medical characteristics of the EMWAjong group (N=376) |
|-----------------|-----|------------------|
| **M** | **SD** | **Range** |
| Age at study (years) | 25.0 | 2.1 | 22.5 - 30.9 |
| **N** | **%** |
| Gender |
| Female | 242 | 64.4 |
| Male | 234 | 35.6 |
| Chronic conditions |
| N | % |
| Visually impaired/blind | 58 | 14.3 |
| Spasm | 49 | 12.0 |
| Rheumatoid arthritis | 46 | 11.3 |
| CFS/migraine | 44 | 10.8 |
| Hearing impaired/deaf | 34 | 8.4 |
| Epilepsy | 34 | 8.4 |
| Back complaints | 31 | 7.6 |
| Intestinal complaints | 24 | 5.9 |
| Lung complaints | 21 | 5.2 |
| Accident damage | 21 | 5.2 |
| Cancer | 23 | 7.1 |
| Paralysis | 17 | 4.7 |
| Muscular dystrophy | 17 | 4.2 |
| Arthritis | 17 | 4.2 |
| Kidney diseases | 16 | 3.7 |
| Skin disease | 9 | 2.2 |
ANXIETY AND DEPRESSION

The EMWAjong group reported higher scores on the anxiety and depression scale than the reference group (p < 0.001). The differences were small to moderate with effect sizes of 0.35 and 0.54 respectively (table 3). In addition, higher percentages (p< 0.01) of the EMWAjong group than of the reference group were at risk (scores ≥ 8) of disorders of anxiety (29.7 versus 17.6 percent; OR=2.1) and depression (17.0 versus 6.0 percent; OR=3.1) (table 4).

HEALTH-RELATED QUALITY OF LIFE

The results of the ANOVA showed lower HRQoL for the EMWAjong group than the reference group on all domains (p<0.001), except for General Mental Health (table 2). Effect sizes ranged from -0.32 for Role limitations due to Emotional problems to –2.14 for Physical Functioning. The ANOVA for the Physical and Mental Component Scale confirmed these findings: the EMWAjong group scored significantly lower than the reference group, with effect sizes of -1.76 and -0.48 respectively.

TABLE 2: HRQoL (RAND-36) of the EMWAjong group versus the RAND-36 reference group; Mean scores, SD and effect sizes

<table>
<thead>
<tr>
<th></th>
<th>EMWAjong group N=376</th>
<th>RAND-36 reference group N=508</th>
<th>F</th>
<th>Effectsize</th>
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<tr>
<td>Social Functioning</td>
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<td>Mean</td>
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<td>SD</td>
<td>23.8</td>
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<td>Role Limitations Physical</td>
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<td>SD</td>
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<td>Role Limitations Emotional</td>
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<td>Mean</td>
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<td>SD</td>
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<td>SD</td>
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<td>SD</td>
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<tr>
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<td>SD</td>
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<td>-1.09</td>
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<tr>
<td>Mean</td>
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<td>-1.76</td>
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<tr>
<td>Mean</td>
<td>32.7</td>
<td>50.0</td>
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<tr>
<td>SD</td>
<td>16.9</td>
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<tr>
<td>Mental Component Scale</td>
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<td>-0.48</td>
</tr>
<tr>
<td>Mean</td>
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<tr>
<td>SD</td>
<td>12.6</td>
<td>9.9</td>
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</table>

* Group differences at p < 0.001 according to ANOVA by group, age and gender. F-value and effectsize for the effect of group

Anxiety and Depression

The EMWAjong group reported higher scores on the anxiety and depression scale than the reference group (p < 0.001). The differences were small to moderate with effect sizes of 0.35 and 0.54 respectively (table 3). In addition, higher percentages (p< 0.01) of the EMWAjong group than of the reference group were at risk (scores ≥ 8) of disorders of anxiety (29.7 versus 17.6 percent; OR=2.1) and depression (17.0 versus 6.0 percent; OR=3.1) (table 4).
Our hypothesis was confirmed; young adults claiming disability benefits for a childhood-onset chronic somatic condition report worse HRQoL and higher anxiety and depression scores than the reference group from the general population. Although these results may be in the expected direction and may also be in line with findings in adult populations with problems in workforce participation as a result of somatic conditions, the results are an indication of the need for support for children and adolescents who grow up with a somatic condition.

The differences in HRQoL between the EMWAjong group and the RAND-36 reference group were substantial, especially in the physical and social domains. The considerable differences in the physical domains fit the assumption that the differences in HRQoL between people with a somatic condition and healthy individuals are greater than in the mental domains.

The results of the regression analyses are presented in table 5. Respondents from the EMWAjong group who have a stable or positive course of disease reported better physical and mental HRQoL and lower levels of anxiety and depression (β = 0.46, β = 0.36, β = -0.22, β = -0.22, respectively) than those with a variable or negative course of disease. In addition, those who use medical devices reported worse physical HRQoL, but better mental HRQoL and less anxiety and depression (β = -0.13, β = 0.16, β = -0.12, β = -0.22, respectively) than those without the use of medical devices. Furthermore, having a congenital disease was associated with better physical HRQoL (β = 0.13), while having a visible disease/disability was associated with worse physical HRQoL (β = -0.16).
people are mainly based on physical limitations. However, the scores on the social domain indicate that these aspects also influence the HRQoL of young adults claiming disability benefits. They may feel restricted in social situations as a result of physical or emotional consequences of their conditions. This is undesirable, especially in adolescence, because close peer relationships are an important source of support for chronically ill or disabled adolescents at a time when they have to face developmental tasks and disease-related challenges.

Research showed that the majority of the young people with a paediatric condition have peer relations and friendships that are similar to those of their peers. Nevertheless, young people with visible and physically handicapping conditions may find dealing with social contexts especially difficult. Adolescents with chronic conditions may become marginalised by peers, being rejected for being different during a period in which body image and identity heavily on conformity. The social aspects of education are a key aspect during adolescence. If the social context does not continue into a working environment due to unemployment, then young people are at risk of social isolation in later life. Therefore, it is important to encourage children and adolescents with a chronic somatic condition to make friends and to participate in social events with peers in order to build up a social life. Moreover, there is a need for preventive interventions that focus on coping skills, as they are important moderators of chronic illness effects. In addition, guidance directed at exploring social activities which are physically feasible for the child or adolescent is recommended.

Even though the differences between the EMWAJong group and the general population regarding their scale scores on the Mental Health domain (one of the domains) were not significant, the EMWAJong group scored significantly worse on the summary scale scores for the overall Mental Component Scale. When we further study this aspect of the HRQoL by examining anxiety and depression, we see that the EMWAJong group scored significantly worse on anxiety as well as depression in comparison with the HADS reference group. Almost double the proportion of the EMWAJong group was at risk of an anxiety disorder, and for a depressive disorder the proportion is almost threefold. Several studies found similar results in adolescents and young adults with chronic conditions that started in childhood.

The results of the regression analyses in this study indicate that a variable or negative course of disease influences HRQoL negatively and may be a risk factor for anxiety and depression in young adult beneficiaries. This finding is in line with results of meta-analyses on anxiety and depression in children and adolescents with chronic physical illnesses. However, due to the cross-sectional design of the study, the direction of the correlation is unknown and causality cannot be proven. The use of medical devices was found to correlate negatively with physical QoL, which we expected. However, those using medical devices reported better mental QoL as well as less anxiety and depression. The use of medical devices potentially improves patients’ psychosocial well-being regardless of their medical status. This could indicate that patients successfully adapt to their medical situation. Alternatively, the young adults benefit from the medical devices because the devices enable them to be independent, in contrast to those who do not use medical devices. Again, causality cannot be proven. Furthermore, the associations of medical devices with HRQoL, anxiety and depression were weak.

Individual differences in emotional functioning and psychological distress may be related to long-term adjustment in adulthood for young adult beneficiaries. It is still unclear which aspect – the physical or psychological part of being chronically ill or disabled – causes worse HRQoL and worse emotional well-being in young adults claiming disability benefits compared to peers from the general population. The literature on adults with chronic illness since childhood points in the same direction; a lower HRQOL and more emotional problems compared to the general population. For this reason, and also in the light of the increasing number of young adults with a chronic disease reaching adulthood because of medical advancements, it is very important to pay attention to the consequences of chronic somatic conditions in an early stage. The results of this study show that paediatricians and other healthcare workers should pay attention not only to the medical but also to the emotional and psychosocial situation of patients growing up with a somatic condition. Systematic assessment of HRQoL, anxiety and depression is not yet part of standard practice, even though paediatricians and their teams know that a part of the population they treat is at risk of problems later in life. The approach in the medical context can frequently be focused on the physical consequences of the somatic condition and its treatment instead of on the patient’s emotional well-being and social life. In addition to healthcare workers and parents, it is a political and social responsibility to support children, adolescents and young adults with somatic limitations in achieving academic and vocational success. Effective support can only be addressed across systems. Cooperation between multidisciplinary rehabilitation teams and special education schools, for example, is necessary in combination with the development of programmes stimulating the children and adolescents in their development. SAVTI (Successful Academic and Vocational Transition Initiative) of the Pediatric Oncology Group of Ontario (POGO) and Emma@work (job mediation for adolescents with a somatic disease) of the Emma Children Hospital (EKZ) in the Netherlands are examples of useful tools.

There are a number of shortcomings of this study that need to be addressed.
might be an underestimation or an overestimation of the problems in this group and this limits the possibility to generalize of our findings to the whole group of young adults with a chronic somatic condition. However, the problems we found in the study group are substantial and therefore socially relevant. Paying attention to this vulnerable group of young adults is of the utmost importance.

CONCLUSIONS

The success of medical treatment in extending the lives of children with chronic conditions means that new challenges emerge. This study demonstrates worse HRQoL and increased levels of anxiety and depression experienced by young adults with disabilities or somatic illness since childhood who have to apply for disability benefits. Although some adolescents and young adults with a childhood-onset chronic somatic condition adapt well into adult life, there are many others who struggle with their overall psychosocial functioning. In medical practice, healthcare providers (including paediatric healthcare providers) should pay more attention to the HRQoL, anxiety and depression of patients growing up with a somatic condition in order to optimise their well-being and adaptation to society at the time of transition to adult life. In future research emotional functioning in young adults with a childhood-onset chronic somatic condition should be studied in more detail. Potential factors influencing HRQoL, anxiety and depression and objective disease characteristics should be taken into account in subgroup analyses in order to determine those individuals most at risk and trends within disability groups. Research is warranted to identify whether stimulating and improving job participation lead to increase of HRQoL and decrease of anxiety and depression in this group.

ACKNOWLEDGMENTS

The authors thank Ad Vingerhoets for making the HADS reference group available to them.
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Ilse Story 3

Met verbaasde blikken van andere mensen vertel ik iedere keer weer met trots dat ik geboren ben op Curaçao. Mijn vader was met zijn beroep bij de marine uitgezonden naar Curaçao voor een aantal jaar. Mijn ouders, zus en broer woonden daar vast. Mijn broer en zus hebben daar de kleine school mee gemaakt, iets wat ik mij niet kan herinneren. Eigenlijk kan ik mij helemaal niets herinneren. Foto’s, daar moet ik het mee doen. Dit is dan ook één van mijn dromen: terugkeren naar het land waar ik geboren ben. Ontdekken en uiteraard genieten van de warme cultuur.

Vanaf mijn derde ben ik opgegroeid in Nederland en door de jaren heen werd ik van een creatief persoon steeds meer iemand die zich volledig wilde gaan focussen op het sporten. Ik deed aan hockey en voor mijn conditie in de zomer extra aan wielrennen. Toen ik eind 2004 een aanbod kreeg om met hockey bij de selectie van Jong-Oranje te komen, heb ik even mijn twijfels gehad over of ik wel of niet, 3 weken later, op wintersport moest gaan. Echter vroeg ik mezelf af ‘Hoe groot is de kans dat juist ik, van alle wintersporters, een ongeluk krijg’. Deze gedachten heb ik helaas niet afgeklopt. Je raad het al, het is mij overkomen. Iemand is over de voorkant van mijn ski’s gegaan, hierdoor verloor ik mijn evenwicht. Met als gevolg: pijn in mijn linkervoet/been. Met hulp van anderen ben ik naar beneden gebracht en verder onderzoek in een ziekenhuis bleef uit. Ze, de leiding van de middelbare school waar ik op dat moment in mijn eindexamenjaar zat, vond dit niet nodig. Niet ernstig genoeg. Tot mijn grote ergens en tot de grote ergens van mijn ouders die machteloos in Nederland zaten af te wachten. De rest van de week werd ik steeds onderaan de piste gezet en aan het einde van de dag weer opgehaald. Vervolgens zijn er in de loop de maanden die volgden diverse fouten gemaakt door artsen en is er gedurende mijn continu aanhoudende gips periodes CRPS (Chronisch Regionaal Pijn Syndroom) ontwikkeld.

Een spier-/zenuwziekte die zorgt voor functieverlies en immense pijn. Als een toen 14 jarig meisje wist ik niet zo goed wat dit in hield of wat de gevolgen zouden kunnen zijn. Deze ziekte is 8 maanden na het ongeluk geconstateerd en 9 maanden na het ongeluk ben ik pas bij de juiste artsen terecht gekomen.

Van topsportster naar invalide. Een harde realiteit waarbij ik, maar ook mijn omgeving, een manier moest vinden om hiermee om te gaan. Gedurende een revalidatie opname van januari ’06 tot juli ’07 heb ik intensief getraind om mijn pijn te leren lopen. Ik had moeite met het moeten overgeven aan de pijn, wat mijn revalidatie proces bemoeilijkte. Dit had ik niet verwacht want ik dacht dat ik als oud-topsportster wel de pijn zou kunnen overwinnen maar de CRPS was mij de baas. Na het plotseling overlijden van mijn allerbeste vriend, be- sefte ik dat het leven kostbaar is. Ik wilde geen leven op bed, ik wilde een leven waar ik in leef! Ik zette alles op alles om weer te leren lopen, niet alleen voor mezelf maar...
Story 3

Meteen contact op genomen met het UWV en vervolgens regede het UWV een eigen parkeerplaats op de Academie waardoor ik met mijn aangepaste auto heen en weer naar Den Haag kon rijden. Op dat moment besefte ik dat er gelukkig ook nog goede mensen op deze wereld bestaan die je willen helpen om het ondanks je handicap zo aangenaam mogelijk te maken. Natuurlijk ben ik niet trots op mijn parkeerplek, wel thuis als op de Academie. Liever ga ik net als ieder andere student met de bus en trein, maar ik ben blij dat ik ze heb zodat ik kan doen wat ik wil doen! In september '11 heb ik een 4-jarige MBO opleiding in drie jaar voltooid. Enorme blijdschap, het voelde alsof ik een jaar had ingehaald. Zo enthousiast en gedreven als ik kan zijn wist ik dat ik nog meer wilde dus deed ik een poging om toelating te doen voor de opleiding grafisch ontwerp aan één van de beste kunstacademies in Nederland. Ik had mijn CRPS onder controle en in goed overleg kan je een hoop bereiken. Van de ± 600 worden er ± 50 mensen aangenomen. Bij het verkrijgen en lezen van het resultaat barstte ik in tranen uit. Tranen van alle ellende die nu werden verrezen door een mijlpaal in mijn leven; ik was trots op mijn parkeerplek, zo aangenaam mogelijk te maken. Natuurlijk ben ik niet trots op mijn parkeerplek, wel thuis als op de Academie. Liever ga ik net als ieder andere student met de bus en trein, maar ik ben blij dat ik ze heb zodat ik kan doen wat ik wil doen! In september '11 kon ik eindelijk beginnen. Alles verliep goed, ik was stabil en ik kon mijn studie goed volbrengen. Echter ben ik onderweg naar Den Haag in oktober 2013 van achtereenvolgens aangereden. Gevolg: een whiplash. De meest zakte wel even in mijn schoenen. Niet weer een ongeluk. Mijn CRPS kreeg een terugslag en lag ik daar maar op bed te liggen, kon geen kant op. In de afgelopen 10 jaar heb ik geleerd om niet op te geven en dat was ik nu ook zeker niet van plan. Vanaf mijn bed heb ik geprobeerd mijn 3e studiejaar door middel van Skype en hulp van studienoten te voltooien. Wonder boven wonder is mij dat gelukt. Ik kan het nog nauwelijks bevatten. Inmiddels is mijn afstudeerjaar begonnen en hoop ik over enkele maanden in juni 2015 mijn Bachelor Grafisch Ontwerp te behalen. Het liefst zou ik ook nog een Master opleiding willen volgen maar helaas valt de studiefinanciering weg waardoor ik mijn twijfels heb gekregen. Daarnaast wacht mij nog een groot ziektehuis traject waarbij een laatste poging willen wagen om mijn pijn te verminderen in mijn been, waardoor studeren ook niet 100% kan. Plus het feit dat ik wanneer ik afgestudeerd ben, een stap zou willen gaan nemen om op mezelf te gaan. Echter zal dit laatste wellicht worden uitgesteld naar 2016 i.v.m. de operatie en herstel.

Op dit moment heb ik werkelijk geen idee wat de toekomst mij zal brengen. Mischien wil ik dit ook niet weten. Het belangrijkste is dat je moet genieten van alle kleine dingen om je heen en de mensen die je lief hebt te koesteren. Het kan de volgende dag zomaar anders zijn. We leven in een maatschappij als allemaal individuen en, maar in werkelijkheid hebben we elkaar nodig om dingen te kunnen realiseren en consumeren. Je bent afhankelijk van elkaar en ik heb nu 2 keer de pech gehad waarbij de ander niet aan het opletten was. Bad lucky! Maar uiteindelijk is het allemaal ergens goed voor, tenminste, dat zegt mijn fysiotherapeut altijd. Ik hoop in juni 2015 mijn geluk moment te hebben en wat daar na gebeurd zie ik vanzelf wel. Ik zeg altijd: “Je bent en je bent en wie je niet accepteert zoals je bent, zoekt het maar uit! Je doet je best en meer kan je niet doen...”. 

Ilse
Health related quality of life and psychosocial developmental trajectory in young female beneficiaries with Juvenile Idiopathic Arthritis

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Heleen Maurice-Stam
Hugo S.A. Heymans
Daniëlle M. Gerlag
Marion A.J. van Rossum
Martha A. Grootenhuis

Lotte Haverman and Eefje J. Verhoof contributed equally to this study.

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ABSTRACT

OBJECTIVES: It is generally recognized that for all children the fulfilling of age-specific psychosocial developmental tasks in childhood is of great importance to adjustment in adult life, including participation in society. For young adults with Juvenile Idiopathic Arthritis (JIA) this is more difficult. We assume that the achievement of psychosocial milestones while growing up (psychosocial developmental trajectory) is also related to labour participation. A proportion of all young adults with JIA have to apply for disability benefits. This study assessed the health related quality of life (HRQOL) and the psychosocial developmental trajectory of young female beneficiaries with JIA compared with peers from the Dutch general population.

METHODS: Young females with disability benefits because of JIA completed the RAND-36 (HRQOL) and the Course of Life Questionnaire (CoLQ; psychosocial developmental trajectory). Differences between respondents and the peer group were tested using analysis of variance and logistic regression analysis by group and age.

RESULTS: The beneficiaries reported worse HRQOL than the peer group and achieved fewer milestones, or achieved the milestones at a later age than the peer group in the autonomy, social and psychosexual domain.

CONCLUSIONS: Young females with JIA who have to apply for disability benefits are at risk for impaired HRQOL and a delay in their psychosocial developmental trajectory. Parents, physicians and other health-care providers should pay systematic attention to the development of social and independent functioning of children with JIA in order to optimize their adaptation to society at the time of transition to adulthood.

INTRODUCTION

Juvenile Idiopathic Arthritis (JIA) is arthritis of unknown aetiology that begins before the age of sixteen years and is more common in girls than in boys. JIA is one of the most common rheumatic diseases in childhood and a major cause of childhood disability. Pediatric rheumatic disorders may have substantial medical and psychological consequences. For example, children and adolescents with JIA have a lower Health Related Quality of Life (HRQOL) and have more problems compared with healthy peers, such as internalizing problems including depression and anxiety.

For all children transition into adulthood is a critical phase. Children and adolescents with chronic diseases are expected to pass similar developmental stages as their non-disabled peers, to leave home, develop psychosocially, and define a role for themselves in the community through employment or other activities. For adults with JIA this is more difficult compared with, for example, healthy siblings. Occupational outcomes of (young) adults with JIA varied in different studies.

In the Netherlands, if young adults are (partially) unable to work because of a chronic disease or disability (at least 25% occupationally disabled before the 17th birthday or during study), they may be eligible for benefits provided by the state social services for young disabled persons: Wajong Act (Work and Labour Support for Young Disabled Persons).

It is generally recognized that the fulfilling of age-specific psychosocial developmental tasks in childhood is of great importance to adjustment in adult life, including participation in society. We assume that the achievement of psychosocial milestones while growing up (psychosocial developmental trajectory) is also related to labour participation. Insight into early determinants of adjustment in adult life may help to develop interventions in pediatric health care to create conditions for better participation in society, including labour participation. Therefore, we want to assess the psychosocial developmental trajectory of young adults with JIA who claim the Wajong benefit, and hypothesize that their psychosocial developmental trajectory is delayed. In addition, we expect that they report lower HRQOL than a norm group of peers from the Dutch general population.
Chapter 4

METHODS

PARTICIPANTS
Data from the database of the Dutch EMWAjong study, a Dutch cross-sectional study examining psychosocial factors affecting the employment of young adults with disability benefits (Wajong) because of chronic somatic diseases or childhood-derived physical limitations, were used. All young adults between 22 and 31 years of age, who claimed this disability benefit in the year 2003 or 2004 received a letter with an invitation to participate in the EMWAjong study. The study was performed according to the regulations of the medical ethical committee of our institute.

MEASURES

Psychosocial developmental trajectory
The psychosocial developmental trajectory was assessed with the Course of Life Questionnaire (CoLQ)\(^\text{10}\). The items concern behavior characteristics of certain age stages, developmental tasks and the limitations children might face when they grow up with a chronic disease. The items are divided into five scales; we used the three developmental scales: autonomy development (6 items, autonomy at home and outside the home); psychosexual development (4 items, love and sexual relations); and social development (12 items, contacts with peers). A higher score on the scales indicates the accomplishment of more developmental milestones. The validity and reliability of the CoLQ scales is moderate to good\(^\text{10}\).

HRQOL
The RAND-36 is a Dutch version of the Medical Outcomes Study-SF-36 Health Survey and almost identical to the Dutch SF-36. The RAND-36 is a multidimensional questionnaire consisting of 36 items, clustered into eight multi-item scales. Higher scores indicate higher levels of functioning or well-being. The validity and reliability of the RAND scales were satisfactory\(^\text{11}\). Overall physical (physical component scale (PCS)) and overall mental health (mental component scale (MCS)) were assessed by principal components analysis using non-orthogonal rotation (Oblimin), based on the assumption that physical health and mental health are interdependent.

Normative data of young adults from the general Dutch population (peer group) are available, recruited through general practitioners in a former study\(^\text{10}\).

RESULTS

PARTICIPANTS
The EMWAjong database contains data from 415 participants with different childhood-derived chronic diseases; 46 young adults (11.1%) reported to have JIA, including 43 females (16.1% of all females in the EMWAjong database). The data of these 43 young females with JIA were used for analyses. The peer group consisted of 269 females. The mean age of the females with JIA was higher than in the peer group, 25.8 (SD = 2.3) vs 24.3 (SD = 3.8) (p<.001).

THE PSYCHOSOCIAL DEVELOPMENTAL TRAJECTORY
The scores of the young females with JIA were lower than the peer group in the domains of social development (19.5 vs 20.9) and psychosexual development (6.7 vs 7.2) but not in the domain of autonomy development (table 1). The effect sizes were moderate (0.6 and 0.4).

Table 1 also shows the individual milestones. With respect to autonomy development, we found that young adults with JIA were less likely than the peer group to have had a paid job during middle/high school (OR=0.26). In addition, we noted significant differences on five items of the social development; during and after middle and/or high school, young females with JIA were less likely than the peer group to have been a member of a sports club (OR=0.33 and OR=0.23), and during middle and/or high school, to have had a best friend (OR=0.34), to have spent leisure time with friends (OR=0.39) and to have been going out to visit a bar or disco (OR=0.29) than the peer group. The results in the psychosexual development domain showed that the young females with JIA were also less likely than the females of the peer group to have had intimate relationships with a boyfriend or girlfriend before the age of 19 years (OR=0.38) or to have had...
Young female beneficiaries with JIA

Chapter 4

sexual intimacy for the first time before the age of 19 (OR=0.47) compared with the peer group.

TABLE 1: Psychosocial developmental trajectory of young adults with JIA compared with the peer group: mean scale scores (SD), effect sizes (d) and the achievement of milestones (OR) in the social, autonomy and psychosexual domains of the CoLQ

<table>
<thead>
<tr>
<th>SCALES</th>
<th>JIA</th>
<th>Peer Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Autonomy development (range 6-12)</td>
<td>43</td>
<td>9.4 (1.5)</td>
</tr>
<tr>
<td>Social development (range 12-24)</td>
<td>43</td>
<td>19.5 (2.8)</td>
</tr>
<tr>
<td>Psychosexual development (range 4-8)</td>
<td>43</td>
<td>6.7 (1.4)</td>
</tr>
</tbody>
</table>

MILESTONES

<table>
<thead>
<tr>
<th>AUTONOMY DEVELOPMENT</th>
<th>N  %</th>
<th>N  %</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular chores/tasks in your family, elementary school</td>
<td>yes</td>
<td>22</td>
<td>51.2</td>
</tr>
<tr>
<td>no</td>
<td>21</td>
<td>48.8</td>
<td>53.0</td>
</tr>
<tr>
<td>Regular chores/tasks in your family, middle and/or high school</td>
<td>yes</td>
<td>28</td>
<td>65.1</td>
</tr>
<tr>
<td>no</td>
<td>15</td>
<td>34.9</td>
<td>38.4</td>
</tr>
<tr>
<td>Paid jobs, middle and/or high school</td>
<td>at the age of ≤ 18 years</td>
<td>26</td>
<td>60.5</td>
</tr>
<tr>
<td>at the age of ≥ 19 years/rever</td>
<td>17</td>
<td>39.5</td>
<td>38</td>
</tr>
<tr>
<td>For the first time vacation without adults</td>
<td>at the age of ≤ 17 years</td>
<td>17</td>
<td>39.5</td>
</tr>
<tr>
<td>at the age of ≥ 18 years</td>
<td>26</td>
<td>60.5</td>
<td>125</td>
</tr>
<tr>
<td>Leaving your parents’ home</td>
<td>not living with your parents</td>
<td>38</td>
<td>88.4</td>
</tr>
<tr>
<td>still living with your parents</td>
<td>5</td>
<td>11.6</td>
<td>79</td>
</tr>
</tbody>
</table>

SOCIAL DEVELOPMENT

<table>
<thead>
<tr>
<th>N  %</th>
<th>N  %</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one year of membership in a sports club / competitive sports, elementary school</td>
<td>yes</td>
<td>37</td>
</tr>
<tr>
<td>no</td>
<td>6</td>
<td>14.0</td>
</tr>
</tbody>
</table>

TABLE 1: Continued

<table>
<thead>
<tr>
<th>SOCIAL DEVELOPMENT</th>
<th>N  %</th>
<th>N  %</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time playing with…, elementary school</td>
<td>friends</td>
<td>37</td>
<td>86.0</td>
</tr>
<tr>
<td>brothers and/or sisters, parents, on your own</td>
<td>6</td>
<td>14.0</td>
<td>32</td>
</tr>
<tr>
<td>At least 1 year of membership in a sports club / competitive sports, middle and/or high school</td>
<td>yes</td>
<td>19</td>
<td>44.2</td>
</tr>
<tr>
<td>no</td>
<td>24</td>
<td>55.8</td>
<td>79</td>
</tr>
<tr>
<td>Number of friends, middle and/or high school</td>
<td>≥ 4</td>
<td>22</td>
<td>51.2</td>
</tr>
<tr>
<td>≤ 4</td>
<td>21</td>
<td>48.8</td>
<td>88</td>
</tr>
<tr>
<td>Best friend, middle and/or high school</td>
<td>yes</td>
<td>25</td>
<td>58.1</td>
</tr>
<tr>
<td>no</td>
<td>18</td>
<td>41.9</td>
<td>52</td>
</tr>
<tr>
<td>Belonging to a group of friends, middle and/or high school</td>
<td>yes</td>
<td>36</td>
<td>83.7</td>
</tr>
<tr>
<td>no</td>
<td>7</td>
<td>16.3</td>
<td>46</td>
</tr>
<tr>
<td>Leisure time, mostly with…, middle and/or high school</td>
<td>friends</td>
<td>32</td>
<td>74.4</td>
</tr>
<tr>
<td>brothers and/or sisters, parents, on your own</td>
<td>11</td>
<td>25.6</td>
<td>30</td>
</tr>
<tr>
<td>Going out to a bar or disco, middle and/or high school</td>
<td>sometimes/often</td>
<td>26</td>
<td>60.5</td>
</tr>
<tr>
<td>never</td>
<td>17</td>
<td>39.5</td>
<td>43</td>
</tr>
<tr>
<td>At least one year of membership in a sports club/competitive sports, after middle and/or high school</td>
<td>yes</td>
<td>7</td>
<td>16.3</td>
</tr>
<tr>
<td>no</td>
<td>36</td>
<td>83.7</td>
<td>147</td>
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PSYCHOSEXUAL DEVELOPMENT

<table>
<thead>
<tr>
<th>N  %</th>
<th>N  %</th>
<th>OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>First girlfriend/boyfriend</td>
<td>at the age of ≤ 17 years</td>
<td>27</td>
</tr>
<tr>
<td>at the age of ≥ 18 years/rever</td>
<td>16</td>
<td>37.2</td>
</tr>
<tr>
<td>Falling in love for the first time</td>
<td>at the age of ≤ 18 years</td>
<td>38</td>
</tr>
<tr>
<td>at the age of ≥ 19 years/rever</td>
<td>5</td>
<td>11.6</td>
</tr>
<tr>
<td>Sexual intimacy for the first time</td>
<td>at the age of ≤ 18 years</td>
<td>30</td>
</tr>
<tr>
<td>at the age of ≥ 19 years/rever</td>
<td>13</td>
<td>30.2</td>
</tr>
<tr>
<td>Sexual intercourse for the first time</td>
<td>at the age of ≤ 18 years</td>
<td>21</td>
</tr>
<tr>
<td>at the age of ≥ 19 years/rever</td>
<td>22</td>
<td>51.2</td>
</tr>
</tbody>
</table>
TABLE 1: Continued

<table>
<thead>
<tr>
<th>SOCIODEMOGRAPHICS</th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>OR</th>
</tr>
</thead>
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<tr>
<td>Marital status</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>married/living together</td>
<td>23</td>
<td>53.5</td>
<td>121</td>
<td>46.4</td>
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<td>single</td>
<td>20</td>
<td>46.5</td>
<td>140</td>
<td>53.6</td>
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<tr>
<td>Education</td>
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<td>11</td>
<td>26.2</td>
<td>49</td>
<td>18.8</td>
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<tr>
<td>low-middle</td>
<td>31</td>
<td>73.8</td>
<td>211</td>
<td>81.2</td>
<td>1.25</td>
</tr>
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</table>

1 JIA versus peer group
A Group difference at p<0.05 according to ANOVA by group and age
B Group difference at p=0.01 according to ANOVA by group and age
* Difference at p<0.05 according to logistic regression analyses by group and age
** Difference at p<0.01 according to logistic regression analyses by group and age
*** Difference at p<0.001 according to logistic regression analyses by group and age

HRQOL

The HRQOL of young females with JIA was significantly lower compared with the peer group on all domains (effect sizes 0.4-2.6), with the exception of the domains of Role limitations emotional and Mental health (table 2).

TABLE 2: Health Related Quality of Life of young adults with JIA compared with the peer group: mean scale scores of the RAND-36, SD and effect sizes (d)

<table>
<thead>
<tr>
<th></th>
<th>JIA</th>
<th>Peer Group</th>
<th>N</th>
<th>Mean (SD)</th>
<th>N</th>
<th>Mean (SD)</th>
<th>d*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>45</td>
<td>51.5 (2.9)</td>
<td>268</td>
<td>91.6 (15.3)</td>
<td>-2.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social functioning</td>
<td>45</td>
<td>69.2 (20.2)</td>
<td>268</td>
<td>85.1 (19.7)</td>
<td>-0.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role limitations physical</td>
<td>45</td>
<td>53.0 (39.8)</td>
<td>268</td>
<td>83.1 (50.7)</td>
<td>-1.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role limitations emotional</td>
<td>45</td>
<td>81.4 (35.1)</td>
<td>265</td>
<td>85.2 (50.5)</td>
<td>-0.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health</td>
<td>45</td>
<td>79.5 (12.5)</td>
<td>268</td>
<td>74.5 (11.6)</td>
<td>0.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitality</td>
<td>45</td>
<td>51.1 (18.8)</td>
<td>268</td>
<td>62.7 (17.1)</td>
<td>-0.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bodily pain</td>
<td>45</td>
<td>52.6 (24.3)</td>
<td>267</td>
<td>83.5 (21.6)</td>
<td>-1.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health perceptions</td>
<td>45</td>
<td>41.9 (20.6)</td>
<td>267</td>
<td>74.3 (18.0)</td>
<td>-1.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical component scale</td>
<td>45</td>
<td>22.2 (11.2)</td>
<td>264</td>
<td>46.8 (11.4)</td>
<td>-2.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental component scale</td>
<td>45</td>
<td>45.3 (9.9)</td>
<td>264</td>
<td>49.1 (10.2)</td>
<td>-0.4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Range 0-100
2 JIA vs peer group
* Difference at p<0.05 according to ANOVA by group and age
** Difference at p<0.01 according to ANOVA by group and age
*** Difference at p<0.001 according to ANOVA by group and age

DISCUSSION

Our study shows significant impairment of HRQOL in almost all domains in young females with JIA and claiming state benefit financial support. Obviously, disability can have lasting and large effects on subjective well-being. Powdthavee found that disability has the most detrimental impact on health satisfaction, followed by less salient aspects that are income, social life, use of leisure time, housing and having a partner. In former studies, impaired physical disability is an important predictor of HRQOL in children and adolescents with JIA. Therefore, besides optimizing drug therapy to gain a state of inactive disease and prevent damage, individualized training programmes for children and adolescents with JIA may be useful to improve physical ability. It is also known that in other chronic diseases, a delayed social development is a predictor of impaired HRQOL. Therefore, it is important to get insight in the (psychosocial) developmental trajectory of young adults with JIA.

Our study shows that the psychosocial developmental trajectory of young females with JIA was delayed. These young adults achieved fewer psychosocial milestones, or achieved the milestones at an older age than the peer group. Younger children with JIA seem to be able to keep up with peers at primary school level, but in middle or high school it seems to be more difficult to keep up with healthy peers. The results on the social development scale indicate that it is important to encourage children and especially adolescents to participate in social events with peers. As summarized by Crosnoe and McNeely, adolescent life the link between peer relations and developmental trajectories is stronger compared with childhood, because individuating from parents – one of the key developmental tasks of adolescents – increases the importance of peer relations compared with family relations. Close peer relationships are an important source of support for chronically ill adolescents at a time when they have to tackle both developmental tasks and disease-related challenges. An important result in the autonomy domain is the low rate of prevocational work experience during middle- or high-school years, while work experience in adolescence is an excellent way to discover interests and skills, and also limitations of the physical capacities. We suggest that the unfavourable labour market situation of our study group is associated with their impaired work experience rate during adolescence, whereas only 61% had a paid job before the age of 18 years compared with 86% of their healthy peers.

Our results underline that young adults with JIA face many additional challenges to negotiate in order to obtain normative developmental milestones and to acquire adaptive functioning in society. For parents with a chronically ill child, lowered expectations and overprotection come into focus. This can lead to a
lowered self-esteem in their child, which can eventually result in a lifetime of underachievement and failure to reach their full potential. These convictions can inhibit the child from developing the personal skills needed to cope with the extra challenges of the disease or disability. Based on our study results, parents may need to stimulate their child in social contacts.

The results of this study show that it is important that health-care providers pay systematical attention to both the medical and psychosocial situation of their patients. All pediatric and adult rheumatologists should be aware that a substantial number of their patients are at risk for problems in later life. Routine assessment of psychosocial, educational and vocational needs can easily be implemented in daily clinical practice for children, adolescents or during transition through computerized and web-based patient-reported outcomes. To offer tailored care a multidisciplinary approach of physicians and other health-care providers such as nurses, occupational therapists and psychosocial teams is required, especially during transition. Finally, it is important for young adults with JIA to acquire successful prevocational work experience. Different interventions or tools concentrate on vocational readiness and stimulating the children and adolescents in their vocational development; for example, Home, Education/employment, peer group Activities, Drugs, Sexuality, and Suicide/depression (HEEADSS; a psychosocial screening interview for adolescents) or a Rheumatology Adolescent Planner (RAP; a component of a transitional care programme for adolescents with JIA).

Some limitations of this study should be addressed. First, this study only concerns women, probably because of the prevalence of JIA in girls. It is unknown which part of all young women with JIA in the Netherlands apply for disability benefits. Therefore, we do not know whether the results are an underestimation or an overestimation of the problems of this group. Secondly, objective information about the disease status of this group of young females with JIA was not available. But since this study concerns the part of these young adults who are not able to earn a full salary as a result of their disease, we assume that their limitations are considerable. Finally, as the treatment of children with JIA has improved over recent decades, it is to be expected that more and more young adults with JIA will have a better quality of life and less overall burden of the disease over time. The young women in our study grew up in the period before the JIA treatment strategy of early intensification and availability of highly effective treatment, including biologics. However, the elucidated problems are substantial and give a point of departure for future research. This should be focused on identification of patients who most likely develop difficulties specifically related to workforce participation and HRQOL and who might benefit from psychosocial support. In addition, more insight into other determinants of integration into the workforce, such as illness cognition and family environment, is warranted.

**CONCLUSION**

This study reports a lower HRQOL and a delay in the psychosocial developmental trajectory faced by young females with JIA who applied for disability benefits. The findings underline the need to monitor HRQOL and the psychosocial developmental trajectory in children/adolescents and young adults with JIA during transitional care. We propose that parents, physicians and other health-care providers should pay systematic attention to the development of social and independent functioning of children with JIA in order to optimize their adaptation to society at the time of transition to adulthood.
REFERENCE LIST

Wat ik me nog het meest herinner aan de aanvraag voor een uitkering, was het stukje lopen van mijn huis naar het gebouw waar ze was gevestigd. Het was namelijk net te ver weg voor mij om het in een keer te belopen zonder een paar minuten mijn benen de rust te geven om weer verder te kunnen. Het was dan ook niet zo zeer dat ik boos ben over het feit dat ik geen uitkering kreeg in die tijd, maar dat men geen rekening hield met mijn gezondheid toen zij mij weer weg stuurde met een of ander telefoonnummer van een of andere contactpersoon die toch niets voor mij kon betekenen en mij niets gaf dan valse hoop met teleurstellingen.

Recht op een werkeloosheidsuitkering had ik niet omdat ik in de laatste maanden als projectadministrateur te weinig had gewerkt. Recht op een bijstandsuitkering had ik niet omdat ik nog thuis woonde vanwege mijn ziekte. Recht op een Wajong had ik niet omdat mijn ziekte actief was na mijn achttiende. Recht op een keuring had ik niet omdat ik geen recht had op een uitkering. Recht op advies had ik wel, maar er was niemand die mij kon adviseren. En na een hele hoop wandelingen belandde ik uiteindelijk weer bij het UWV, waar iemand speciale gevallen interessant vond en de tijd wou nemen om het voor mij uit te zoeken. Een paar dagen later kreeg ik via een ingesproken berichtje op mijn mobiel te horen dat ik mijn ziekte moest verzwijgen om weer full time te gaan werken. Als ik dan zes maanden in dienst was kon ik stoppen en een uitkering aanvragen en me laten keuren door het UWV. Een prachtig advies, alleen was er een probleem. Die wandelingen hadden haar tol geëist en mijn ziekte had zich gemanifesteerd als een draak in een porseleinkast vol met dromen. De enige die nu nog wat voor mij kon betekenen waren mijn vrienden, mijn familie en mijn neuroloog. Het was jaren later dat we probeerden om weer die ziekte uit de kast te drukken.

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Via een nieuwe behandeling kreeg de ziekte geen kans meer en ik er in een klap een hele hoop. Helaas maar voor heel even. Het duurde niet lang voordat ik besefte dat handarbeid voor mij nog te zwaar was en al het andere door de economische crisis en de zwarte gaten in mijn cv onbereikbaar was geworden. De mooiste reactie van al lemaal vind ik nog steeds: ‘Sorry, maar u past niet helemaal binnen ons profiel’. Het duurde dan ook niet lang voordat ik dacht in geen enkel profiel te passen en omdat ik geen zin had om nog een keer heen en weer te lopen liep ik weg in mijn eigen wereld. Dit was dan ook het moment waarop een Wajong uitkering goed voor mij zou zijn geweest.

Het had mij het gevoel gegeven dat ik in ieder geval bekend stond als een patiënt met een chronische ziekte waar de overheid en het bedrijfsleven iets om geeft in plaats van een niemand die bijna nergens recht op heeft en die het liefst in het niets zou moeten verdwijnen. En dat laatste deed ik dan ook. Natuurlijk had ik mijn familie en vrienden nog, maar uiteindelijk konden zelfs die niets meer voor mij
doen toen ik naar de dokter stapte om later met behulp van een psycholoog mijzelf te redden van mijzelf. Inmiddels is de ziekte er nog steeds, maar gelukkig heb ik mijzelf en deze wereld weer herverden. Ik loop nog steeds heen en weer, nu in een distributiecentrum op zoek naar dozen met levensmiddelen om te verzamelen voor de winkels die ze nodig hebben. Het werk is ruim onder mijn niveau en zwaar, maar ik heb onlangs een nieuwe vriendin ontdekt in Emma at Work, die zich inzet voor jongeren met een chronische ziekte. Wellicht dat zij mij het zetje kunnen geven die ik nodig heb op de arbeidsmarkt en ik mij kan richten op een nieuwe droom, het inrichten van een eigen huisje.
Psychosocial well-being in young adults with chronic illness since childhood: the role of illness cognitions

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ABSTRACT

BACKGROUND: More and more pediatric patients reach adulthood. Some of them are successfully integrating in adult life, but many others are not. Possibly Illness cognitions (IC) - the way people give meaning to their illness/disability - may play a role in individual differences on long-term adjustment. This study explored the association of IC with disease-characteristics and Health Related Quality of Life (HRQoL), anxiety and depression in young adults with a disability benefit due to childhood-onset chronic condition.

METHODS: In a cross-sectional study, young adults (22-31 years, N=377) who claimed a disability benefit because of a somatic condition since childhood, completed the Illness Cognition Questionnaire (acceptance-helplessness-benefits), RAND-36 (HRQoL) and HADS (anxiety and depression) online. Besides descriptive statistics, linear regression analyses were conducted to predict (1) illness cognitions by age, gender and disease-characteristics, and (2) HRQoL (Mental and Physical Component Scale), Anxiety and Depression by illness cognitions, controlling for disease-characteristics, age and gender.

RESULTS: Respectively 90.2%, 83.8% and 53.3% of the young adults with a disability benefit experienced feelings of acceptance, benefits and helplessness. Several disease-characteristics were associated with IC. More acceptance and less helplessness were associated with better mental ($\beta=0.31; \beta=-0.32$) and physical ($\beta=0.16; \beta=-0.15$) HRQoL and with less anxiety ($\beta=-0.27; \beta=0.28$) and depression ($\beta=-0.29; \beta=0.31$).

CONCLUSIONS: IC of young adult beneficiaries were associated with their HRQoL and feelings of anxiety and depression. Early recognition of psychological distress and negative IC might be a key to the identification of pediatric patients at risk for long-term dysfunction. Identification of maladaptive illness cognitions enables the development of psychosocial interventions to optimise their well-being and adaptation to society.

BACKGROUND

Due to improved treatment possibilities and the positive consequences for life expectancy, the number of chronically ill children who live for longer is increasing, and more pediatric patients with somatic conditions are living into adulthood 1, 3. For these children, transition into adulthood is a critical phase. Children and adolescents with chronic illnesses are expected to go through similar developmental stages as their healthy peers; they will leave home, develop psychosocially, and define their role in the community through employment or other activities 3. For patients with impairments, reaching these developmental stages can be challenging. Research findings indicate that school-aged children with chronic conditions, regardless of their diagnosis, are more limited in their participation in everyday life than their peers 4-5. Also, research has showed that adolescents and young adults with disabilities often follow atypical developmental patterns when compared to their peers without a disability 6-8 and that they are at risk of poor educational, vocational and social outcomes in adulthood 4, 9-11.

In the Netherlands, some 500,000 children (14%) are growing up with a chronic condition and 90% of them will reach adulthood 1. As a result, many patients with a childhood-onset chronic condition will reach the age at which they enter the labour market. In the Netherlands, young people who are partially or fully incapable of working, due to a childhood-onset chronic condition, may be eligible for a benefit under the scheme for young disabled persons: Wajong (the Invalidity Insurance Act for Young Disabled Persons). This Act provides income support as well as support to find employment and if necessary support at the work place. A Wajong benefit is payable no earlier than the 18th birthday, for as long as the inability to work lasts and ends when the recipient reaches the age of 65. The level of benefit received under the terms of the Act depends on age and the amount someone can earn from a job; Wajong income support is a supplementary payment on top of what a young person with a chronic disease or handicap is able to earn from work.

Although some of the young adults growing up with a childhood-onset chronic condition make a good adjustment to adult life, many others struggle with the impact of their condition on overall well-being and adaptation to social life 9, 12, 15. The nature and magnitude of their problems in adult life can vary greatly from patient to patient, even in those with the same diagnosis. Symptom severity is often insufficient to fully explain their adverse effects upon functioning. The discrepancy between the level of illness-related dysfunction in the physical, mental and social domain and the underlying pathology of the disease has given rise to hypotheses about the contribution of psychosocial factors to health out-
comes in patients with chronic illnesses. When patients are diagnosed with an illness they generally develop an organised pattern of beliefs about their condition. These illness perceptions or cognitive representations directly influence the individual’s emotional response to the inherently aversive character of a chronic condition, to maintain a sense of balance and to achieve a satisfying quality of life. This in turn determines how patients respond to the chronic condition in their coping behaviour such as adherence to treatment. It has been commonly assumed that the way adult patients perceive and think about their illness accounts for much of the individual differences in their physical and psychological health status. Specifically, patients who report high levels of helplessness and low levels of acceptance with regard to their illness, emphasize the negative aspects of their condition. They generalize their illness cognitions, defined as cognitive reactions to an uncontrollable, long-term stressor of coping with and adjusting to a chronic condition, to all facets of daily life and consequently experience worse physical and psychological functioning. In this view, illness cognitions (IC) can be considered as prognostic factors predicting physical functioning, psychological distress and therefore possibly adaptation to society.

Many instruments that are used to assess illness cognitions measure them as disease-specific cognitions or as trait-like constructs unrelated to chronic illness. Instruments that generalize across chronic diseases would offer an opportunity to study the common mechanisms that contribute to individual differences in health outcomes. Furthermore, most instruments focus on maladaptive cognitions that predict unfavourable long-term outcomes in chronic diseases. However, knowledge on both maladaptive and adaptive cognitions can contribute to fully understanding individual differences in adjusting to chronic illness. It also can yield new opportunities for psychosocial support. Therefore, Evers et al. developed an instrument, the Illness Cognitions Questionnaire (ICQ), that assesses a basic set of three generic illness cognitions applicable across a range of chronic diseases and that focus on both unfavourable and favourable ways of adjusting to chronic diseases by emphasizing the negative meaning through helplessness cognitions, decreasing the negative meaning by acceptance cognitions or adding a positive meaning by cognitions of perceived benefits.

Most of the research on IC has focused on adults while much less attention has been paid to younger people who grew up with a chronic condition. Also, the IC of young adult beneficiaries as a group has never been studied. Since they can be considered as the most vulnerable young adults with chronic conditions—those who have to apply for disability benefits as a result of their conditions—it is important to know how and to what extent the IC affect their well-being. Given the increase in the number of children and adolescents with a childhood-onset chronic condition and the growing number of them applying for disability benefits, it is essential to gain insight into their IC in order to be able to develop strategies to support this vulnerable population towards adulthood independence. The present study focussed on generic IC in young adult beneficiaries (Wajong benefits as a result of a chronic somatic illness or disability since childhood) in order to be able to develop strategies for psychosocial support that might optimise well-being and adaptation in society. Specifically, this study examines (1) illness cognitions in young adults with Wajong benefits in relation to disease-characteristics, and (2), associations of illness cognitions with health related quality of life (HRQoL), anxiety and depression, independent of the contribution of disease-characteristics, age and gender. It was hypothesized that the illness cognitions acceptance and benefits are associated with a higher HRQoL and lower feelings of anxiety and depression and vice versa for helplessness.

METHODS

PROCEDURES

This study was conducted within the framework of a large cross-sectional study EMWAjong (a contraction of ‘EMMA’ from Emma Children’s Academic Medical Centre) and ‘Wajong’ (the name of the disability benefit), a study directed at investigating psychosocial functioning in young adults with a Wajong benefit for a childhood-onset chronic somatic condition and the factors affecting their vocational success. There could be complex interactions between problems which are a direct result of the chronic condition and its treatment, and possible psychosocial problems, which are an underlying reflection of growing up with a chronic condition and effect on life and social/economic status of these young adults. This manuscript focuses on the type and magnitude of generic illness cognitions affecting the lives of young adults who have grown up with a somatic condition. In this article we will refer to this group as ‘young adults claiming disability benefits’. All young adults between 22 and 31 years of age who claimed a Wajong benefit in the year 2003 or 2004 for a chronic somatic condition were invited in 2009 to participate in EMWAjong via a letter. The invitation letter was printed on Emma Children’s Hospital paper and in the letter was clearly stated that the benefits agency wasn’t involved in this study. Participation meant completing an online questionnaire. Those with no sustainable work opportunities (classified as fully incapable for work) were excluded because the EMWAjong study aimed to identify factors that could help to improve vocational success.
The role of illness cognitions

Chapter 5

MEASURES

Illness cognitions were assessed with the ICQ *16 that measures generic illness beliefs across chronic conditions. The ICQ is a 18-item questionnaire that contains three six-item scales related to cognitive ways patients ascribe meaning to chronic illness: helplessness (focusing on the negative consequences of the disease and generalizing them to functioning in daily life; e.g.: “My illness limits me in everything that is important to me”), acceptance (acknowledging being chronically ill and perceiving the ability to manage the negative consequences of the disease; e.g.: “I have learned to live with my illness”) and perceived benefits (also perceiving positive, long-term consequences of the disease, e.g.: “Dealing with my illness has made me a stronger person”). Items are scored on a four-point Likert scale (1 = not at all, 2 = somewhat, 3 = to a large extent, 4 = completely). Scale scores for the three illness cognitions are calculated by summing up the item scores. For each scale the mean item score was calculated by dividing the scale score by the number of the items, resulting in a mean item scale score from 1 to 4. Higher scores indicate that the illness cognition is stronger pres-

Those with serious cognitive impairment or psychiatric conditions were also excluded because the EMWAjong study was directed at young adults with childhood-onset somatic conditions. Besides, it may be assumed that other mechanisms play a role in growing up with psychiatric conditions than growing up with somatic conditions.

In total, 2,046 persons were invited to take part in the study. To maintain the privacy of the beneficiaries, the invitation letter was sent by UWV, the Employee Insurance Agency. The letter contained a personal log in code, a password and a link to the online questionnaire. After two weeks, participants received a reminder letter. Participants who completed the entire questionnaire received a gift voucher. The study was performed according to the regulations of the medical ethical committee. Due to the once-only internet-based nature of the survey, no formal approval by the medical ethics committee was required.

PARTICIPANTS

A total of 415 young adults with a chronic somatic condition participated in the study (response rate 20.1%). A total of 38 respondents were removed because of an incomplete ICQ; data from 377 participants could be used for the analyses: 243 women (64.5 %) and 134 men (35.5 %), mean age 25.0 years (SD = 2.1; range 22.5-30.9). Non-responders differed from responders with respect to gender: 51.4% vs. 64.5 % women (p < 0.05). The study group consists of young adults with a variety of consequences of chronic conditions, e.g. childhood cancer, asthma, muscular diseases, blindness, trauma. The demographic and disease-characteristics of the EMWAjong group are listed in Table 1.

TABLE 1: Characteristics of young adults with disability benefits

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>N</th>
<th>%</th>
</tr>
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<tr>
<td>Female gender</td>
<td>243</td>
<td>64.5</td>
</tr>
<tr>
<td>M</td>
<td>SD</td>
<td>Range</td>
</tr>
<tr>
<td>Age at study (years)</td>
<td>25.0</td>
<td>2.1</td>
</tr>
<tr>
<td>Disease characteristics</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Congenital disorder</td>
<td>200</td>
<td>53.1</td>
</tr>
<tr>
<td>Perceptible disability</td>
<td>159</td>
<td>42.2</td>
</tr>
<tr>
<td>Course of illness</td>
<td>148</td>
<td>39.3</td>
</tr>
<tr>
<td>Worse/variable</td>
<td>156</td>
<td>41.4</td>
</tr>
<tr>
<td>Stable/positive</td>
<td>221</td>
<td>58.6</td>
</tr>
<tr>
<td>Chronic conditions</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Visually impaired/blind</td>
<td>51</td>
<td></td>
</tr>
</tbody>
</table>

MEASURES

Illness Cognitions

Ilness cognitions were assessed with the ICQ *16 that measures generic illness beliefs across chronic conditions. The ICQ is a 18-item questionnaire that contains three six-item scales related to cognitive ways patients ascribe meaning to chronic illness: helplessness (focusing on the negative consequences of the disease and generalizing them to functioning in daily life; e.g.: “My illness limits me in everything that is important to me”), acceptance (acknowledging being chronically ill and perceiving the ability to manage the negative consequences of the disease; e.g.: “I have learned to live with my illness”) and perceived benefits (also perceiving positive, long-term consequences of the disease, e.g.: “Dealing with my illness has made me a stronger person”). Items are scored on a four-point Likert scale (1 = not at all, 2 = somewhat, 3 = to a large extent, 4 = completely). Scale scores for the three illness cognitions are calculated by summing up the item scores. For each scale the mean item score was calculated by dividing the scale score by the number of the items, resulting in a mean item scale score from 1 to 4. Higher scores indicate that the illness cognition is stronger pres-
ent in the respondent. The ICQ has strong internal consistency and reliability, and good construct and predictive validity across chronic conditions. Cronbach’s alpha in the present study was 0.84 for helplessness, 0.88 for acceptance, and 0.84 for perceived benefits.

Health Related Quality of Life

HRQoL was assessed using the RAND-36. The RAND-36 is a Dutch version of the MOS-SF-36 Health Survey and is almost identical to the Dutch SF-36. The RAND-36 is a multidimensional questionnaire consisting of 36 items with standardized response choices, clustered in 8 multi-item scales: Physical Functioning (10 items), Social Functioning (2 items), Role limitations owing to Physical health problems (4 items), Role limitations owing to Emotional problems (3 items), general Mental Health (5 items), Vitality (4 items), Bodily Pain (2 items), and General Health perceptions (5 items). All raw scale scores were converted to a 0-100 scale, with higher scores indicating higher levels of functioning or well-being. The validity and reliability of the RAND scales were satisfactory. Among the EMWAjong group we found Cronbach’s alphas of 0.75 to 0.95.

Overall physical and mental health was assessed by aggregating all scale scores according to the algorithm described by Ware and Kosinski, yielding to the so-called Physical Component Scale (PCS) and to the Mental Component Scale (MCS). The scale weights were derived from Principal Components Analysis (PCA) with the RAND-36 data of a Dutch reference group, using a non-orthogonal rotation (Oblimin), on the basis of the assumption that physical health and mental health are interdependent. According to the weights derived from the PCA, the eight scales of the RAND-36 are represented in the PCS and MCS. The PCS reflects the physical aspects of HRQoL; Physical Functioning, Role limitations owing to Physical health problems and Bodily Pain are most strongly represented. MCS reflects the mental aspects of HRQoL; general Mental Health, Role limitations owing to Emotional problems and Social Functioning are most strongly represented.

Anxiety and Depression

Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS). The 14 items are scored on a four-point scale (0–3), producing a total score ranging from 0 to 21, for depression (7 items) – and anxiety (7 items). Higher scale scores indicate more anxiety or depression symptoms in the past week. The Dutch version of the HADS showed satisfactory validity and reliability. In this study, the internal consistency (Cronbach’s alpha) of the anxiety scale was 0.83 and of the depression scale 0.75.

Disease characteristics

Due to privacy reasons, no information about the chronic conditions of the participants was provided by the benefits agency. This information was therefore derived through beneficiaries’ self reports. The questions concerning disease-characteristics were based on existing questionnaires and recommendations of experts in the field. The following dichotomous disease-related variables were used: congenital disorder (yes/no), the nature of the disease process over time (“course of disease”: stable or positive vs negative or variable), daily use of medication (yes/no), need for medical devices in daily life, e.g. hearing aid and wheelchair (yes/no), tiredness (yes/no), limitations in use of fingers/hands, sight, hearing, and not being able to sit/stand for half an hour (yes/no), perceptible disability (yes/no).

STATISTICAL ANALYSIS

The Statistical Package for Social Sciences (SPSS) Windows version 16.0 was used for all the analyses. First, illness cognitions were analysed with descriptive statistics. Second, linear regression analyses were performed to predict the illness cognitions Acceptance, Helplessness and perceived Benefits by disease-characteristics while controlling for age and gender. Finally, linear regression analysis was performed to predict HRQoL, as expressed by the Mental and Physical Component Scale (RAND-36), Anxiety and Depression (HADS) by the illness cognitions, while controlling for disease-characteristics, age and gender. In line with Cohen, binary-coded variables of 0.3 were considered small, 0.5 medium and 0.8 large. For continuous variables, regression coefficients of 0.1 were considered small, 0.3 medium and 0.5 large. A significance level of 0.05 was used for all analyses.

RESULTS

ILLNESS COGNITIONS

The young adult beneficiaries reported the following mean item scores on the four-point ICQ subscales: Acceptance 2.95; Helplessness 2.10; perceived Benefits 2.86. In addition, to indicate the proportion of young adult beneficiaries who experienced at least some feelings of Acceptance, Helplessness and Benefits, the proportions of respondents with mean item scores ≥ 2 (indicating that the presence of the illness cognitions was “somewhat” to “completely”) were studied. It was found that 90.2% of the respondents experienced feelings of Acceptance, which was 83.8% in the case of perceived Benefits. 53.3% of the respondents had feelings of Helplessness to a greater or lesser degree.
The role of illness cognitions

**TABLE 2: Standardized Regression Coefficients $\beta$ for the relation of disease characteristics with illness cognitions (ICQ)**

<table>
<thead>
<tr>
<th></th>
<th>Acceptance $(\beta)$</th>
<th>Helplessness $(\beta)$</th>
<th>Benefits $(\beta)$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DEMOGRAPHIC CHARACTERISTICS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.01</td>
<td>0.02</td>
<td>0.05</td>
</tr>
<tr>
<td>Female gender $^a$</td>
<td>0.07</td>
<td>-0.16 $^{**}$</td>
<td>0.14 $^*$</td>
</tr>
<tr>
<td><strong>DISEASE CHARACTERISTICS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital disorder $^a$</td>
<td>0.08</td>
<td>-0.07</td>
<td>-0.05</td>
</tr>
<tr>
<td>Stable or positive course of illness $^a$</td>
<td>0.20 $^{***}$</td>
<td>-0.23 $^{***}$</td>
<td>0.05</td>
</tr>
<tr>
<td>Medication $^b$</td>
<td>-0.15 $^{**}$</td>
<td>0.11 $^*$</td>
<td>-0.01</td>
</tr>
<tr>
<td>Medical devices $^b$</td>
<td>0.11</td>
<td>-0.11 $^*$</td>
<td>0.00</td>
</tr>
<tr>
<td>Tiredness $^b$</td>
<td>-0.12 $^*$</td>
<td>0.13 $^*$</td>
<td>0.13 $^*$</td>
</tr>
<tr>
<td>Hands and/or fingers $^b$</td>
<td>0.03</td>
<td>-0.04</td>
<td>-0.04</td>
</tr>
<tr>
<td>Vision $^b$</td>
<td>0.03</td>
<td>0.02</td>
<td>0.00</td>
</tr>
<tr>
<td>Audition $^b$</td>
<td>-0.03</td>
<td>0.06</td>
<td>-0.03</td>
</tr>
<tr>
<td>Sitting $^b$</td>
<td>-0.12 $^*$</td>
<td>0.17 $^{**}$</td>
<td>0.00</td>
</tr>
<tr>
<td>Standing $^b$</td>
<td>0.07</td>
<td>0.06</td>
<td>0.08</td>
</tr>
<tr>
<td>Disability is perceptible $^a$</td>
<td>0.03</td>
<td>0.15 $^{**}$</td>
<td>0.02</td>
</tr>
<tr>
<td>$F$</td>
<td>4.95</td>
<td>6.92</td>
<td>1.77</td>
</tr>
<tr>
<td>$df$</td>
<td>15,36</td>
<td>15,36</td>
<td>15,36</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.15 $^{**}$</td>
<td>0.17 $^{**}$</td>
<td>0.06 $^*$</td>
</tr>
</tbody>
</table>

1. Regression coefficients were based on linear regression analyses corrected for age and gender
   a coding: yes=1, no=0
   b coding: ‘problems with (the use of) …’ yes=1, no=0
   * $p < 0.05$
   ** $p < 0.01$
   *** $p < 0.001$

Table 2 shows the standardized regression coefficients for the relation of disease characteristics with Acceptance, Helplessness and Benefits (ICQ), corrected for age and gender. Those with a stable or positive course of illness reported more Acceptance ($\beta = 0.20$) and less Helplessness ($\beta = -0.23$) than those with a variable or negative course of disease. In addition, those who use medication reported less Acceptance ($\beta = -0.15$) and more Helplessness ($\beta = 0.11$), while using medical devices is associated with less Helplessness. Furthermore, tiredness was associated with less Acceptance ($\beta = -0.12$) and more Helplessness ($\beta = 0.13$) and Benefits ($\beta = 0.13$); having problems with sitting was also associated with less Acceptance ($\beta = -0.12$) and more Helplessness ($\beta = 0.17$). Finally, respondents with a perceptible disability reported more Helplessness ($\beta = 0.15$). All significant regression coefficients are considered of small size.

**ILLNESS COGNITION IN RELATION TO HEALTH RELATED QUALITY OF LIFE, ANXIETY AND DEPRESSION**

The contribution of illness cognition to Health Related Quality of Life, Anxiety and Depression, independent of the contributions of disease-characteristics, age and gender, are presented in table 3.

**TABLE 3: Standardized Regression Coefficients $\beta$ for the relation of illness cognitions (ICQ) with HRQoL (RANDS-36) $^1$, Anxiety and Depression (HADS)**

<table>
<thead>
<tr>
<th></th>
<th>MCS $(\beta)$</th>
<th>PCS $(\beta)$</th>
<th>Anxiety $(\beta)$</th>
<th>Depression $(\beta)$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DEMOGRAPHIC CHARACTERISTICS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.02</td>
<td>-0.03</td>
<td>0.01</td>
<td>-0.04</td>
</tr>
<tr>
<td>Female gender $^a$</td>
<td>-0.05</td>
<td>-0.07</td>
<td>0.08</td>
<td>-0.05</td>
</tr>
<tr>
<td><strong>DISEASE CHARACTERISTICS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital disorder $^a$</td>
<td>-0.06</td>
<td>0.07</td>
<td>0.03</td>
<td>0.05</td>
</tr>
<tr>
<td>Stable or positive course of disease $^a$</td>
<td>0.14 $^*$</td>
<td>0.21 $^{**}$</td>
<td>-0.02</td>
<td>-0.04</td>
</tr>
<tr>
<td>Medication $^b$</td>
<td>0.03</td>
<td>-0.12 $^{**}$</td>
<td>-0.03</td>
<td>-0.01</td>
</tr>
<tr>
<td>Medical devices $^b$</td>
<td>0.10</td>
<td>-0.13 $^{**}$</td>
<td>-0.06</td>
<td>-0.15 $^*$</td>
</tr>
<tr>
<td><strong>DEMOGRAPHIC CHARACTERISTICS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tiredness $^b$</td>
<td>-0.17 $^{**}$</td>
<td>-0.14 $^{**}$</td>
<td>0.12</td>
<td>0.00</td>
</tr>
<tr>
<td>Hands and/or fingers $^b$</td>
<td>0.13 $^{**}$</td>
<td>-0.10 $^*$</td>
<td>-0.10</td>
<td>-0.07</td>
</tr>
<tr>
<td>Vision $^b$</td>
<td>-0.03</td>
<td>0.09 $^*$</td>
<td>0.01</td>
<td>-0.01</td>
</tr>
<tr>
<td>Audition $^b$</td>
<td>0.01</td>
<td>0.00</td>
<td>-0.01</td>
<td>0.00</td>
</tr>
<tr>
<td>Sitting $^b$</td>
<td>-0.01</td>
<td>-0.06</td>
<td>0.01</td>
<td>-0.02</td>
</tr>
<tr>
<td>Standing $^b$</td>
<td>0.04</td>
<td>-0.36 $^{**}$</td>
<td>0.05</td>
<td>0.08</td>
</tr>
<tr>
<td>Disability is perceptible $^a$</td>
<td>0.01</td>
<td>-0.06</td>
<td>-0.05</td>
<td>0.04</td>
</tr>
</tbody>
</table>

1. Regression coefficients were based on linear regression analyses corrected for disease characteristics, age and gender
   a coding: yes=1, no=0
   b coding: ‘problems with (the use of) …’ yes=1, no=0
   * $p < 0.05$
   ** $p < 0.01$
   *** $p < 0.001$

Feelings of Acceptance of the disease or disability were associated with better mental and physical HRQoL ($\beta = 0.31$, $\beta = 0.16$), less anxiety ($\beta = -0.27$) and less depression ($\beta = -0.29$), while having feelings of helplessness were associated...
with worse mental and physical HRQoL ($\beta = -0.32$, $\beta = -0.15$) and higher levels of anxiety ($\beta = 0.28$) and depression ($\beta = 0.31$). In addition, perceiving benefits of the disease or disability was associated with less depression ($\beta = -0.14$). The regression coefficients were small to medium.

DISCUSSION

The present study focussed on generic illness cognitions of young adults with a disability benefit because of a somatic condition and on the relation of illness cognitions with emotional well-being in order to get insight in possible determinants of long-term adjustment in society. As far as we know, this is the first study on generic illness cognitions of young adults with a childhood-onset somatic condition. The results show that illness cognitions of these young adults are associated with emotional well-being.

A rather high level of acceptance and perceived benefits was found, indicating that the majority of the young adults with Wajong benefits in this study have learned to live with their illness or disability and even perceives some long-term beneficially consequences of their long term conditions. As they have been limited since childhood this may have influenced their acceptance and perception of possible benefits in a positive way. However, one should realize that the high levels of acceptance and perceived benefits we found in our study could be a result of selection bias. It is conceivable that young adults who have not accepted their disease yet, were less declined to participate in studies on psychosocial functioning, such as the present study. Helplessness in contrast, a cognition with a substantial negative impact, was present in a considerable part (53.3%) of the respondents. This indicates that the young adult beneficiaries in this study feel an inability to control a particular situation and emphasizes the negative aspects of their condition in daily functioning, which can lead to deterioration of their physical and psychological functioning. Several disease-characteristics were associated with the illness cognitions, particularly those with a positive/stable course of illness scored higher on acceptance and lower on helplessness. However, those associations were not strong.

The illness cognitions acceptance and helplessness seemed to be associated with HRQoL, expressed by overall physical and mental quality of life, as well as with feelings of anxiety and depression in young adults with a disability benefit because of a chronic somatic condition. Though the direction of the correlation could not be established, it is plausible to assume that acceptance of the illness or disability, learning to live with it, influences HRQoL positively and reduces feelings of anxiety and depression. However, depression and anxiety can affect cognitions as well. Stronger feelings of helplessness appeared to be associated with worse HRQoL and higher levels of anxiety and depression. Young adult beneficaries experiencing a great deal of helplessness are more likely to see their futures in adulthood as uncertain which could be a risk factor for the development of psychological distress over time. In addition, acceptance and helplessness were twice as strongly associated with mental quality of life than with physical quality of life, indicating that these illness cognitions are more important predictors of mental aspects of quality of life than of physical aspects.

Levels of perceived benefits were not associated with levels of HRQoL and to a low degree to anxiety and depression. Our results suggest that acceptance and helplessness are possibly better predictors of distress than the perceived benefits of the chronic illness or disability. This is in line with research concerning the Benefit and Burden Scale for Children, a questionnaire that intends to measure potential benefit and burden of illness in children. It was found that disease-related burden was strongly associated with almost all psychological outcomes, while benefit finding was not.

The correlation between the illness cognitions and emotional well-being indicates that HRQoL, anxiety and depression hold disease-related elements. In other words, the illness cognitions of young adult beneficiaries are relevant for their psychological functioning. These findings are in line with studies in adult populations with chronic illness. The modest contribution of disease-characteristics on HRQoL, anxiety and depression, supports the notion that there is only a weak relationship between biomedical parameters and psychosocial well-being. Illness cognitions on the other hand seem to contribute to individual differences in young adult beneficiaries regarding their psychosocial well-being and possibly long-term adjustment.

There are a number of shortcomings of this study that need to be addressed. First, the representativeness of the sample should be taken into account. The act Wajong is a Dutch benefit. Most countries have no specific benefit for young disabled people. Furthermore, it is unknown which part of all young adults with a chronic illness or disability in the Netherlands apply for Wajong benefits. Therefore, it is advisable to be cautious and conservative while interpreting results of this study and extrapolating the findings to a larger population or to other countries. Another limitation is the response rate of 20%, though it is important to notice that this is a very average response rate among young adults with Wajong benefits. Due to the growing interest in the labour market position of young adults claiming disability benefits, they receive too many invitations to participate in all the different studies. Moreover, it is likely that respondents did not fill in the questionnaire because the invitation letter was sent by the benefits agency. Although the questionnaire was anonymous, beneficiaries...
might be afraid of losing their benefit. Alternatively, those with better HRQoL were less eager to participate because of reluctance to feel stigmatized. On the contrary, among those who did participate social desirability could be a threat to the validity of the results in this study. Unfortunately, as a result of the need to respect the privacy of the beneficiaries, there is too little information regarding the non-responders to be able to pronounce upon selection bias. Anyway, it is hard to derive conclusions that are generally applicable to young adults with disability benefits because of the heterogeneity of both the illness diagnoses and illness severity in the Wajong population.

Another limitation concerns the assessment of illness cognitions. Though the ICQ was originally developed for people with a chronic illness, we used the ICQ also for young adults with a physical disability not caused by an illness. It is not known whether the ICQ is suitable for the assessment of illness cognitions in those with a pure physical disability but it can be assumed to be so. Furthermore, we did not study psychosocial factors that may predispose to individual difficulties in illness cognitions, for example personality. In future research this should be addressed.

Caution is called for interpreting the results of our study because the regression coefficients reflect that rather small portions of emotional well-being are explained by illness cognitions. In addition, causality could not be proven because of the cross-sectional nature of the study. Prospective, longitudinal research should confirm the direction of the present findings in order to be able to develop cognitive behavioural programs directed at the limitation of unhelpful cognitions and the development of personal skills needed to cope with the extra challenge of growing up with a chronic illness or disability. From a theoretical point of view, in depth exploration of IC including possible moderating effects of age and gender, could be interesting and add to the understanding of adjustment of young adults grown up with chronic disease.

Notwithstanding the limitations of the study, the results add to the understanding of adjustment of young adults with a childhood-onset chronic illness or disability. It is of importance that paediatric as well as adult healthcare providers and other professionals are aware of those psychosocial factors such as illness cognitions that contribute to emotional well-being of children, adolescents and young adults with somatic conditions. Special attention should be paid to coping with illness or disability during developmental transitions. For adolescents, transition into adulthood is a critical phase, characterised by multiple transitions including transition from family life to independent living and from education to employment. Because success in adulthood is closely related to positive social and emotional development earlier 34, it is recommended to monitor and support children and adolescents in an early stage. Early support and attention to social determinants of health would provide a chance to recruit patients with significant risks for unfavourable outcomes in later life and could stimulate patients in taking an active stance towards their medical condition. But also in adult healthcare, attention to possible consequences of illness cognitions and its relation to well-being seems sensible from a comprehensive, lifespan perspective on health care for young people with chronic conditions 35. Special attention should be paid to the transfer from school to workforce participation. After transitioning from a school setting, an important metric for social success in adult life is employment 36. There is increasing evidence that illness cognitions could play a role in work participation. Negative illness cognitions may lead to a feeling of being unwell that is not consistent with the diagnosed health condition, but equally may lead to incapacity to work. A review study of Hoving et al 37 exploring the relationship between illness perceptions and work participation in patients with somatic diseases and complaints found promising evidence. The number of studies in the review was limited, but all included studies found significant associations between one or more illness perception dimensions and measures of work participation. In particular, all studies found that non-working people perceive more negative consequences of their illness. Although cause and consequence cannot be distinguished, these studies provided valuable information about illness perceptions in relation to employment.

CONCLUSIONS

Although the study design does not justify conclusions with regard to causality, the results contribute to our understanding of the influence of young adult’s IC on their emotional well-being. Health care workers should pay systematic attention to the emotional well-being of patients growing up with a somatic condition and its relation with IC. Attention in an early stage of treatment yield opportunities for optimising the patient’s well-being and, because of this, maybe also their adaptation to society and a more fulfilling life. This support must be incorporated in a lifespan perspective in paediatric, transitional, and adult health care services for persons with a childhood-onset condition. A next step in research should be longitudinal studies focused on identifying individuals most likely to develop difficulties as a result of their IC, in order to be able to develop strategies for psychosocial support. Moreover, longitudinal research is needed on the relation between IC and successful labour participation in young adults who have grown up with a chronic somatic condition. It is also highly relevant to compare in future research different conceptualizations of illness cognitions, in addition to factors, such as coping strategies and social support, for the predic-
tion of the health status in this specific patient group.

With the recognition of the psychosocial impact of a somatic condition in childhood on psychological well-being in later life comes the growing awareness of the need to develop psychosocial supportive programs. Systematic assessment of emotional functioning is not yet part of standard practice but effective routine assessment of emotional well-being could easily be implemented in daily clinical practice for children and adolescents through computerized and web-based patient reported outcomes. The assessment of generic IC might be a valuable complementary tool for screening of psychological risk factors and tracing patients who may benefit from psychological interventions.

**REFERENCE LIST**


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In maart 2010 kreeg ik de diagnose te horen. Pulmonale Hypertensie (PH). Wat is het? Een zeldzame ongeneeslijke longaandoening. Vanaf die dag ben ik aan de medicijnen gegaan en sindsdien is mijn leven veranderd. Een uitkering aanvragen. Maar, ik ben nog zo jong dacht ik. Ik moet nog 22 worden! Met veel moeite heb ik een Wajong aanvraagformulier ingevuld en opgestuurd. Kort erna ben ik uitgenodigd voor een gesprekje bij de arts. Ik heb alles meegegeven naar die afspraak wat er in de brief stond. En, omdat PH een zeldzame ziekte is, dacht ik, dat het wel fijn zou zijn om een informatiefolder mee te nemen voor de arts. Aangekomen bij de arts heb ik alles (medicijnen, folders, kopie paspoort etc.) uitgestald op tafel. Ze keek me aan en ze wuifde met minachting haar hand en zei: “stop dat maar weer terug, dat heb ik niet nodig!” Ik gaf haar het foldertje over PH en weer kreeg ik een snauw van haar terug en binnen 15 min. stond ik weer buiten. Geen medische keuring, maar gewoon een klein gesprekje. En toch, ook al was ik opgelucht dat dit voorbij was, voelde ik me ontzettend rot. Hoe kan een vrouw die arts is voor het UWV zo ongeïnteresseerd in verschillende ziektebeelden? Tuurlijk, ik snap wel dat zij heel veel aanvragen krijgen en dus veel mensen moeten keuren. Maar op deze manier vond ik dit gesprek, of wat eigenlijk een medische keuring had moeten zijn, niet fijn. Ik dacht ook echt dat ik zou worden afgewijzen, omdat het overkwam dat zij mij totaal niet geloofde. Tsja, wat wil je, ik ben onzichtbaar ziek. Eenmaal toch te horen gekregen dat ik in aanmerking kom voor een Wajong uitkering. Blij, opgelucht en toch heel erg raar! Ik ben een student en ik krijg geld van UWV, omdat ik eigenlijk gewoon nooit meer fulltime kan gaan werken. Uiteindelijk heb ik ook mijn studie moeten laten gaan. Ik kon het niet meer aan. En nu? Op zoek naar werk, want ook al ben ik ziek, thuis zitten is helemaal niet voor mij weggelegd! Op gesprek bij mijn arbeidstdeskundige voor een kennismakingsgesprek en ook eventueel kijken voor opties naar werk. Leuk, dacht ik. Vol goede moed en aangepast CV ben ik naar het werkbedrijf geweest. Samen met mijn arbeidstdeskundige liep ik naar haar kantoor en er zat toen een vrouw bij die alleen ging observeren. Ik had mijn CV al op tafel gelegd. Ze begon het gesprek en vroeg waarom ik gestopt was met mijn studie. Na dat uitgelegd te hebben, legde ze een stapel papieren voor mijn neus neer. Allemaal vacatures, en eigenlijk allemaal callcenter werk. Ik legde haar uit dat ik niet op zoek was naar zo’n baan, want zo’n baan is niet van mijn niveau en ik kom dan nooit meer uit dat werk vandaan. Ik zou graag wat anders willen en had het op prijs gesteld als zij eerst mijn CV zou bekijken, voordat zij met allerlei vacatures aan kwam zetten. Ook dit gesprek was snel klaar en we hadden afgesproken dat zij voor mij op zoek ging naar iets passends. Uiteindelijk dus helemaal niks meer van haar gehoord.

Toen ben ik bij Emma at Work terecht gekomen en snel gekoppeld naar mijn allereerste baantje bij een sieraden/kra lenwinkel. Leuk om te doen, maar ik wilde meer. Want het was maar 1 dag in de week
en voor maar 2 uurtjes. Uiteindelijk kwam er een vacature vrij voor gastvrouw bij de een tuinbouw expo. Dit heb ik gedaan van april 2012 t/m oktober 2012. Met plezier gewerkt en ben daarna snel doorgestroomd naar mijn volgende baan bij een grote bank, waar ik nu nog steeds werkzaam ben. Snel in de eerste paar maanden dat ik werkzaam was bij de bank, kreeg ik een brief van UWV. Ik moest geld terugbetalen. En het ging niet om een tientje, maar om honderden euro’s. Ik heb blijkbaar teveel uitgekeerd gekregen al die tijd dat ik bij de tuinbouw expo werkte, en dat geld wilde UWV terug. Sindsdien (ongeveer dec. 2012) ben ik constant bezig om geld terug te betalen. Mijn “schuld” van de tuinbouw expo is nog steeds niet afbetaald en nu zijn er weer 2 schulden bijgekomen; van mijn werk bij de bank. Nu ben ik nog steeds bezig om maandelijks een bedrag terug te betalen aan UWV. Het doet me pijn, want de motivatie om minder te werken, of misschien wel helemaal niet meer te werken, wordt steeds groter. Ik word constant tegengewerkt, het is zelfs zoveel geld wat ik moet terugbetalen, dat ik niet eens op mezelf kan wonen. Ik hou gewoon te weinig geld over om een appartementje te huren.

En het enige response wat ik van UWV krijg is, als ik bel, “misschien is het handiger om 1 van de 2 baantjes op te geven. Dat is voor ons makkelijker rekenen.” Maar hoe kan een instantie die eigenlijk zo min mogelijk uitkeringen wilt uitgeven, je zo demotiveren in de dingen die je leuk vindt? Ze zouden ons, de jongeren, moeten aanmoedigen om juist te werken. Al heb je 3 baantjes, maar dat betekent voor het UWV dat zij minder geld hoeven uit te geven aan ons.

Ik ben blij dat ik een uitkering heb, want anders kwam ik helemaal niet rond, maar de manier waarop ik word tegengewerkt om iets goeds te doen is gewoon niet leuk. Voor wat werk ik dan? Ik hoop dat de schuld snel is afbetaald en dat zij niet nog eens een rekenfoutje maken, want mijn frustratie wordt alleen maar groter en mijn motivatie minder, ook al ben ik hier, bij de bank, helemaal op mijn plek. Maar werken om schulden af te betalen is nooit mijn insteek geweest, maar om mijn sociale contacten te behouden, verder te kunnen groeien en genieten van al deze momenten nu ik nog fit en stabiel genoeg ben om te gaan werken. Want er komt een dag, dat ik volledig op de zak van UWV kan en/of moet gaan teren, omdat ik dan niet meer in staat ben om zelf geld te verdienen.
Are survivors of childhood cancer with an unfavourable psychosocial developmental trajectory more likely to apply for disability benefits?

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Chapter 6

Cancer survivors with and without disability benefits

ABSTRACT

OBJECTIVES: The aim of this study is to investigate whether an unfavourable psychosocial developmental trajectory while growing up with childhood cancer is related to a smaller likelihood of labour participation in adult life.

METHODS: A total of 53 childhood cancer survivors (CCS) with and 313 CCS without disability benefits, and 508 peers from the general Dutch population (reference group) completed the Course of Life Questionnaire (CoLQ) about the achievement of psychosocial developmental milestones. Differences between the three groups were tested conducting ANOVA with contrasts (scale scores CoLQ) and logistic regression analysis (individual milestones). Effect sizes and Odds Ratios (OR) were calculated.

RESULTS: Compared to the reference group, both CCS with and CCS without benefits reported lower scale scores with respect to Social and Psychosexual development. CCS with disability benefits had lower Social (d=-0.6; p<0.001) and Psychosexual (d=-0.4; p<0.01) scale scores than the CCS without disability benefits. CCS with disability benefits scored less favourable (p<0.01) than peers from the general population on 14 out of 22 psychosocial milestones while the number was only 6 for those without disability benefits.

CONCLUSIONS: CCS with an unfavourable developmental trajectory while growing up were more likely to apply for disability benefits in adulthood than CCS with a more favourable development. Early recognition and support is warranted. Further research is needed on risk factors of application for disability benefits. In addition, research should show whether stimulating the achievement of developmental milestones while growing up will create conditions for a better labour market position.

INTRODUCTION

The enormous increase in the number of survivors of childhood cancer (CCS) who reach adulthood in recent decades has intensified the need to investigate the consequences of both the disease and its treatment. While growing up with (a history of) cancer, CCS face stressors and challenges they have to negotiate in order to obtain normative development and maintain adaptive functioning. Cancer and its treatment often increase children’s dependence on their parents and decrease the participation in peer-based and school-based activities. Cognitive problems and non-attendance at school as a result of the disease and treatment appeared to result in less educational achievement.

For all adolescents transition into adulthood is a critical phase, characterised by transition from family life to independent living and transition from education to employment. Chronic illness may complicate the transition to adulthood. The labour market position of adults with a chronic disease can be characterized as problematic, with regard to getting a job as well as job continuation. Overall, CCS are nearly twice as likely to be unemployed than healthy controls.

If young adults in the Netherlands are (partially) unable to work because of a chronic disease or disability, they may be eligible for benefit provided by the state social services for young disabled persons: Wajong (act Wajong and Labour support Young Disabled Persons).

So far, little is known about the early determinants of integration of CCS into the workforce. It is generally recognized that the fulfilling of age-specific psychosocial developmental tasks in childhood is of great importance to adjustment in adult life, and the transition to adulthood is closely related to positive social and emotional development earlier on. The burden of cancer, treatment, hospitalization and long term medical sequelae interfere with this process in children with cancer. From previous research it is known that young adult CCS show a less favourable developmental trajectory than peers from the general population, in terms of the achievement of milestones regarding social, psychosexual and autonomy development. A delayed developmental trajectory may affect Quality of life and socio-demographic outcomes in adulthood. For example, CCS were found to live at their parents home longer after reaching adulthood than their peers, and they were less likely to be married or living together.

It is important to study associations between the psychosocial developmental trajectory and labour participation in adulthood. The aim of this study is to investigate whether an unfavourable psychosocial developmental trajectory while growing up is related to a smaller likelihood of labour participation in adult life. We hypothesized that CCS with disability benefits had achieved fewer psychosocial developmental milestones than CCS without disability benefits.
Chapter 6

The psychosocial developmental trajectory was assessed with the Course of life questionnaire (CoLQ) \(^\text{13}\). The CoLQ measures the achievement of psychosocial developmental mile-stones. The items concern behaviour characteristic of certain age-stages, developmental tasks, and the limitations children might face when they grow up with a chronic or life-threatening disease. The items are based on the literature and on clinical experience. Most questions ask retrospectively whether the respondent had achieved certain psychosocial developmental milestones or at what age he/she achieved the milestone. The answers are dichotomized (1= milestone not achieved; 2= milestone achieved), if necessary, before being added up to scale-scores.

The items are divided into five scales: Autonomy development (6 items, autonomy at home and outside the home; range 6-12); Psycho-sexual development (4 items, love and sexual relations; range 4-8); Social development (12 items, contacts with peers; range 12-24); Anti-social behaviour (4 items, misbehaviour at school and outside it; range 4-8); and Substance use and gambling (12 items; range 12-24). A higher score on the scales indicates the accomplishment of more developmental milestones, the displaying of more anti-social behaviour or more substance use and gambling. Apart from the five scales, the questionnaire measures socio-demographic outcomes in young adulthood. Based on Stam et al \(^\text{13}\) we accepted the validity, test-retest reliability and internal consistency of the CoLQ to be sufficient for our study.

Reference data are available from 508 young adults aged 18-30 years (mean age 24.2 (± 3.8), 53% female; response rate 63%) from the general Dutch population, recruited through general practitioners in a former study (GPs) \(^\text{13}\). The GPs were asked to select randomly ten patients from their lists whose surnames started with a given letter of the alphabet, and who were of a given sex and age. The inclusion criteria were: aged 18-30 years and no history of cancer. The GPs sent the anonymous questionnaire to the patients.

In the present study the data from Autonomy, Psychosexual and Social development were used. Item- as well as scale scores were analysed, but the scale score of Autonomy development showed too low internal consistency to be included in the analyses. Furthermore, the following socio-demographic outcomes were analysed: marital status (married/living together versus single) and educational level (highest level completed: low, middle, high).

STATISTICS

The CoL scale-scores of the groups were compared using analysis of variance (ANOVA) by group, age and gender. Pair wise group differences were tested by ANOVA with contrasts: (1) CCS with benefits versus CCS without benefits; (2) CCS with benefits versus reference group; (3) CCS without benefits versus reference group. In addition, the differences between CCS with and CCS without benefits were expressed in effect sizes (d), calculated by dividing the difference in mean score between those with and without disability benefits by the pooled standard deviation. We considered effect sizes of up to 0.2 to be small, effect sizes of about 0.5 to be moderate and effect sizes of about 0.8 to be large \(^\text{20}\).

In order to gain a detailed insight into the psychosocial developmental trajectory, differences between the groups (CCS with benefits – CCS without benefits – reference group) were tested on (dichotomized) item level – indicating the achievement of a milestone – using logistic regression analyses by group, age and gender. In addition, odds ratios (OR) for group (CCS with versus CCS without disability benefits) were assessed.
A significance level of 0.01 was used for all analyses, conducted with the Statistical Package for Social Sciences (SPSS) Windows version 16.0.

RESULTS

PARTICIPANTS

Characteristics of CCS with (N=53; 34 from the VOLG-study and 19 from the EMWAjong-study) and without (N=313 from the VOLG-study) disability benefits were presented in table 1. Most remarkable is that 40.4% of those with disability benefits were CCS of a brain tumour versus 5.4% of those without disability benefits (p<0.001).

TABLE 1: Characteristics: CCS with disability benefits versus CCS without disability benefits

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No Benefits</th>
<th>Sign (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M (SD)</td>
<td>25.1 (3.0)</td>
<td>24.3 (4.0)</td>
</tr>
<tr>
<td>range</td>
<td>18.1 - 31.0</td>
<td>17.7 - 31.1</td>
</tr>
<tr>
<td>N</td>
<td>53</td>
<td>313</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M (SD)</td>
<td>7.3 (4.3)</td>
<td>6.8 (4.8)</td>
</tr>
<tr>
<td>range</td>
<td>0 - 17</td>
<td>0 - 16</td>
</tr>
<tr>
<td>N</td>
<td>52</td>
<td>313</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>male (N)</td>
<td>37.7 (20)</td>
<td>51.4 (26)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>leukaemia/lymphoma</td>
<td>52.7 (7)</td>
<td>50.2 (7)</td>
</tr>
<tr>
<td>solid tumours</td>
<td>26.9 (4)</td>
<td>44.4 (3)</td>
</tr>
<tr>
<td>brain tumours</td>
<td>10.4 (3)</td>
<td>5.4 (1)</td>
</tr>
</tbody>
</table>

1 According to independent samples t-test
2 According to X²-test

PSYCHOSOCIAL DEVELOPMENTAL TRAJECTORY

Psychosocial milestones: scale scores

Compared to the reference group, both CCS with and CCS without benefits reported lower scale scores with respect to Social and Psychosexual development. CCS with disability benefits had lower Social and Psychosexual scale scores than the CCS without disability benefits. Differences were of moderate effect size, -0.6 for Social development and -0.4 for Psychosexual development (table 2).

TABLE 2: Psychosocial developmental trajectory of CCS with disability benefits versus CCS without disability benefits: Mean scale score in the Social and Psychosexual domain, and Effect size

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCALE SCORES M (SD) N</td>
<td>M (SD) N</td>
<td>d M (SD) N</td>
</tr>
<tr>
<td>Social development</td>
<td>18.6 (5.3) 50</td>
<td>20.3 (2.8) 282</td>
</tr>
<tr>
<td>Psychosexual development</td>
<td>6.2 (1.5) 50</td>
<td>6.7 (1.4) 307</td>
</tr>
</tbody>
</table>

M= Mean scale score; SD= Standard Deviation; d= effect size (Benefits versus No Benefit); *a p < 0.01: Benefits versus No Benefits, corrected for age and gender
**a p < 0.001: Benefits versus No Benefits, corrected for age and gender
*a p < 0.01: Benefits versus Reference, corrected for age and gender
**a p < 0.01: Benefits versus Reference, corrected for age and gender
*b p < 0.01: No Benefits versus Reference, corrected for age and gender
**b p < 0.001: No Benefits versus Reference, corrected for age and gender

Psychosocial milestones

Compared to the reference group CCS with disability benefits were less likely to achieve 3 out of 6 milestones of Autonomy, 7 out of 12 milestones of Social development and 4 out of 4 milestones of Psychosexual development. For CCS without disability benefits the numbers were: 1 of 6 (Autonomy), 3 out of 12 (Social) and 2 out of 4 (Psychosexual).

When comparing CCS with to CCS without benefits, in the Autonomy domain it was found that CCS with disability benefits were less likely than those without disability benefits to have had a paid job during middle/high school (OR=0.4), and/or to have left the parents home (OR=0.4). Regarding three milestones in the Social domain, CCS with disability benefits were less likely than those without disability benefits to have achieved the milestones (playing with friends, leisure time with friends, going out to bar or disco), with OR’s ranging from 0.3 – 0.4 (table 3).

In the Psychosexual domain it was found that CCS with disability benefits were less likely to have fallen in love for the first time before the age of 19 (OR=0.4) and to have had sexual intimacy for the first time before the age of 19 (OR=0.4).

TABLE 3: Psychosocial developmental trajectory of CCS with disability benefits versus CCS without disability benefits: achievement of milestones (%) in the Autonomy, Social and Psychosexual domain, and Odds Ratio

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUTONOMY DEVELOPMENT</td>
<td>% N</td>
<td>% N OR [95% CI] % N</td>
</tr>
<tr>
<td>Regular chores/tasks in your family, elementary school</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>55.8 (28)</td>
<td>125</td>
</tr>
<tr>
<td>no</td>
<td>46.2 (24)</td>
<td>59.8 186</td>
</tr>
</tbody>
</table>
TABLE 3: Psychosocial developmental trajectory of CCS with disability benefits versus CCS without disability benefits: achievement of milestones (%) in the Autonomy, Social and Psychosexual domain, and Odds Ratio

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AUTONOMY DEVELOPMENT</strong></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Paid jobs, elementary school</td>
<td>yes</td>
<td>22.6</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>77.4</td>
</tr>
<tr>
<td>Regular chores/tasks in your family, middle and/or high school</td>
<td>yes</td>
<td>71.7</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>28.3</td>
</tr>
<tr>
<td>Paid jobs, middle and/or high school</td>
<td>at the age of 18 or younger</td>
<td>62.3</td>
</tr>
<tr>
<td></td>
<td>at the age of 19 or older</td>
<td>37.7</td>
</tr>
<tr>
<td>For the first time vacation without adults</td>
<td>at the age of 17 or younger</td>
<td>50.2</td>
</tr>
<tr>
<td></td>
<td>at the age of 18 or older</td>
<td>69.8</td>
</tr>
<tr>
<td>Leaving your parents home</td>
<td>not living with your parents</td>
<td>53.8</td>
</tr>
<tr>
<td></td>
<td>still living with your parents</td>
<td>46.2</td>
</tr>
<tr>
<td><strong>SOCIAL DEVELOPMENT</strong></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>At least one year of membership in a sports club / competitive sports, elementary school</td>
<td>yes</td>
<td>67.9</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>32.1</td>
</tr>
<tr>
<td>Number of friends in kindergarten through third grade, elementary school</td>
<td>4 or more</td>
<td>56.6</td>
</tr>
<tr>
<td></td>
<td>less than 4</td>
<td>45.4</td>
</tr>
<tr>
<td>Number of friends in fourth-sixth grade, elementary school</td>
<td>4 or more</td>
<td>52.8</td>
</tr>
<tr>
<td></td>
<td>less than 4</td>
<td>47.2</td>
</tr>
<tr>
<td>Best friend, elementary school</td>
<td>yes</td>
<td>62.3</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>37.7</td>
</tr>
<tr>
<td>Most of the time playing with… elementary school</td>
<td>friends</td>
<td>65.5</td>
</tr>
<tr>
<td></td>
<td>brothers and/or sisters, parents, on your own</td>
<td>36.5</td>
</tr>
</tbody>
</table>

TABLE 3: Continued

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SOCIAL DEVELOPMENT</strong></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>At least one year of membership in a sports club / competitive sports, middle and/or high school</td>
<td>yes</td>
<td>45.3</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>54.7</td>
</tr>
<tr>
<td>Number of friends, middle and/or high school</td>
<td>4 or more</td>
<td>50.9</td>
</tr>
<tr>
<td></td>
<td>less than 4</td>
<td>49.1</td>
</tr>
<tr>
<td>Best friend, middle and/or high school</td>
<td>yes</td>
<td>64.2</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>35.8</td>
</tr>
<tr>
<td>Belonging to a group of friends, middle and/or high school</td>
<td>yes</td>
<td>58.5</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>41.5</td>
</tr>
<tr>
<td>Leisure time, mainly with… middle and/or high school</td>
<td>friends</td>
<td>56.6</td>
</tr>
<tr>
<td></td>
<td>brothers and/or sisters, parents, on your own</td>
<td>43.3</td>
</tr>
<tr>
<td>Going out to a bar or disco, middle and/or high school</td>
<td>sometimes/often</td>
<td>54.9</td>
</tr>
<tr>
<td></td>
<td>never</td>
<td>45.1</td>
</tr>
<tr>
<td>At least one year of membership in a sports club / competitive sports, after middle and/or high school</td>
<td>yes</td>
<td>28.3</td>
</tr>
<tr>
<td></td>
<td>no</td>
<td>71.7</td>
</tr>
<tr>
<td><strong>PSYCHOSEXUAL DEVELOPMENT</strong></td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>First girlfriend/boyfriend</td>
<td>at the age of 17 or younger</td>
<td>56.6</td>
</tr>
<tr>
<td></td>
<td>at the age of 18 or older</td>
<td>43.4</td>
</tr>
<tr>
<td>For the first time falling in love</td>
<td>at the age of 18 or younger</td>
<td>75.0</td>
</tr>
<tr>
<td></td>
<td>at the age of 19 or older</td>
<td>25.0</td>
</tr>
</tbody>
</table>
TABLE 3: Continued

<table>
<thead>
<tr>
<th>PSYCHOSEXUAL DEVELOPMENT</th>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the first time sexual intimacy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at the age of 18 or younger</td>
<td>51.0 <strong>b</strong></td>
<td>26</td>
<td>71.0 *<strong>a</strong></td>
</tr>
<tr>
<td>at the age of 19 or older/never</td>
<td>49.0</td>
<td>25</td>
<td>29.0</td>
</tr>
</tbody>
</table>

For the first time sexual intercourse |          |             |           |
| at the age of 18 or younger | 34.6 **b** | 18 | 48.9 | 152 | 0.5 [0.3;1.0] | 58.5 296 |
| at the age of 19 or older/never | 65.4 | 34 | 51.1 | 159 | 41.5 210 |

OR = odds ratio (Benefits versus No Benefits corrected for age and gender)
CI = Confidence Interval of the OR
*a*  p < 0.01: Benefits versus No Benefits, corrected for age and gender
**a**  p < 0.001: Benefits versus No Benefits, corrected for age and gender
*b*  p < 0.01: Benefits versus Reference, corrected for age and gender
**b**  p < 0.001: Benefits versus Reference, corrected for age and gender
*c*  p < 0.01: No Benefits versus Reference, corrected for age and gender

Regarding marital status, CCS with and CCS without disability benefits did not differ but both were less likely to be married or living together than the reference group (table 4). Finally, CCS with disability benefits were more likely to be low educated than the reference group and the CCS without disability benefits: 57.7%, 29.4% and 31.2%, respectively (table 4).

TABLE 4: Psychosocial developmental trajectory of CCS with disability benefits versus CCS without disability benefits: Socio-demographic milestones (%) and Odds Ratio

<table>
<thead>
<tr>
<th>SOCIO-DEMOGRAPHICS</th>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>married/living together</td>
<td>21.2 <strong>b</strong></td>
<td>11</td>
<td>31.9 *<strong>a</strong></td>
</tr>
<tr>
<td>single</td>
<td>78.8</td>
<td>41</td>
<td>68.1</td>
</tr>
</tbody>
</table>

Educational level ¹

<table>
<thead>
<tr>
<th></th>
<th>Benefits</th>
<th>No Benefits</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>low</td>
<td>57.7 <strong>b</strong></td>
<td>30</td>
<td>31.2</td>
</tr>
<tr>
<td>middle or high</td>
<td>42.3</td>
<td>22</td>
<td>68.8</td>
</tr>
</tbody>
</table>

OR = odds ratio (Benefits versus No Benefits corrected for age and gender)
CI = Confidence Interval of the OR
¹ Highest level completed: Low: Primary Education, Technical and Vocational Training, Lower and Middle General Secondary Education. Middle: Middle Vocational Education, Higher General Secondary Education, Pre-university Education. High: Higher Vocational Education, University
*a*  p < 0.01: Benefits versus No Benefits, corrected for age and gender
**a**  p < 0.001: Benefits versus No Benefits, corrected for age and gender
*b*  p < 0.01: Benefits versus Reference, corrected for age and gender
**b**  p < 0.001: Benefits versus Reference, corrected for age and gender
*c*  p < 0.01: No Benefits versus Reference, corrected for age and gender

DISCUSSION

It has already been known that children who grow up with a disease are at risk of an unfavourable developmental trajectory, especially children with cancer and end-stage renal failure ¹⁵, ¹². The results of the present study showed that young adult CCS with disability benefits scored even more unfavourable in terms of milestones in autonomy, social and psychosexual development than CCS who did not apply for disability benefits. CCS with benefits scored less favourable than peers from the general population on 14 out of 22 milestones while the number was 6 for those without disability benefits. These findings indicate that the developmental trajectory while growing up could be predictive of job participation in adulthood. More specifically, we found that social activities with peers and having paid jobs in adolescence were associated with a smaller likelihood of applying for disability benefits in young adulthood. Though we did not prove causality between the achievement of milestones while growing up and applying for disability benefits in young adulthood, the fact that the developmental trajectory temporally preceded the disability benefits, gives an indication.

One satisfying development in recent decades is that systematic monitoring and screening of CCS, both medically and psychosocially, have become standard in many hospitals, as part of the evaluations in the long-term follow-up clinic. Screening of psychosocial developmental milestones is particularly advisable at important developmental transitions, for example transition to secondary education and transition to post-secondary education and/or employment.

The results of our study indicate that stimulating social participation in terms of activities with peers and paid jobs could increase CCS’ likelihood of job participation in adulthood. If needed, interventions directed at social integration and autonomy of CCS should be offered. Psychological support could be necessary especially in adolescence because adolescents with a chronic disease may become marginalized by peers, rejected for being different at a time when body image and identity so largely depend on conformity ²². Psychologists should prepare CCS for interaction with their peers (e.g. what to tell friends about the disease and how to deal with physical limitations in relation to peers). It is also recommended to support parents in treating CCS as normally as possible within the family; helping their children to develop the personal skills they need to cope with the challenges of growing up with cancer.

For adolescent CCS, it is important to have a (small) paid job because it offers the possibility to gain work experience, to earn own money and it improves their self-esteem. If needed, CCS should be supported at achieving academic and vocational success. SAVTI (Successful Academic and Vocational Transition Ini-
In conclusion, CCS with an unfavourable developmental trajectory while growing up were more likely to apply for disability benefits. This indicates that CCS of central nervous tumours were nearly five times more likely to be unemployed. Moreover, CCS with serious cognitive problems were not included because they were unable to complete the questionnaires. It is worth considering alternative methods of data collection to get insight into CCS with serious cognitive problems. In addition, the results are based on a rather small sample of CCS with disability benefits from two different studies, one with a low response rate. So our results cannot be generalized to all CCS.

In conclusion, CCS with an unfavourable developmental trajectory while growing up were more likely to apply for disability benefits in adulthood than CCS with a more favourable development. Early recognition and support is warranted. Further research is needed on risk factors of application for disability benefits. In addition, research should show whether stimulating the achievement of developmental milestones while growing up will create conditions for a better labour market position.

**REFERENCE LIST**


Als ik mijn ouders mag geloven, was ik een vrolijke, makelijke baby. Ik ben opgegroeid met twee geweldige ouders, die er altijd voor mij zijn, vooral als ik getroost moest worden. Als klein kind was ik vrolijk en spontaan, een echte spring in het veld. Ik was overal voor in. Op de basisschool ging het allemaal goed, ik ontwikkelde mij normaal, was populair en had een aantal hechte vriendinnen. We deden alles samen. School was dan ook niet moeilijk voor mij, mijn toekomst keek mij met een grote glimlach tegemoet. Het eerste jaar van de middelbare school was erg wennen, alles was anders. Nu was ik een van de jongste pubers. Het ging goed op school, ik haalde goede cijfers. Als ik een keer niet leerde voor een overhoring en een onvoldoende kreeg, was het niet erg, want dat haalde ik dan weer op.

Ik werd wakker met een hoofdpijn die ik nog nooit eerder gevoeld had. Ik deed mijn ogen open en zag voor mij een onbekende vrouw. Hoe langer ik naar haar keek, hoe beken-
der zij werd: het was mama’s beste vriendin, Lilian. Waarom was ze hier? Ik wist het niet. Het was midden in de nacht, ik zat nog in mijn pyjama. Ze keek bezorgd naar mij. Ik dacht dat er iets met mama was. Ze was die dag door haar rug gegaan, er moest dus wel iets met haar aan de hand zijn. Toen zag ik twee vreemde mannen praten met mama. Wat doen die mannen hier? Een van hen liep naar mij toe en scheen met zijn zaklamp in ogen. Iedereen keek naar mij. Papa vertelde dat de mannen ambulancebroeders zijn en me straks meenemen naar het ziekenhuis. Ik hoorde het wel, maar snapte het niet. Waarom moest ik mee? Ik doe mijn mond open om wat te zeggen, maar ik kan niet praten. Ik kijk angstig rond. Ik merk ook dat mijn mond en tong vol met wondjes zitten. Ik snap het allemaal niet meer. Ik ben moe, heel erg moe, misselijk en die verschrikkelijke hoofdpijn! Waar komt het allemaal vandaan? Lilian neemt het over van papa: ‘Je hebt een epilepsie aanval gehad.’

Vanaf die dag is mijn hele leven totaal veranderd. Ik veranderde, van het ene moment in het andere moment, van een vrolijk en spontaan spring in het veld in een meisje zonder levenslust, zonder toekomst verwachtingen en zonder energie. Altijd moe. Er volgden veel onderzoeken en er werd inderdaad als diagnose gesteld: epilepsie. Mijn aanvallen veranderden in de loop der jaren. Vaak kreeg ik overdag aura’s, d.w.z. kleine aanvallen, en ’s avonds in mijn slaap een grote aanval. Door de aura’s en de medicatie was ik vaak uitgeput en heb daarom veel lessen op school moeten verzuimen. We zijn bij de stichting epilepsie instellingen Nederland, ook wel SEIN genoemd, terecht gekomen. Ik kreeg daar een neuroloog toegewezen die gespecialiseerd is in epilepsie. Zij kon al mijn vragen beantwoorden. Ze was altijd eerlijk tegen mij en gaf mij nimmer valse hoop. Bij SEIN moest ik opnieuw worden ‘ingesteld’, d.w.z. een nieuwe EEG scan, een nieuwe MRI scan en andere medicatie. We kregen nu ook te horen dat mijn epilepsie in het taalgebied ontstaat. Voor mij werden gelijk een hoop dingen duidelijker. Na een aura duurde het even voor spreken en luisteren weer mogelijk was. Naast dat het erg lang kan duren de juiste woorden te vinden, vergeet ik ook telkens begrippen, feitjes en wetenswaardigheden. Dit kan mij erg frustreren. Het gevoel hebben dat je het wel weet, maar er net niet bij kunnen is zo vermoeiend!

Gelukkig had ik op school een hechte vriendengroep. Zij begrepen mij als het niet helemaal ging. Ik wilde alles blijven doen wat wij altijd deden, zoals tot het einde van een feestje blijven net als de rest, want stel je voor dat ik iets miste. Dit putte mij zo uit, dat ik daar later voor moest boeten. In die periode lieten mijn ouders mij gaan, maar zowel zij als ik zagen al snel in dat het niet ging. Ik moest keuzes maken; een goed presteren op school of uitgaan met mijn vrienden. Een keuze die ik als puber liever niet wilde maken. Ik wilde beide! Het waren dan ook dat mijn ouders die op de rem trapten en mij de keuzes voorlegde. Een aanval krijgen betekende een week niet naar
Getting to work: factors associated with work participation in young adults with a childhood-onset chronic condition

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In preparation
ABSTRACT

INTRODUCTION: The number of children with a somatic childhood-onset chronic condition is increasing. A part of the young adults grown up with a chronic childhood condition has to apply for disability benefits. Understanding the relation between employment and characteristics of young adults with disability benefits could yield starting points for interventions to create conditions for an optimal labour market position. The aim of the study was to get insight in the disease characteristics, work characteristics, illness cognitions and work motivation of young adults with disability benefits as a result of chronic conditions and to explore the association with the likelihood of being employed.

METHODS: In a cross-sectional study, young adults (N=353, 22-31 yrs, 66% female) claiming disability benefits completed an online questionnaire concerning disease characteristics, work characteristics, the Illness Cognition Questionnaire (acceptance-helplessness-benefits) and work motivation (subscale of the Work and Life Attitudes Survey). Univariate analyses and logistic regression analyses were conducted to investigate whether successful employment (as at least 12 hours a week during at least 6 months since applying for disability benefits) was associated with the above mentioned variables.

RESULTS: In total, 38.2% were successfully employed since they applied for disability benefits. Many young adults - whether successful or not in the work force - reported to need work adjustments, in particular adjustment in working hours (43.2%). A small minority (46.1%) of the young adults with disability benefits had a paid job during high school. Compared to unsuccessfully employed beneficiaries, a greater proportion of successful beneficiaries reported a need for support at work (32.1% vs 21.6%; χ² 4.75, p=0.003), successful beneficiaries reported less feelings of helplessness (Mean 11.46 vs 12.91; T=2.84, p=0.005) and had a greater work motivation (Mean 19.28 vs 17.68; T=-3.71; p=0.000), and a greater proportion of the parents who considered work important for their child (89.6% vs 64.8%; χ² 26.45; p=0.000). When controlling for socio-demographic and disease characteristics, only the extent to which parents consider work important for their child remained significant (OR 3.47, p=0.001).

CONCLUSION: There is a complex relationship among disease characteristics, work characteristics, illness cognitions, work motivation and employment in young adults with disability benefits as a result of a chronic condition. This study found differences between young adults with disability benefits who are successful at the work force compared to those who are not, regarding the need for support at work, feelings of helplessness, parents who consider work important for their child and work motivation. Future research should focus on longitudinal patterns, factors of influence on (early) work participation and whether stimulating the motivation while growing up will create conditions for a better labour market position.

INTRODUCTION

For most people, work is an important part of life. Besides money, employment offers many other, immaterial advantages such as the possibility for self-development, social relationships, development of skills, daily routines, and, in many cases, meaning in life 1,2. Having a chronic disease or disability often negatively affects the capacity to participate in gainful employment. In various studies, the labour market position of people with a chronic disease or disability is found to be problematic, with regard to getting a job as well as job continuation 1,3-5. This, in turn, leads to a variety of economic, social and quality of life problems 6. Several studies among people with chronic somatic diseases show lower income levels 7,8, lower Health Related Quality of Life (HRQoL) 9-11, worse mental health such as more anxiety and depression 12-14 in non-workers than in those who are participating in the workforce.

Most of the research on the work experiences of people with chronic conditions has focused on adults while much less attention has been paid to the employment patterns of younger people with chronic conditions just entering the workforce. However, employment and its skill-building opportunities are essential elements for a successful transition to adulthood for young people 15. The shift out of school into occupation is a developmental stage in which young people gain increasing sense of control over their lives, experience a greater responsibility, and form an identity which they can use to shape their sense of self that will likely endure through-out adulthood 16. Avoiding unemployment in early adulthood is particularly important because the decisions and actions that occur during this time can affect income levels and occupational achievement across the lifespan.

In the Netherlands, young people who are partially or fully incapable of working, due to a childhood-onset chronic condition, may be eligible for a benefit under the scheme for young disabled persons: Wajong (Disablement Assistance Act for Handicapped Young Persons). Although some of these young adults are unable to work in any way because of their limitations, others can work (part-time) and are willing to. But when these young adults who are able to work attempt to begin their vocational careers they do not seem to succeed in the
Chapter 7

Getting to work: factors associated with work participation

Previous studies on factors that promote or hinder work participation in young people with chronic conditions showed among others socio-demographic factors (like age, gender, education, geographic location and the number of people living in the household), medical factors (like severity of disability, type and duration of disability), psycho-social factors (such as coping and motivation) as determinants for successful work participation and duration of disability), psycho-social factors (such as coping and motivation) as determinants for successful work participation.

Research in adult populations with sole somatic chronic conditions indicates that disease-related but also external and personal factors contribute to the likelihood of work participation. The ability to work in adult populations with chronic conditions can vary greatly from patient to patient, even in those with the same diagnosis. The discrepancy between the level of condition-related dysfunction in the work force and the underlying pathology of the condition has given rise to studies about the contribution of psychosocial factors to work outcomes in patients with chronic conditions. Psychosocial factors as illness cognitions and work motivation are found to be related to employment. Non-working patients were more likely to have maladaptive illness perceptions. Maybe these factors are also important for work participation of young adults with childhood-onset chronic conditions because of a somatic condition since childhood.

The number of children with a somatic childhood-onset chronic condition is increasing. A part of the young adults grown up with a chronic childhood condition has to apply for disability benefits. Understanding the relation between employment and characteristics of young adults with disability benefits could yield starting points for interventions to create conditions for an optimal labour market position. The aim of the study was twofold. First, we aimed to get insight in the disease characteristics, work characteristics, illness cognitions and work motivation of young adults with disability benefits as a result of chronic conditions. Second, we aimed to explore whether work characteristics, illness cognitions and work motivation are associated with the likelihood of being employed.

METHODS

PROCEDURES

This study was conducted within the framework of a large cross-sectional study (EMWAjong), a study directed at investigating psychosocial functioning in young adults with a Wajong benefit due to a childhood-onset chronic somatic condition and factors affecting their vocational success. In this article we will refer to this group as ‘young adults claiming disability benefits’. All young adults between 22 and 31 years of age who claimed a Wajong benefit in the year 2003 or 2004 for a chronic somatic condition were invited to participate in EMWAjong via a letter. Participation meant completing an online questionnaire. Those with no sustainable work opportunities (classified as fully incapable for work) were excluded because the EMWAjong study aimed to identify factors that could help to improve vocational success. Those with serious cognitive impairment or psychiatric conditions were also excluded because the EMWAjong study was directed at young adults with childhood-onset somatic conditions.

In total, 2,046 persons were invited to take part in the study. To maintain the privacy of the beneficiaries, the invitation letter was sent by UWV, the Dutch benefits agency. The letter contained a personal log in code, a password and a link to the online questionnaire. After two weeks, participants received a reminder letter. Participants who completed the entire questionnaire received a gift voucher. The study was performed according to the regulations of the medical ethical committee; due to the once-only nature of the survey, no formal approval by the medical ethics committee was required.

MEASURES

Socio-demographic variables

Next to gender and age, level of education (low/middle/high), living situation (non-independent/independent) and marital status (single/married or cohabitation) were measured as background variables.

Disease characteristics

Due to privacy reasons, no information about the chronic conditions of the participants was provided by the benefits agency. This information was therefore derived through beneficiaries’ self reports. The questions concerning the disease characteristics were chosen based on existing questionnaires and recommendations from experts in the field. The following dichotomous disease-related variables were used in the present study: congenital disorder (yes/no), visible disease/disability (yes/no), the nature of the disease process over
time ("course of disease": stable or positive vs negative or variable), daily use of medication (yes/no), need for medical devices in daily life, e.g. hearing aid and wheelchair (yes/no), limitations in use of fingers/hands, sight, hearing, and being able to sit/stand for half an hour (yes/no) and fatigue (no or mild/serious).

**Work characteristics**

Following the common Dutch definition of labour participation, employment was defined in this study as: having a paid job of at least 12 hours a week for an uninterrupted period of 6 months, since applying for disability benefits. Work characteristics used were: requirements for work participation (adjusted working hours, adjusted work place, transport to work, adjusted tasks, support at work, nothing, other) and (parttime) job during high school (yes/no).

**Illness Cognitions**

Illness cognitions were assessed with the ICQ that measures generic illness beliefs across chronic conditions. The ICQ is a 18-item questionnaire that contains three six-item scales related to cognitive ways patients ascribe meaning to chronic illness: helplessness (focusing on the negative consequences of the disease and generalizing them to functioning in daily life; e.g.: "My illness limits me in everything that is important to me"), acceptance (acknowledging being chronically ill and perceiving the ability to manage the negative consequences of the disease; e.g.: "I have learned to live with my illness") and perceived benefits (also perceiving positive, long-term consequences of the disease, e.g.: "Dealing with my illness has made me a stronger person"). Items are scored on a four-point Likert scale (1 = not at all, 2 = somewhat, 3 = to a large extent, 4 = completely). Scale scores for the three illness cognitions are calculated by summing up the item scores. For each scale the mean item score was calculated by dividing the scale score by the number of the items, resulting in a mean item scale score from 1 to 4. Higher scores indicate that the illness cognition is strong.

**Statistical analysis**

The Statistical Package for Social Sciences (SPSS) Windows version 20 was used for all analyses. First, socio-demographic characteristics, disease characteristics, work characteristics (requirements for work participation, job during high school), illness cognitions (benefits, acceptance, helplessness) and work motivation (motivation of the young adult, extent to which parents consider work important for their child) were analysed with descriptive statistics and separately presented for those young adults who were successful employed and who were not.

Second, univariate analyses were conducted (chi-square tests and T-tests) to explore associations of successful employment (at least 12 hours a week during at least 6 months since applying for disability benefits) with work characteristics, illness cognitions and work motivation. Finally, all variables were entered simultaneously in a logistic regression model to investigate whether successful employment was associated with work characteristics, illness cognitions and work motivation, while controlling for the effect of disease characteristics and socio-demographics (age, gender, education). Odds ratio (Exponent B) was used as measure of association. A significance level of 0.05 was applied to the analysis.

**RESULTS**

A total of 415 young adults with a chronic somatic condition participated in the study (response rate 20.1%). Non-responders differed from responders with respect to gender: 51.4% vs. 64.3% women (p<0.05). Sixty-two respondents were removed from the analyses because of missing data regarding employment, so that the data of (maximum) 353 young adults could be used for analyses.

**Characteristics of young adults with disability benefits**

Of the young adults with disabilities benefits, 38.2% have had a paid job since they applied for disability benefits, meaning that they were successfully employed at least 12 hours a week during at least 6 months since they applied for...
disability benefits.

The socio-demographic and disease characteristics of successful and unsuccessful young adults with disability benefits are listed in Table 1. The young adults, 66.0% female, were aged 25.0 on average. One third (34.8%) reported a low level of education. The majority (73.1%) was not married or living together, while 54.7% reported to live independently. They suffered from diverse chronic conditions, characterized as stable/positive (57.5%) or variable/negative (42.5%), congenital (46.7%), requiring daily medicine (53.8%) and requiring medical devices (47.6%). Fatigue is the most frequently reported limitation (43.1%).

### TABLE 1: Socio demographic and disease characteristics of young adults with disability benefits according to successful work participation

<table>
<thead>
<tr>
<th></th>
<th>Unsuccessful employment</th>
<th>Successful employment</th>
<th>Total (N =353)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=218 (61.8%)</td>
<td>N=135 (38.2%)</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Age</td>
<td>24.79</td>
<td>25.27</td>
<td>24.98</td>
</tr>
<tr>
<td>SD Age</td>
<td>1.93</td>
<td>2.16</td>
<td>2.03</td>
</tr>
<tr>
<td>N % N % N %</td>
<td>N % N % N %</td>
<td></td>
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</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Female</td>
<td>149 (68.3%)</td>
<td>84 (62.2%)</td>
<td>233 (66.0%)</td>
</tr>
<tr>
<td>Male</td>
<td>69 (31.7%)</td>
<td>51 (37.8%)</td>
<td>120 (34.0%)</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>75 (36.9%)</td>
<td>41 (31.5%)</td>
<td>116 (34.8%)</td>
</tr>
<tr>
<td>Middle</td>
<td>110 (54.2%)</td>
<td>67 (51.5%)</td>
<td>177 (53.2%)</td>
</tr>
<tr>
<td>High</td>
<td>18 (8.9%)</td>
<td>22 (16.9%)</td>
<td>40 (12.0%)</td>
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<tr>
<td><strong>Living situation</strong></td>
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<td></td>
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</tr>
<tr>
<td>Non-independent</td>
<td>105 (48.2%)</td>
<td>55 (40.7%)</td>
<td>160 (45.3%)</td>
</tr>
<tr>
<td>Independent</td>
<td>113 (51.8%)</td>
<td>80 (59.3%)</td>
<td>193 (54.7%)</td>
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<tr>
<td><strong>Marital status</strong></td>
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<tr>
<td>Single</td>
<td>166 (76.1%)</td>
<td>92 (68.1%)</td>
<td>258 (73.1%)</td>
</tr>
<tr>
<td>Married/cohabitation</td>
<td>52 (23.9%)</td>
<td>43 (31.9%)</td>
<td>95 (26.9%)</td>
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<tr>
<td><strong>Condition/illness</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visually impaired/blind</td>
<td>32 (65.3%)</td>
<td>17 (34.7%)</td>
<td>49 (13.9%)</td>
</tr>
<tr>
<td>Spasm</td>
<td>26 (65.0%)</td>
<td>14 (35.0%)</td>
<td>40 (11.3%)</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>26 (63.4%)</td>
<td>15 (36.6%)</td>
<td>41 (11.6%)</td>
</tr>
<tr>
<td>CFS/migraine</td>
<td>22 (64.7%)</td>
<td>12 (35.3%)</td>
<td>34 (9.6%)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>15 (50.0%)</td>
<td>15 (50.0%)</td>
<td>30 (8.5%)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>10 (62.5%)</td>
<td>6 (37.5%)</td>
<td>16 (4.5%)</td>
</tr>
<tr>
<td>Back complaints</td>
<td>16 (61.5%)</td>
<td>10 (38.5%)</td>
<td>26 (7.4%)</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>17 (68.0%)</td>
<td>8 (32.0%)</td>
<td>25 (7.1%)</td>
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</table>

### TABLE 1: Continued

<table>
<thead>
<tr>
<th></th>
<th>Unsuccessful employment</th>
<th>Successful employment</th>
<th>Total (N =353)</th>
</tr>
</thead>
<tbody>
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<td></td>
<td>N=218 (61.8%)</td>
<td>N=135 (38.2%)</td>
<td></td>
</tr>
<tr>
<td>Hearing impaired/deaf</td>
<td>16 (76.7)</td>
<td>8 (33.3)</td>
<td>24 (6.8)</td>
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<tr>
<td>Intestinal complaints</td>
<td>13 (61.9)</td>
<td>8 (38.1)</td>
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<td>Lung complaints</td>
<td>14 (73.7)</td>
<td>5 (26.3)</td>
<td>19 (5.4)</td>
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<tr>
<td>Paralysis</td>
<td>12 (63.2)</td>
<td>7 (36.8)</td>
<td>19 (5.4)</td>
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<tr>
<td>Cancer</td>
<td>9 (47.4)</td>
<td>10 (52.6)</td>
<td>19 (5.4)</td>
</tr>
<tr>
<td>Accident damage</td>
<td>12 (75.0)</td>
<td>4 (25.0)</td>
<td>16 (4.5)</td>
</tr>
<tr>
<td>Kidney disease</td>
<td>12 (80.0)</td>
<td>3 (20.0)</td>
<td>15 (4.2)</td>
</tr>
<tr>
<td>Skin disease</td>
<td>5 (62.5)</td>
<td>3 (37.5)</td>
<td>8 (2.3)</td>
</tr>
<tr>
<td>Heart disease</td>
<td>6 (85.7)</td>
<td>1 (14.3)</td>
<td>7 (2.0)</td>
</tr>
<tr>
<td>Liver disease</td>
<td>4 (80.0)</td>
<td>1 (20.0)</td>
<td>5 (1.4)</td>
</tr>
<tr>
<td>Other</td>
<td>70 (64.2)</td>
<td>39 (35.8)</td>
<td>109 (30.9)</td>
</tr>
<tr>
<td><strong>Disease characteristics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Course of disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variable/Negative</td>
<td>108 (49.5)</td>
<td>42 (31.1)</td>
<td>150 (42.5)</td>
</tr>
<tr>
<td>Stable/Positive</td>
<td>110 (50.5)</td>
<td>93 (68.9)</td>
<td>203 (57.5)</td>
</tr>
<tr>
<td><strong>Visible disability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>119 (54.6)</td>
<td>46 (34.1)</td>
<td>165 (46.7)</td>
</tr>
<tr>
<td>No</td>
<td>99 (45.4)</td>
<td>89 (65.9)</td>
<td>208 (53.3)</td>
</tr>
<tr>
<td><strong>Congenital disorder</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>113 (51.8)</td>
<td>75 (55.6)</td>
<td>188 (46.7)</td>
</tr>
<tr>
<td>No</td>
<td>105 (48.2)</td>
<td>60 (44.4)</td>
<td>165 (43.3)</td>
</tr>
<tr>
<td><strong>Daily medicine use</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>122 (56.0)</td>
<td>68 (50.4)</td>
<td>190 (53.8)</td>
</tr>
<tr>
<td>No</td>
<td>96 (44.0)</td>
<td>67 (49.6)</td>
<td>163 (46.2)</td>
</tr>
<tr>
<td><strong>Medical devices</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>116 (53.2)</td>
<td>52 (38.5)</td>
<td>168 (47.6)</td>
</tr>
<tr>
<td>No</td>
<td>102 (46.8)</td>
<td>83 (61.5)</td>
<td>185 (52.4)</td>
</tr>
<tr>
<td><strong>Limitations of sight</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>59 (27.1)</td>
<td>28 (20.7)</td>
<td>87 (24.6)</td>
</tr>
<tr>
<td>No</td>
<td>159 (72.9)</td>
<td>107 (79.3)</td>
<td>266 (75.4)</td>
</tr>
<tr>
<td><strong>Limitation of hearing</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>19 (8.7)</td>
<td>9 (6.7)</td>
<td>28 (7.9)</td>
</tr>
<tr>
<td>No</td>
<td>199 (91.3)</td>
<td>126 (93.3)</td>
<td>325 (92.1)</td>
</tr>
<tr>
<td><strong>Limitations to stand half an hour</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>107 (49.1)</td>
<td>40 (29.6)</td>
<td>147 (41.6)</td>
</tr>
<tr>
<td>No</td>
<td>111 (50.9)</td>
<td>95 (70.4)</td>
<td>206 (58.4)</td>
</tr>
</tbody>
</table>
In Table 2 the requirements for work participation, job during high school, illness cognitions, work motivation and the proportion of the parents who considered work important for their child are presented. Many young adults with disability benefits reported to need work adjustments, in particular adjustment in working hours (43.2%). Almost half (46.1%) of the young adults with disability benefits had a paid job during high school. The mean item scores of the illness cognitions show that the young adults with disability benefits accept their condition to a certain degree (2.94; score range 1-4), perceive some long-term beneficial consequences of their conditions (2.86; score range 1-4) and feel an inability to control a particular situation and emphasizes the negative aspects of their condition in daily functioning (2.06; score range 1-4). The mean item score of 3.1 (score range 1-4) for work motivation indicates that the young adults want to be engaged in work to a considerable degree. The young adults indicated that most of their parents (74.4%) considered work important for their child. 

TABLE 2: Requirements for work participation, job during high school, illness cognitions, work motivation and parent who consider work important of young adults with disability benefits

<table>
<thead>
<tr>
<th>Requirement for work participation (N=347)</th>
<th>Unsuccessful employment</th>
<th>Successful employment</th>
<th>Total (N =353)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adjusted working hours</strong></td>
<td>97</td>
<td>46.5%</td>
<td>150</td>
</tr>
<tr>
<td><strong>Adjusted work place</strong></td>
<td>72</td>
<td>33.8%</td>
<td>113</td>
</tr>
<tr>
<td><strong>Transport to work</strong></td>
<td>62</td>
<td>29.1%</td>
<td>104</td>
</tr>
<tr>
<td><strong>Adjusted tasks</strong></td>
<td>49</td>
<td>23.0%</td>
<td>72</td>
</tr>
<tr>
<td><strong>Support at work</strong></td>
<td>46</td>
<td>21.6%</td>
<td>89</td>
</tr>
</tbody>
</table>

1 12 hours a week during at least 6 months since they applied for disability benefits

Associations of employment with work characteristics, illness cognitions and work motivation

The results of the univariate analyses (Table 2) showed that the proportion of successfully employed beneficiaries that needed support at work was greater than that proportion in the unsuccessful beneficiaries ($\chi^2=4.75$, $p=0.003$). The successfully employed beneficiaries experienced less feelings of helplessness than the unsuccessful beneficiaries ($T=2.84$, $p=0.005$). Work motivation of the beneficiaries and parents who consider work important for their child were greater in successful than in unsuccessful beneficiaries ($T=3.71$, $p=0.000$ and $\chi^2=26.45$, $p=0.000$, respectively).

When all variables were entered simultaneously in a logistic regression model,
including socio-demographic and disease characteristics (Table 3), parents who consider work important for their child remained significant. Greater likelihood of successful employment was associated with parents who considered work important for their child (OR 3.47, *p=0.001). Besides, two disease-related characteristics appeared to be associated with successful employment. Limitations to sit half an hour was associated with a greater likelihood of successful employment (OR 3.15, **p=0.036), while young adults who used medical devices were less likely to be successfully employed (OR 0.55, ***p=0.049).

**TABLE 3:** Associations of successful employment with disease characteristics, work characteristics, illness cognitions and work motivation in young adults with disability benefits (N=332)

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>S.E.</th>
<th>Exp(B)</th>
<th>lower</th>
<th>upper</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>0.11</td>
<td>0.07</td>
<td>1.12</td>
<td>0.98</td>
<td>1.28</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>-0.06</td>
<td>0.29</td>
<td>0.94</td>
<td>0.53</td>
<td>1.66</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td>0.29</td>
<td>0.30</td>
<td>1.34</td>
<td>0.74</td>
<td>2.41</td>
</tr>
<tr>
<td><strong>Disease characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Congenital condition</td>
<td>0.20</td>
<td>0.31</td>
<td>1.33</td>
<td>0.73</td>
<td>2.31</td>
</tr>
<tr>
<td>Congenital disorder</td>
<td>0.29</td>
<td>0.29</td>
<td>1.34</td>
<td>0.75</td>
<td>2.38</td>
</tr>
<tr>
<td>Visible disability</td>
<td>-0.46</td>
<td>0.33</td>
<td>0.63</td>
<td>0.33</td>
<td>1.20</td>
</tr>
<tr>
<td>Medical devices</td>
<td>-0.61</td>
<td>0.31</td>
<td>0.55***</td>
<td>0.30</td>
<td>1.00</td>
</tr>
<tr>
<td>Daily medicine use</td>
<td>0.25</td>
<td>0.28</td>
<td>1.29</td>
<td>0.74</td>
<td>2.24</td>
</tr>
<tr>
<td>Limitations to sit half an hour</td>
<td>1.15</td>
<td>0.55</td>
<td>3.15**</td>
<td>1.08</td>
<td>9.17</td>
</tr>
<tr>
<td>Limitations of sight</td>
<td>-0.25</td>
<td>0.33</td>
<td>0.78</td>
<td>0.41</td>
<td>1.48</td>
</tr>
<tr>
<td>Limitations of hearing/deaf</td>
<td>-0.68</td>
<td>0.54</td>
<td>0.51</td>
<td>0.18</td>
<td>1.46</td>
</tr>
<tr>
<td>Limitations to stand half an hour</td>
<td>-0.52</td>
<td>0.32</td>
<td>0.60</td>
<td>0.32</td>
<td>1.15</td>
</tr>
<tr>
<td>Fatigue</td>
<td>-0.52</td>
<td>0.32</td>
<td>0.60</td>
<td>0.32</td>
<td>1.11</td>
</tr>
<tr>
<td>Limitations in hand/finger</td>
<td>0.40</td>
<td>0.29</td>
<td>1.49</td>
<td>0.84</td>
<td>2.62</td>
</tr>
<tr>
<td><strong>Requirements for work participation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport to work</td>
<td>0.47</td>
<td>0.30</td>
<td>1.60</td>
<td>0.88</td>
<td>2.90</td>
</tr>
<tr>
<td>Adjusted work place</td>
<td>0.18</td>
<td>0.31</td>
<td>1.20</td>
<td>0.66</td>
<td>2.21</td>
</tr>
<tr>
<td>Adjusted working hours</td>
<td>-0.15</td>
<td>0.31</td>
<td>0.88</td>
<td>0.48</td>
<td>1.60</td>
</tr>
<tr>
<td>Adjusted tasks</td>
<td>-0.09</td>
<td>0.36</td>
<td>0.92</td>
<td>0.45</td>
<td>1.86</td>
</tr>
<tr>
<td>Support at work</td>
<td>0.46</td>
<td>0.31</td>
<td>1.58</td>
<td>0.85</td>
<td>2.93</td>
</tr>
<tr>
<td><strong>Job during high school</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Job during high school</td>
<td>0.26</td>
<td>0.28</td>
<td>1.29</td>
<td>0.75</td>
<td>2.23</td>
</tr>
<tr>
<td><strong>Illness cognitions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>-0.03</td>
<td>0.03</td>
<td>0.97</td>
<td>0.91</td>
<td>1.02</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.03</td>
<td>0.04</td>
<td>1.03</td>
<td>0.96</td>
<td>1.11</td>
</tr>
<tr>
<td>Helplessness</td>
<td>-0.02</td>
<td>0.04</td>
<td>0.98</td>
<td>0.91</td>
<td>1.06</td>
</tr>
<tr>
<td><strong>Work motivation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work motivation</td>
<td>0.07</td>
<td>0.04</td>
<td>1.07</td>
<td>0.99</td>
<td>1.16</td>
</tr>
<tr>
<td>Parents consider work important for their child</td>
<td>1.24</td>
<td>0.39</td>
<td>3.47***</td>
<td>1.61</td>
<td>7.45</td>
</tr>
</tbody>
</table>

*1 12 hours a week during at least 6 months since they applied for disability benefits
**p=0.049; ***p=0.036; ****p=0.001

**DISCUSSION**

Although some young adults with disability benefits as a result of chronic conditions since childhood make a good adjustment to working life, many others struggle with the impact of their condition on work participation. These young adults are at the very beginning of their vocational career, but they already have trouble with entering and staying at the labour market. Even though all respondents in this study are declared (party) capable of work, only a minority of the respondents have had a paid job since they applied for disability benefits (38.2%). Since our study population consists of young adults with heterogeneous conditions with different levels of illness severity, a part of the unsuccessful work participation may be explained by the fact that some respondents had a more severe type of condition. This would be in line with previous research which showed that those with a more severe disability experienced more difficulty in finding and maintaining a job 31, 32. However, our results show that the labour market position of young adults with disability benefits appears not primarily to be related to disease related factors since few disease related factors appeared to be associated with employment. Only the use of medical devices and the limitation to sit were associated with unemployment. Both could be indicators of illness severity.

Many young adults with disability benefits – successful in the work force or not - reported to need work adjustments to be able to participate in the work force. Adjusted working hours, adjustment in the work place and transport to work were the most frequently mentioned adjustments, especially by those unsuccessful in the work force. Need for support at work was significantly higher in those who have been successful at the labour market. However, it is unknown whether the respondents, who indicated support at work as a crucial factor for successful employment, get actual support. There may be a group who would have liked help, but did not receive it. When people are unable to fulfill their jobs en drop out because of a lack of support or perceived lack of support, there is a danger that their motivation to work will gradually decrease 23.

A rather high level of acceptance and benefits was found, indicating that the majority of the young adults with Wajong benefits in this study have learned to live with their illness or disability and even perceives some long-term beneficially consequences of their conditions. As they have been limited since childhood this may have influenced their acceptance and perception of possible benefits in a positive way. Respondents without successful work experience reported significant more feelings of helplessness, a cognition with a substantial negative impact. This might indicate that the young adult beneficiaries without work feel an inability to work or to get employed. The young person’s own motivation

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**TABLE**

**DISCUSSION**

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turned out to be an important ingredient in achievement in occupational outcomes. Those with a firmer work motivation are more likely to participate successfully on the labour market. This is in line with studies which have found that having high aspirations is associated with better employment outcomes in early adulthood, independently of other characteristics such as parental background or schooling. Among the young adults with chronic conditions, motivation likely leads to greater initiative to search for employment. In addition, motivated people receive more guidance or support to find a job, and coaches and employers react positively to motivated individuals.

An explanation for a lower motivation may lie in the fact that the young adults do not consider themselves as capable of work and, therefore, do not have the ambition to be employed. Young adults with parents who indicate work as important for their child were significantly more successful in the labour market. This result could be clarified in several ways. Parents may improve young adult’s motivation and set goals for them through motivational conversations and encouragement. Another explanation could point at extra parental support in finding and maintaining a job. Those parents who consider their child’s work participation more important may put extra effort themselves in job arrangement and support on the work floor. It is unknown if parents who consider work less important for their child do so because of realistic expectations of the child’s capabilities or just because of lowered expectations and overprotection. There seems to be a delicate balance between the importance of parental support for disabled young people on the one hand, and their occasional tendency to underestimate their youngster’s capabilities on the other.

To assist parents in the guidance of their child, it is important that, from a young age, the future of these children and adolescents is discussed with parents in a positive, but realistic light. Youth with disabilities typically have less involvement in work experiences than their peers during high school and often encounter barriers when striving for independence. In this study, only a small minority (46.1%) of the young adults with disability benefits had a paid job during high school.

Our results didn’t give a clear picture of factors associated with successful employment and therefore suggest that there is a complex relationship among demographic factors, treatment, and psychosocial functioning and employment. There are a lot of aspects influencing the individual employment outcomes. Early, tailored solutions are needed.

First, youth with chronic conditions need to be informed about what is possible and feasible for them in the labour market. Teachers and health care providers are required to pay attention to reasonable prospects for education and work. They can help to formulate realistic goals and empowering the adolescent or young adult for participation despite their limitations.

Second, youth with chronic conditions need to explore their vocational capabilities and interests. Young people with a childhood onset can be unfamiliar with their capabilities and interests. Youth with chronic health conditions typically have less involvement in household chores and work experiences than their peers during high school. Early experiences with different kinds of tasks can help to identify preferences and possibilities as well as needed adjustments in the workplace. Third, they need support to develop skills to find work. Some key challenges for young people with a chronic condition or disability include disclosing their condition to employers and asking for accommodations at work. Training programs, job search assistance and job placement could increase the likelihood of obtaining employment for young adults with chronic conditions. If these vocational preparatory efforts are not made, the child may not develop the skills, confidence and motivation to be effective in work environments. The need for support may vary depending on the underlying type of health condition, age, the level of individual functioning and environmental factors. The support needs can change over time and should be continually evaluated to provide the young adults with strategies to address their limitations in the workplace.

Periodic monitoring of young people with chronic conditions for educational or vocational delays is needed and should be expanded to include recommendations for evaluating those at high risk for poor employment outcomes. For that reason, health care providers, school supervisors and transition counsellors should be aware of possible delays and should offer knowledge about resources and vocational services available to young persons with chronic conditions or disabilities and their parents. SAVTI (Successful Academic and Vocational Transition Initiative) of the Pediatric Oncology Group of Ontario (POGO) and Emma@work (job mediation for youth with a somatic disease) of different children’s hospitals in the Netherlands are examples of valuable programs.

There are a number of shortcomings of this study that need to be addressed. First, the measurement of work participation is complicated. We used the common definition of work participation; 12 hours per week for an uninterrupted period of 6 months. However, it is known that some young adults with Wajong benefits work less hours a week for a period of years or several periods shorter than six months. Another definition of work participation might have given other results.

Second, this study examined only a limited number of factors influencing successful work participation. The prediction of successful work participation is problematic since the possible relationship of various factors with work participation is complex. There is a very wide range of sociological, psychological and
Chapter 7

Therefore, the generalizability of our findings to the whole group of young adults with chronic conditions is limited. New studies should focus on longitudinal patterns, factors of influence on (early) work participation and whether stimulating the motivation while growing up will create conditions for a better labour market position. For that purpose, the development of an accurate and complete database on the employment position of young persons with chronic conditions over years, disaggregating them for e.g. type and severity of disability, support needed, support utilized, job characteristics, gender and age is warranted. These statistics should be updated annually to be used in longitudinal studies that analyse the extent to which chronic illness affects the work participation and amount of support needed.

CONCLUSION

Survival rates for children who have a chronic disease have increased dramatically in the last 30 years and will likely further increase because of medical advancements. In the light of this enormous increase and the fact that employment conveys health and social benefits, improving employment opportunities for young adults grown up with a chronic condition should be given a high priority in society. Some factors found in this study are not changeable, but other factors like the level of support, motivation and illness cognitions can be influenced. This study gives starting points for future research and the development of interventions which could lead to successful work participation. The results indicate that more consistent, early and rigorous monitoring of the child in a lifespan perspective is needed. Screening on moments of transition e.g from primary school to secondary school, and from education to employment, can give insight in the developmental pathway of youth with chronic conditions, including vocational readiness. By identifying the vocational development and the factors that influence the work participation of youth with chronic conditions, a better match between work ability, work interventions and work demand can be found. Also, interventions aimed at vocational training (including work objectives, defining the work related need for support, coping strategies, occupational balance, finding a (suitable) job and realistic career goals should be developed and tested. It is hoped that our increasing knowledge will benefit all children and youth with health-related problems of today who are the adults of tomorrow.
REFERENCE LIST

04. Varekamp I, de VG, Heutink A, van Dijk FJ: Empowering employees with chronic diseases; development of an intervention aimed at job retention and design of a randomised controlled trial. BMC Health Serv Res 2008, 8: 224.
36. Verhoof E, Maurice-Stam H, Grootenhuis M: ACTION study. 2012. Amsterdam, Psychosocial Department, Emma Children’s Hospital AMC.
General discussion
As a result of improved efficacy of treatments and care for life-threatening pediatric conditions, the survival of children with serious congenital or acquired diseases in developed countries has increased during the last decades. With the increased rates of successful treatment and its positive effect on life expectancy, the focus has shifted to the consequences of growing up with a chronic condition for the development in youth and the adaption to adult life. Along with continued efforts to improve survival rates in childhood chronic conditions, attention must be paid to how this population manages the challenge of growing up with a chronic somatic condition and their outcomes in adulthood. It is socially relevant to determine whether the (often hidden) consequences of the success in pediatrics affect the growing up and subsequent participation and independence in society. Therefore, the purpose of this study was to evaluate the psychosocial and emotional functioning in young adults with a Wajong benefit for a childhood-onset chronic somatic condition and the factors affecting their vocational success and wellbeing. Insights herein provide the opportunity to develop preventive and supportive interventions for young people with chronic illness to prepare for independence and work participation in adulthood. This allows us to maximize opportunities for young people, despite their condition and treatment, to participate in society. The main research questions of this study were as follows:

1. How does the psychosocial developmental trajectory (course of life) of young adults with disability benefits as a result of a somatic condition compare to that of a reference group?
2. How does the Health Related Quality of Life (HRQoL) and anxiety and depression of young adults with disability benefits as a result of a somatic condition compare to that of reference groups?
3. What are the Illness Cognitions (IC) of young adults with disability benefits as a result of a somatic condition? Is there an association of IC with HRQoL, anxiety and depression in this study population?
4. Is there a difference in the psychosocial development trajectory of young adults with and without a disability benefit?
5. What are the disease characteristics, work characteristics, and work motivation of young adults with disability benefits as a result of chronic conditions and the association of those factors and IC with the likelihood of being employed?
MAIN FINDINGS

1. COURSE OF LIFE (RESEARCH QUESTION 1 AND 4)
Growing up with a chronic condition poses potential risk to the psychosocial functioning and development. Findings of this study provide evidence that young adults with disability benefits with a chronic condition demonstrate delayed developmental trajectories across the transition to adolescence and adulthood with regard to developmental milestones compared to their peers from the general population. The course of life of our study group was found to be delayed since they proved to have achieved fewer milestones in all domains (social, autonomy and psychosexual development, substance use and gambling, anti-social behaviour), or to have achieved the milestones when they were older than their peers (chapter 2). Our results of the psychosocial developmental trajectory of young females with disability benefits because of JIA underlie this finding (chapter 4). The young female beneficiaries achieved fewer milestones or reached the milestones at a later age than the peer group in the autonomy, social and psychosexual domain. Younger children with JIA seem to be able to keep up with peers at primary school level, but at middle or high school it seems to be more difficult to keep up with healthy peers. Possibly differences between children with chronic conditions and their peers become more salient in late childhood and adolescence, since developmental tasks occur more rapidly and peers becomes more important in this stage of life compared to parents and teachers. Hence, this may cause an age-associated increase of effects of the chronic illness on the development in young adulthood.

As far as we know this is the first study that compared the psychosocial developmental trajectory of young adult beneficiaries due to chronic conditions with the psychosocial developmental trajectory of young adults with chronic conditions who did not apply for disability benefits (chapter 6). The study among childhood cancer survivors (CCS) showed that young adult CCS with disability benefits scored more unfavourable in terms of milestones in autonomy, social and psychosexual development than CCS who did not apply for disability benefits. CCS with disability benefits scored less favourable than peers from the general population on 14 out of 22 milestones while the number was 6 for those without disability benefits. In young adults with chronic kidney diseases and thyroid diseases similar results were found. The young adults who did not apply for a disability benefit proved to have a more favourable development in terms of developmental milestones than those who had to apply for the disability benefit. These findings indicate that the developmental trajectory while growing up could be predictive of job participation in adulthood. More specifically, social activities with peers and having paid jobs in adolescence were associated with a smaller likelihood of applying for disability benefits in young adulthood. Though causality cannot be proven between the achievement of milestones while growing up and applying for disability benefits in young adulthood, the fact that the developmental trajectory temporally preceded the disability benefits, gives an indication. It can be assumed that this is also the case for youth growing up with other chronic conditions. This possible causality between the achievement of milestones while growing up and applying for disability benefits in young adulthood is important information for the support for youth with chronic conditions. On the one hand, we expect and hope that stimulating the achievement of developmental milestones improves the likelihood of job participation. On the other hand, we could expect that CCS with disability benefits have to deal with serious medical consequences of the disease and treatment; too serious to be able to work and having led to a hampered developmental trajectory and lower educational level.

In sum, becoming an adult can be particularly challenging for youth with chronic health conditions since managing the disease or disability conflicts their age related developmental process, resulting in a higher risk for a delay in reaching independence in adolescence and young adulthood. The findings of this study are in line with previous findings, given that we already know that young adults who have grown up with a disease are at risk for a delayed CoL compared with the peer group. Particularly the CoL of patients with end-stage renal disease and survivors of childhood cancer was found to be hampered. Our study concerned the part of those physical impaired young adults who are not able to earn a full salary as an effect of their condition and therefore applied for disability benefits. Given the fact that young adult CCS with disability benefits scored even more unfavourable in terms of milestones in their development than CCS who did not apply for disability benefits, we can consider young adults with a somatic disease or disability since childhood who have to apply for disability benefits as the most vulnerable group.

2. HRQOL AND ANXIETY AND DEPRESSION
The knowledge and measurement of HRQoL in young adults with chronic conditions is still at an early stage of development. This study helps to decline this gap in knowledge in particular for the vulnerable group of young adults with a disability benefit. We found worse HRQoL experienced by young adults claiming disability benefits compared with peers from the general population (chapter 3). The differences in HRQoL between the EMWAjong group and the reference group were substantial, especially in the physical and social domains. The considerable differences in the physical domains fit the assumption that the differences in HRQoL between people with a somatic condition and healthy
people are mainly based on physical limitations. However, the scores on the social domain indicate that social aspects also influence the HRQoL of young adults claiming disability benefits. They may feel restricted in social situations as a result of physical or emotional consequences of their conditions. This is undesirable, especially in adolescence, because close peer relationships are an important source of support for chronically ill or disabled adolescents at a time when they have to face developmental tasks and disease-related challenges. Obviously a chronic condition or disability can have large effects on well-being in young adulthood for those who have to apply for disability benefits, but much is still unknown.

Our study also points out that young adults with disability benefits scored significantly worse on feelings of anxiety as well as depression in comparison with the reference group. Almost double the proportion of the study group was at risk of an anxiety disorder, and for a depressive disorder the proportion is almost threefold, which are alarming numbers. Several studies found similar results in adolescents and young adults with chronic conditions that started in childhood. Our finding is also in line with results in adult populations. In the Netherlands, 40 percent of all adults with a chronic illness or disability had a high risk of psychiatric problems such as anxiety or depression. This percentage was significantly higher than the 20-25% found in the general Dutch population in 2005.

Individual differences in emotional functioning and psychological distress may be related to the adjustment of young adult beneficiaries in young adulthood. Also, previous research has shown that the course of life of young adults with a chronic condition is related to their quality of life. In particular, the social development appears to be associated with the perceived quality of life in young adulthood. Moreover, emotional functioning and psychological distress seems to be related to work participation of young adults with disability benefits. Young adults with disability benefits who participated in the workforce reported a better HRQoL than those without successful work participation. And those who have ever worked feel less depressed than young adults with disability benefits who have never worked successfully at the labour market. For this reason, and also in the light of the increasing number of young adults with a chronic disease reaching adulthood because of medical advancements, it is very important to pay attention to the emotional consequences of chronic somatic conditions in an early stage.

3. ILLNESS COGNITIONS
This study provided the first findings on generic illness cognitions of young adults with a childhood-onset somatic condition (chapter 5). In line with previous studies in adult populations, the used questionnaire showed strong internal consistency and reliability in our study group. A rather high level of acceptance and perceived benefits was found, indicating that the majority of the young adults with disability benefits in this study have learned to live with their illness or disability and even perceive some long-term beneficial consequences of their conditions. The fact that their chronic condition has limited them since childhood may have influenced their acceptance and perception of the possible benefits in a positive way. Helplessness in contrast, a cognition with a substantial negative impact, was present in more than half of the respondents. This indicates that the young adult beneficiaries in this study feel an inability to control a particular situation and emphasize the negative aspects of their condition in daily functioning, which is related to deterioration of their physical and psychological functioning.

Furthermore, our findings indicate that the illness cognitions of young adult beneficiaries are relevant for their psychological functioning. The illness cognitions acceptance and helplessness were associated with HRQoL as well as with feelings of anxiety and depression in young adults with a disability benefit because of a chronic somatic condition. Though the direction of the correlation could not be established, it is plausible to assume that acceptance of the illness or disability, learning to live with it, influences HRQoL positively and reduces feelings of anxiety and depression. Lebovidge et al found similar results among youth with chronic arthritis—a more positive attitude toward illness was associated with lower levels of anxiety and with depressive symptoms. However, depression and anxiety can affect cognitions as well. Stronger feelings of helplessness appeared to be associated with worse HRQoL and higher levels of anxiety and depression. Young adult beneficiaries experiencing a great deal of helplessness are more likely to see their futures in adulthood as uncertain which could be a risk factor for the development of psychological distress over time. Again, the direction of the correlation could not be established.

The finding that illness cognitions of young adult beneficiaries are associated with their emotional well-being is also in line with studies in adults with chronic illness. The modest contribution of disease-characteristics to HRQoL, anxiety and depression, supports the notion that there is only a weak relationship between biomedical parameters and psychosocial well-being. Illness cognitions on the other hand, do contribute considerably to individual differences in young adult beneficiaries regarding their psychosocial well-being and possibly long-term adjustment. This means that health care providers are increasingly called upon to help children, adolescents and young adults to cope with the psychological and social aspects of a chronic condition. To do so it is important to assess the attitudes and cognitions toward illness among youth and to develop.
interventions to help youth cope with their conditions, and providing interventions to accept their situation.

4. WORK
Although some young adults with disability benefits as a result of chronic conditions since childhood make a good adjustment to working life, many others struggle with the impact of their condition on work participation. These young adults are at the very beginning of their vocational career, but they already have trouble with entering and staying at the labour market (chapter 7). This study found differences between young adults with disability benefits who are successful at the work force compared to those who are not, regarding the need for support at work, feelings of helplessness, parents who consider work important for their child and work motivation.

We found that only a small minority (46.1%) of the young adults with disability benefits had a paid job during high school. This is in line with other studies; youth with disabilities typically have less involvement in work experiences than their peers during high school and often encounter barriers when striving for independence. In line with this, it is alarming that many of the young adults with a range of chronic conditions or disabilities do not work as much as they are able to in young adulthood. Even though all respondents in this study are declared capable of work, only a minority of the respondents have had a paid job since they applied for disability benefits (38.2%). In other words, the majority ‘grows into disability benefits’ and is at risk of worse vocational outcomes regardless of the specific health condition.

Many young adults with disability benefits – successful in the work force or not – reported to need work adjustments to be able to participate in the work force. Adjusted working hours, adjustment in the work place and transport to work were the most frequently mentioned adjustments, especially by those unsuccessful in the work force. The need for support at work was significantly higher in those who have been successful at the labour market. Further, young adults without successful work experience reported significant more feelings of helplessness, a cognition with a substantial negative impact. This might indicate that the young adult beneficiaries without work feel an inability to work or to get employed. Also, the young person’s own motivation turned out to be an important ingredient in occupational outcomes. Those with a firmer work motivation are more likely to participate successfully on the labour market. This is in line with studies which have found that having high aspirations is associated with better employment outcomes in early adulthood, independently of other characteristics such as parental background or schooling. Among the young adults with chronic conditions, motivation likely leads to greater initiative to search for employment. In addition, motivated people receive more guidance or support to find a job, and coaches and employers react positively to motivated individuals. An explanation for a lower motivation may lie in the fact that the young adults do not consider themselves as capable of work and, therefore, do not have the ambition to be employed. Young adults with parents who indicate work as important for their child were significantly more successful in the labour market. It is unknown if parents who attach less importance to the work participation of their child do so because of realistic expectations of the child’s capabilities or just because of lowered expectations and overprotection. There seems to be a delicate balance between the importance of parental support for disabled young people on the one hand, and their occasional tendency to underestimate their youngster’s capabilities on the other.

Our results didn’t give a clear picture of factors associated with successful employment and therefore suggest that there is a complex relationship among demographic factors, treatment, and psychosocial functioning and employment. Some factors found in this study are not changeable, but other factors like the level of support, motivation and illness cognitions can be influenced. This study gives starting points for the development of interventions which could lead to successful work participation. Screening on moments of transition e.g from primary school to secondary school, and from education to employment, can give insight in the developmental pathway of youth with chronic conditions, including vocational readiness. By identifying the vocational development and the factors that influence the work participation of youth with chronic conditions, a better match between work ability, work interventions and work demand can be found. Also, work interventions aimed at vocational training (including work objectives, defining the work related need for support, coping strategies, occupational balance, finding a suitable job) and realistic career goals should be developed and tested.
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<td>Young adults with disability benefits reported worse HRQOL than the reference group in all eight domains of the RAND-36 except for General mental health.</td>
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**TABLE 1: Summary of the results of the studies presented in this thesis**

- **Purpose:** The beneficiaries reported worse HRQOL than the reference group in all eight domains of the RAND-36 except for General mental health.
- **Measures:** The beneficiaries achieved fewer milestones or achieved the milestones at later age than the reference group, in the autonomy, social and psychosexual domains.
- **Main results:** In conclusion, young adults with disability benefits are at risk for impaired HRQOL and a delay in their psychosocial developmental trajectory.
Chapter 7

Purpose

Work characteristics, illness cognitions and work motivation of young adults with disability benefits and the association with the likelihood of being employed.

Sample characteristics

- Young adult beneficiaries N=353 of which information about work was available
- Age at study: M=25.0 yrs (22.5–30.9)
- 66% female
- Successfully employed N = 135 (38.2)
- Unsuccessfully employed N = 218 (61.8)

Measures

- Course of life questionnaire (LVJV)

Main results

- Compared with the reference group, both CCS with and CCS without disability benefits had lower scale scores in the social and psychosexual domain.
- CCS with disability benefits had lower scale scores in the social and psychosexual domain than CCS without disability benefits.
- CCS with disability benefits scored less favourable than the reference group on 14 out of 22 psychosocial developmental milestones.
- CCS without disability benefits scored less favourable than the reference group on 6 out of 22 psychosocial developmental milestones.
- In conclusion, CCS with an unfavourable developmental trajectory while growing up were more likely to apply for disability benefits in adulthood than CCS with a more favourable development.
METHODOLOGICAL CONSIDERATIONS AND DIRECTIONS FOR FUTURE RESEARCH

METHODOLOGICAL CONSIDERATIONS

The EMWAjong-study elaborates on the current literature by focussing on the consequences of growing up with a chronic disease on psychosocial development, emotional well-being and employment in a population of beneficiaries with somatic conditions. The use of a uniform measurement at one time point, including different diagnosis groups with age of the respondents ranging from 18-30 years old, led to a comprehensive set of information of a relatively large sample of Wajong beneficiaries with somatic conditions. However, the results of the EMWAjong study must be considered in light of a number of limitations. First of all, the cross-sectional design of this study made it impossible to distinguish ‘cause and consequence’. Moreover, this study is not inclusive, there may be other factors that affect psychosocial functioning, emotional well-being and labour participation, for example the amount of received support, personality, other medical characteristics and attitudes towards employment.

With regard to the generalizability of the results it should be noted that the act Wajong is a Dutch benefit; most countries have no specific benefit for young disabled people. Therefore, it is advisable to be cautious and conservative while interpreting results of this study and extrapolating the findings to a larger population or to other countries. In this regard, the response rate of 20% is also a limitation, though it is important to notice that this is a very average response rate among young adults with disability benefits. Due to the growing interest in the labour market position of young adults with disability benefits, they are often invited to participate in several studies. Moreover, it is possible that respondents did not fill in the questionnaire because the invitation letter was sent by the benefits agency. Although the questionnaire was anonymous, beneficiaries might be afraid of losing their benefit. Alternatively, those with better psychosocial functioning or emotional well-being might be less eager to participate because of reluctance to feel stigmatized. In addition, among those who did participate social desirability could be a threat to the validity of the results in this study. As a result of the non-responders bias there may be an under- or overestimation of the results of this group and this limits the possibility to generalize our findings to the whole group of young adults with a chronic somatic condition. As a result of the need to respect the privacy of the beneficiaries, we were lacking the information regarding the non-responders to be able to pronounce upon a potential selection bias.

Regarding the generalizability of the results, it should also be noted that, not all young adults with chronic conditions apply for a disability benefit. Individuals with an adequate level of independent functioning may not deem it necessary to apply for a disability benefit. It is unknown which part of the young adults with a chronic condition in the Netherlands apply for disability benefits. As we only included those young adults applying for a disability benefit, it is not possible to generalize our results to young adults with chronic conditions not applying for disability benefits. And additionally, our study focussed on those who applied for disability benefits because of somatic conditions. For that reason the results cannot be extrapolated to other groups with a Wajong benefit.

One should realize that the conclusions were based on the results found in a highly heterogeneous study population, consisting of numerous diagnoses with various levels of illness severity and consisting of young adults suffering from more than one medical condition. Due to the study design we were not able to determine whether the conclusions are applicable to specific disease categories. Also, the variety of chronic somatic conditions in the research population prevents the identification of high risk subpopulations within this population of young adult disability benefit recipients. Although we did control for some disease characteristics in this study, disease characteristics merit greater attention as potentially mediating variables in future research.

Another methodological limitation concerns the questionnaire used. It was developed for the EMWAjong-project and included validated instruments, with adequate psychometric properties, as well as a number of questions adapted from other questionnaires, and questions developed by the researchers. For the questions developed by the researchers no information regarding reliability and validity was available. The clarity and applicability of the questions was pre-tested by 10 respondents who met the inclusion criteria, and based on their comments, the questionnaire was adjusted. The final questionnaire consisted of six parts which contained multiple questions. The length of the questionnaire could have led to a lower completion rate and poorer quality responses as a result of respondent fatigue. Furthermore, to complete the questionnaire the respondents must have been able to read and understand the questions. This could have resulted in an underrepresentation of respondents with a low education level.

The measurement of work participation is complicated. We used the common definition of work participation; 12 hours per week for an uninterrupted period of 6 months. However, it is known that some young adults with disability benefits work less hours a week for a period of years or several periods shorter than six months. Another definition of work participation might have given other results. In addition, the prediction of successful work participation point out to be problematic since the possible relationship of various factors with work participation is highly complex, and we could only study a number of possible determinants.
The use of a self-report measure and a single informant increased the possibility of finding relations that are in fact the result of shared method variance, meaning that the association between constructs may be due to the method used. In future research this problem could be solved by using a combination of for instance self-report and observations and multiple informants. In addition, it is worth considering alternative methods of data collection. In this study a quantitative research method was used. However, qualitative methods enable exploration of the complex processes and experiences of young adults and could offer a deeper understanding of the everyday challenges of youth growing up with chronic conditions.

**DIRECTIONS FOR FUTURE RESEARCH**

Future research should focus on the very long-term effects of growing up with a chronic somatic condition. It is socially relevant to know how those children with a chronic somatic condition since childhood go further in the rest of their (adult) life. It is important to study whether the disparities between those with and those without a childhood onset somatic condition change when growing older. For example, from dialysis patients with end stage renal disease since childhood it is known that after the age of 30 years, a substantial proportion of nearly two-third had remained employed, despite their deteriorating physical condition. This could also be the case for other groups. It is important to monitor youth with chronic conditions – with and without benefits – over a (life) long period. It is also important to identify those most likely to develop difficulties and which factors are associated with these difficulties. This study gave a point of departure. There are, however, other interesting factors that may affect the psychosocial development, the emotional well-being, social participation and labour participation, for example, coping skills, personality, the amount of received support, attitudes towards employment, parental support. Research on the relation of medical characteristics with developmental trajectory and disability benefits is also warranted.

Future research should also focus on whether stimulating the achievement of developmental milestones while growing up will create conditions for a better labour market position. We need longitudinal research focussing on life course into adulthood and person–environment interactions. In addition, we need to know who would benefit from support and what kind of support is most effective, specific to the psychosocial development, quality of life and work force participation. More consistent, early and rigorous monitoring of the child in a lifespan perspective is needed. Screening on moments of transition can give insight in the developmental pathway of youth with chronic conditions. This should be a component in medical guidelines.

Screening on moments of transition e.g. from primary school to secondary school, and from education to employment, can give insight in the developmental pathway of youth with chronic conditions, including vocational readiness. By identifying the vocational development and the factors that influence the work participation of youth with chronic conditions, a better match between work ability, work interventions and work demand can be found. Also, work interventions aimed at vocational training (including work objectives, defining the work related need for support, coping strategies, occupational balance, finding a (suitable) job) and realistic career goals should be developed and tested. The development of an accurate and complete database on the employment position of young persons with chronic conditions over years, disaggregating them for e.g. type and severity of disability, support needed, support utilized, job characteristics, gender and age is warranted. These statistics should be updated annually, to be used in longitudinal studies that analyze the extent to which chronic illness affects the work participation and amount of support needed.

In sum, the whole area of work is under-researched and lacks funds to do so. The outcomes for disabling conditions arising out of childhood need to be known, as this may have direct influence on the planning of medical interventions and availability of support. Also, insight in the influence, the role and the challenges of parents of a child with a chronic condition is important. With the ACTION study we made a good start in what is a very sensitive and complex area.

Further research into the field of the complex association between parental functioning and child adjustment outcomes is strongly recommended. It is hoped that our increasing knowledge will benefit all children and youth with health-related problems of today who are the adults of tomorrow.

**REFLECTIONS**

The results of this study add to the understanding of the transition to adulthood and adult experiences and outcomes of young adults with disability benefits as a result of a childhood-onset chronic illness or disability. The psychosocial development, emotional wellbeing and economic position of this group are affected negatively. Three general interpretations in line with the findings may be drawn.

**REALISTIC EXPECTATIONS**

The concept of emerging adulthood is important when looking at realistic social outcomes and independence for all youth, but especially youth with chronic conditions. Emerging adulthood is a phase of the life span between adolescence and full-fledged adulthood which encompasses late adolescence and early adult-
The existing view on youth with chronic conditions or disabilities is largely out a childhood onset. It is important that our society provide the extra time and appropriate support they need to walkthrough their steps along their diverging developmental pathways. Therefore, the treatment and support must focus on person-centred and tailored actions for this vulnerable group. The Wajong population is highly heterogeneous consisting of numerous diagnoses and each diagnose can have several levels of illness severity. Besides, most young adults with disability benefits have more than one condition and their preferences and needs for support – and should not decide for them what is needed. Individualized person-centred care, strengthening independence and wellbeing from childhood, throughout adolescence and into adulthood, should get our attention during adolescence and emerging adulthood in clinical practice.

MEANINGFUL PARTICIPATION

The existing view on youth with chronic conditions or disabilities is largely focused on medical optimization and the achievement of indicators of adulthood such as finishing education, starting a career, leaving home. Many of these indicators are normative in nature resulting in disadvantaged or ‘negative’ outcomes, or at least a delayed trajectory. Although it is very important to know the developmental trajectory of young people growing up with physical challenges in order to respond to their needs, it is of utmost importance to avoid a deficit-focused approach. All children, including those with physical limitations, are in a constant state of ‘becoming’ and the outcome is unknown.

Therefore, we need a strength-based approach focussed on positive and individualized outcomes such as citizenship and meaningful participation that are significant to all youth with chronic conditions or disabilities and their families. The interpretation of meaningful participation varies from person to person. Therefore, we need to encourage youth to explore their possibilities and preferences for education, employment, or other activities in a safe, supportive and stimulating environment right from the start. It is through positive, developmentally appropriate life experiences throughout their childhood and adolescence and regular opportunities for participation and inclusion that youth can prepare for a successful and meaningful participation in adult life.

INDIVIDUALIZED CARE

In order to realise meaningful participation for youth with somatic conditions, we need to focus on person-centred and tailored actions for this vulnerable group. The Wajong population is highly heterogeneous consisting of numerous diagnoses and each diagnose can have several levels of illness severity. Besides, most young adults with disability benefits have more than one condition and every individual has personal needs and preferences. An approach that’s helpful for one person could be unsupportive for another. Consequently, various levels or types of care, support and interventions may be needed. We should ask children, adolescents and young adults with chronic conditions, at any time, about their preferences and needs for support – and should not decide for them what is needed. Individualized person-centred care, strengthening independence and wellbeing from childhood, throughout adolescence and into adulthood, should get our attention during adolescence and emerging adulthood in clinical practice.

CLINICAL AND SOCIETAL IMPLICATIONS

In order to maximize opportunities for young people growing up with chronic somatic conditions and to realise meaningful participation in society several adjustments – in different areas, on different levels – in the care for those with a childhood onset are needed.
PHYSICAL, PSYCHOSOCIAL AND EMOTIONAL CARE IN A LIFESPAN PERSPECTIVE

The approach in the medical context is frequently focused on the physical consequences of the somatic condition and its treatment instead of the patient’s emotional well-being and social outcomes. In our traditional biomedical approach the focus, appropriately, is on stopping, limiting or at least controlling the disease, for example, ensuring acceptable blood glucose levels in diabetes mellitus, or ‘fixing’ the impairments in persons’ body function and structure, for example, reducing the incidence of bladder infections in spina bifida. To do so, pediatricians measure and weight their patients to monitor the physical growth and health of their patients. There are growth curves and other markers which can indicate whether there is a deviation from the norm. However, the results of this study show that all health care providers currently treating children with chronic conditions should pay systematic attention to their medical but also to their emotional and psychosocial development as well. In other words, health care providers’ awareness of the effect of growing up and living with childhood illness and disability in all aspects of life is essential. They can incorporate physical, psychosocial as well as emotional outcomes by aiming at optimal living and participation in society.

If possible, it is important to monitor the psychosocial development and symptoms of psychological distress in an early stage, prior to adolescence when differences in for example autonomy behaviour may appear more salient. This would provide a chance to recruit patients with significant risks for an unfavourable psychosocial or psychological outcome for interventions to avert possible negative consequences, such as social problems, academic problems or the development of psychopathology. But also in adult healthcare, attention to possible risks of consequences of the condition and its relation to well-being and social participation seems sensible for people with chronic conditions. This is particularly important since it is known that patients with a childhood-onset are at increased risk for a delayed course of life and of educational, vocational, and social problems during lifespan. Therefore, the focus should be a lifespan perspective of care.

To achieve optimal support for these young people, health care workers should have knowledge about possible gaps in the course of life and the emotional and social wellbeing of their patients. In order to do so, systematic assessment of the ongoing emotional, psychosocial, educational, and vocational needs during the developmental process should be an integral component of the comprehensive care of chronically ill or disabled patients with a childhood-onset. To systematically assess psychosocial and emotional functioning and to monitor this over time Patient Reported Outcomes (PROs) can be used by professionals in pediatric and adult health care through computerized and web-based applications. By using patient reported outcomes (PROs) such as developmental milestones, emotional well-being and HRQoL questionnaires in daily clinical practice care, physicians, psychologists, and nurses can adequately identify the specific problems in different domains of people growing up with chronic conditions. Systematically reporting PROs to the pediatrician during the consultation can facilitate communication about HRQoL and the psychosocial and emotional development. When psychologists and physicians work together, PROs can be used to closely monitor youth with chronic illnesses in a multidisciplinary context and referral to psychosocial interventions can be better facilitated.

This developmental care should be continued during the health care transition and in adult health care.

THE ROLE OF HEALTHCARE PROVIDERS

Health care providers – e.g. physicians, nurses, psychological care givers – are in a good position to guide their patients in dealing with a childhood-onset health condition while aiming at social participation and life satisfaction. By guiding the patient and their family members through the important tasks of childhood, adolescence and young adulthood, the health care providers can set the stage for the patients to live a satisfactory life. They can help the youngsters and their families to develop positive attitudes and realistic expectations about their abilities in a society where self-sufficiency and independence receive widespread recognition and social endorsement. Health promotion, healthcare regimen education, peer contact, early vocational awareness, education, alternatives to work, and leisure time use could be topics to discuss. There are also needs for sex education, preparation for parenthood, and genetic counselling. To provide appropriate guidance of the children with a chronic condition and their families, health care providers should view the patient in the context of his or her life; as an integrated individual in a system of family, friends, school, work and society. However, owing to the continuous specialization in health care and lack of time, the main focus and goals of treatment in pediatrics are focussed at the control of a disease and its symptom in isolation. Therefore, it is recommended that all physicians apply the World Health Organization’s International Classification of Functioning, Disability and Health framework which focuses on functioning in society. This will help them understand youths’ functioning beyond the medical diagnosis, to address the sometimes complex interaction between person and environment and to develop a comprehensive care plan based on the youths’ needs in paediatrics and beyond. In rehabilitation care this approach is more common and could serve as an example in pediatric care more generally.
Consequently, there is a need for more effective training of healthcare professionals working with persons growing up with a childhood condition. Pediatricians need competences such as skills in ‘communication’, ‘collaboration’ and ‘health advocacy’ as much as their ‘medical expertise’ to help youth with chronic conditions. Educational training programmes for health care professionals in pediatrics and adult health care are needed to create an optimal blend of knowledge, skill, attitudes, and experience in the medical and social issues of persons growing up with a childhood condition. This investment might be well applied, as the health care should be more efficient and effective. Provided that such investment secures better outcomes on individual level and - in the end - societal level, investments should pay off in the long run.

HEALTH CARE TRANSITION

The ‘lifespan perspective in a continuum of care’ becomes increasingly important when young people with chronic conditions have to leave pediatrics and transfer to adult medicine. Although moving on to adult care is seen by most youth, parents and health care providers as a positive step on the road towards adulthood, virtually all studies on youth with chronic conditions or disabilities indicate that the reality is that transition remains problematic. It is important to warrant a health care continuum serving the development of people with a childhood onset. Next to the transition in care all other topics that have been discussed in pediatric practice must continue in adult health care since most patients are developmentally delayed at the moment of the transfer. In line with all the transitions young people with a childhood onset have to make, the process of health care transition should start early with a lifespan perspective to development. Also, special attention should be paid to the transfer readiness. Not all adolescents are ready for the transfer to adult health care at the same time. Repeated discussions on the health care transition could further enhance the readiness for the transfer to adult care. In addition, valuing the personal characteristics of youth and identifying their needs, wishes and aspirations for health care and societal future is very important to provide effective transitional care in an individualized way.

Due to the cultural and organizational differences between pediatric and adult services there are many potential barriers to achieve a successful health care transition. Van Staa et al. noticed a discrepancy between the priorities of health care professionals in the transition from pediatrics to adult care and the way in which transition of care is being practiced at the moment in the Netherlands. According to the health care professionals, promotion of self-management and social participation are important areas for improvement. Structural interventions aimed at preparation for transition of care and promotion of more independence are rare. Essential elements of a transition program such as transition protocols, individual action plans, and the use of a transition coordinator or transition clinic need to be implemented. Tailored, joint plans are the basis for sound health care planning complemented with a focus on education, social integration, independent living, vocational training, and employment. Sound transition planning for young people with chronic conditions can integrate these areas in health care by connecting pediatric and adult health care. During this process the health care team will play a role both as a referring care giver and as a coordinator of services for the child and family.

FAMILY

Family perspective

Another important issue in health care for young people growing up with chronic conditions is the young adult within the family perspective. Pediatric conditions affect the entire family. The experience of a pediatric illness or disability challenges the balance within the family system and probably disrupts all family members. Although there is a considerable body of research related to the problems of children with chronic conditions, less has been written about the impact of their physical impairments on family dynamics as the child moves through adolescence into adulthood.

Being a parent of a child with a chronic condition may have several emotional, physical and social consequences. As children mature and become more capable, most young people pursue advanced independence. In families with children with chronic conditions this road to independence can be extremely stressful, especially if a child does not become successfully independent when expected. Parents may express major concerns about the child’s physical prognosis and how it would affect future educational and work prospects, social interactions, emotional well-being and requirements for physical care. Parents of a chronically ill child, especially mothers, report high levels of anxiety and depression which in turn influences the parent-child interaction. For example, maternal depression is found to be associated with a more negative mother-child relationship and parental depressive symptoms were found to reduce concern for children’s feelings and interests. Parental psychosocial problems may also have an effect on the physical health of the chronically ill child. For instance, maternal depression was found to influence the child’s adherence to therapy, and asthmatic children of caregivers with a depressive or anxiety disorder had lower pulmonary function and asthma control. In a study in children with sickle cell disease, a direct association was shown of parenting stress with disease severity and healthcare utilization of their child.
Beside emotional impact, having a chronically ill child also influences family and social life as parents provide most of the daily care for their children. This daily care involves management of the illness or disability, which can be complex and is increasingly transferred from the hospital to the home (e.g., home dialysis, intravenous alimentation). Further care giving tasks comprise finding and coordinating appropriate care for their child, incorporating the care into family life, managing the consequences on siblings, and keeping the responsibilities of caring in balance with personal needs. In general, being a parent of a child with a chronic disease is a risk factor for experiencing negative consequences on HRQoL, employment and leisure activity time. In addition, for some parents responsibilities and the burden of care for the child will increase instead of decrease as the child ages and moves to adulthood. They contribute sizable material and emotional support through their children’s late twenties and into their early thirties.

Research on the psychological impact of having a brother or sister with a health condition has been sparse too. The sibling relationship is one of the most intense, influential, and lengthy relationships in our lifetime. Siblings have a powerful influence in shaping each other’s identity. When one sibling is seriously ill or disabled, the impact would be profound on the others. Healthy siblings also face multiple challenges in growing up with an impaired sibling, such as exposure to the physical and emotional pain of their brother’s or sister’s condition, fear, parental distress, and extended separation from the ill child and the parents because of hospitalizations. Studies have found siblings to be poorly adjusted to childhood chronic illness and disability, reporting increased behavioural and social problems, high levels of anxiety and restriction of family activities. In contrast, other researchers found siblings coping well by the experience of having an ill sister or brother or unclear findings have been reported. A meta-analysis of Sharpe and Rossiter found psychological functioning (i.e., depression, anxiety), peer activities, and cognitive development scores were lower for siblings of children with a chronic illness compared to controls. Illnesses that impact on the daily functioning of the sibling have the most profound impact on their wellbeing. Also, the awareness that they might have to take care for their brother or sister when their parents are no longer capable to do so, could be experienced by the siblings as a serious burden.

In general, families are often overburdened in extending support to children with chronic conditions as they make their way through this extended process of becoming an adult. Health care providers should view the child, adolescent or young adult with a chronic condition in the context of his or her family. An awareness of the effect of living with childhood illness and disability on parents and siblings is essential to healthcare professionals to give the information and support which they need and to match the level of risk to appropriate interventions. Unfortunately, research has shown that it is hard to integrate approaches such as family-centred services and long-term care for the child, in health care services. PROs can be used to screen for risk within the family. Such family screening tools are scarce in pediatric psychology. Recently, the Psychosocial Assessment Tool (PAT) is developed, which is a brief parent-report screening tool of psychosocial risk (e.g., financial resources, social support, stress reactions, child problems, and sibling problems) in families that cope with pediatric illness. The PAT is described as a promising screening tool in families of children with cancer, kidney transplantation, inflammatory bowel disease and sickle cell disease.

The role of parents: overprotection and lowered expectations
A growing body of evidence supports the association between parental/family functioning and child adjustment outcomes in childhood chronic illness. The achievement of independence is an important issue in the upbringing of all children, but in the case of a child with chronic condition it appears to play an extra important role. Parents of children with a childhood onset disease often use a planned approach in order to stimulate the independence of the child. They encourage and stimulate the child’s progress to the next level of development, one step at the time. Some parents indulge their children since these children already have to deal with the challenges of their condition, other parents are very strict on their children to prepare them for a rough world. In a study among parents of children with disability benefits, the ACTION-study, it was found that almost all parents use their own knowledge, experience and skills to compensate the limited knowledge, experience and skills of their children with disability benefits. Their help was sometimes successful in reaching the goals of their child. Also, the children of parents who attached more importance to independence and work, appeared to be more likely to have passed the psychosocial development milestones (including independence and social development) and to have paid work. Causality cannot be proven as the direction of the relationship is not known and many other factors play probably an important role, such as the physical capabilities of the young adults. For example, if independence and work for the young adult is not realistic, it is likely that parents adjust their expectations and goals. Their attitude towards the child’s independence and work could be based on what parents deem feasible for the child. The other hand, parents may have unrealistic expectations of their child. Realistic expectations are helpful, too low expectations are not. The consequences of unrealistically lowered expectations are multiple and can cause low self-esteem, poor decision making abilities, and less personal control.
Parents of young people with chronic physical illness are, on average, more overprotective than other parents, possibly leading to adjustment problems in their child caused by limited autonomy development. Parents who overprotect the child with a disease or disability will continue to overprotect as the child enters adolescence and young adulthood and inadvertently promote dependence on others. Overprotection inhibits the child from developing the personal skills needed to cope with the extra challenge of the chronic condition. In addition, overprotective parents may avoid talking with their children about negative emotions related to the disease, such as anxiety for the course of the illness, sadness about victimization by peers, and uncertainty about the future.

The way parents deal with the condition of their child (illness cognitions) and their burden of care provide clues for early detection of emotional problems (anxiety and depression) in parents. The knowledge that the care for their children is for ever can be very stressful. The following risk factors for parental emotional problems emerged from the ACTION study: insufficient support from family, problems with their own health, insufficient acceptance of the condition of the child and the feeling that the child's condition determines their lives. Positive feelings and acceptance of the condition reduced feelings of anxiety and depression. All parents report that it is very hard to support their children in a balanced and useful way and to take their own perspective into account as well. In sum, many parents are worried about the future of their child, and they may have difficulties balancing protection and realistic stimulation of their child. Lowered expectations and overprotection of the child with an impairment can result in a life time of underachievement and failure to reach their full potential. Effective parenting is characterized by providing useful support to their child, while avoiding unrealistic low expectations or overprotection. This is of utmost importance during adolescence and emerging adulthood; the period of trying out different possibilities in different aspects of life. However, finding this balance is already difficult for parents of healthy children, not to mention for parents of children with a chronic condition. Parents need support in these areas; how to effectuate optimal parenting of a child with a chronic condition? Although the available research evidence is far from conclusive, the reported impact of parent’s functioning on child adjustment does support the need to target parenting in interventions for youth with chronic conditions. Systematic attention to the well-being of the parents, their burden of care and the way they deal with the child’s condition is needed.

**POLICY**

The social security system of the Netherlands is based on social insurances and supplementary income support provisions. The main principle of the system is that all members of society must be able to play an equally active role in society. The government states that social rights and duties are two sides of the same coin, which means that those who are capable to work must work. In recent years a paradigm change in Dutch vocational policy took place from ‘protection’ to ‘participation’. Paid work is now explicitly valued above income compensation. This is partially due to the increase in the total cost of social assistance, and because employment is seen as an important condition for the wellbeing of individuals and society.

Certain groups may need support in finding their place in the labour market. The Dutch government has a task to create conditions for an inclusive society in which young people with health problems or disabilities can participate in the labour market and in society in general. To stimulate employment, the government should base the policy and laws on the notion that impaired people must be enabled to participate. The policy and laws have a high symbolic value because it stands for welcome signals from society. However, the legislation for the group of young people with chronic conditions changed three times in the last seven years. During this period, the indications for benefits have gradually been redefined more strictly and access to support has been tightened. These mixed signals – assigning importance to participation in society along with reducing support for young people with health problems or disabilities at the same time – might indicate that our society does not know how to deal with a group of young people unable to participate in the work force in the common way.

These dual signals can be seen in the new legislation once again. The Participation Act will enter into force on 1 January 2015 (see appendix). One of the goals of the new Participation Act is to enhance participation in the labour market by people with a disability. However, from 2015 on, only disabled young persons who are fully and permanently incapacitated to work are eligible to the Wajong. The group of persons currently receiving Wajong benefit payments (everyone admitted before 1 January 2015) will be assessed on their ability to work. Persons receiving Wajong benefit payments who do not have the ability to work will keep their benefit payments of 75 percent of the statutory minimum wage (SMW). Persons receiving Wajong benefits with the ability to work will be entitled to another social security benefit which means a decrease in their income to 70 percent of the SMW as from 1 January 2018. Municipalities are given a central role in the implementation of the Participation Act. The municipalities will be responsible for the provision of benefits and reintegrations of new young disabled persons with the ability to work, and for a sheltered employment scheme for those who cannot perform regular work. Although additional funds will be made available to assist this group in getting a job, finding competitive
employment and gaining financial independence may be very hard for the most part of young adults with chronic conditions since the decentralization is also expected to generate additional savings. The efforts on improving the likelihood of successful participation of young adults with chronic conditions in the labour market are at odds with the goal of additional savings. Lobby organizations for the handicapped and large employers organizations are critical of the initiative and claim that it is doomed to fail because it will sideline several groups of handicapped people. Notwithstanding the positive, effective components in this regulation this amendment is considered as a hidden cutback by many.

Other countries struggle with the promotion of labour participation of young people with health complaints as well. In the majority of European countries an increase in disability-related income support and benefits granted to young people was noted (Eurofound, 2012; www.apa.org; www.disability-europe.net). Despite the different initiatives, like the European Pact on the Equal Rights of Persons with Disabilities (2009) as well as different country policies to support young adults with disabilities to be included in the labour market, it is unclear what needs to be done to ensure increased work participation of individuals with disabilities 105.

COOPERATION BETWEEN INSTITUTES

Any debate about the consequences of the ‘pediatric success story’ must consider the impact on all different institutes involved in maximising independence and autonomy in youth growing up with chronic conditions. As the transition to adulthood evolves, so too must society’s institutions - like healthcare, schools, employers, the Employee Insurance Agency (UWV), regional and local authorities - and their mutual cooperation. The fact that young people and their families struggle with the new reality of a longer and more demanding pathway into emerging adulthood and adult life, indicates that existing institutions may need to change 83 and new co-operations have to be arranged. The existing institutions are usually designed but also restricted within certain aspects of life, as addressed by health, education and social welfare 73. However, today’s effective support can only be addressed across systems with a shared long-time perspective. Close collaboration between agencies, a transdisciplinary approach of the professionals involved and the use of key workers can be helpful in meeting the often-changing complex needs of youth with chronic conditions, as well as the needs of their parents. Even if each of the organisations involved is committed to act holistically, due to their different core business, they will still miss certain aspects relevant for the life of the adolescent and young adult 73. For different institutions to collaborate, not only are political decisions required but also the finances for the co-ordination making sure that the provided services are less fragmented or duplicated and therefore more efficient.

IMPROVING WORK PARTICIPATION

This study points out the need for early attention to the achievement of developmental milestones and the development of skills and attitudes that young adults with chronic conditions need for future employment. Therefore, caregivers, teachers and health care providers have to be aware of problems with achieving age-typical milestones and refer to psychosocial services if necessary. In addition, young people with impairments are entitled to more support regarding vocational participation before the age of 18 (when benefits can first be claimed). First, these youth need to be informed about what is possible and feasible for them in the labour market. Teachers and health care providers are required to pay more attention to reasonable prospects for education and work. They can help to formulate realistic goals and empowering the adolescent or young adult for participation despite their limitations. Second, youth with chronic conditions need to explore their vocational capabilities and interests. Young people with a childhood onset can be unfamiliar with their capabilities and interests. Youth with chronic health conditions typically have less involvement in household chores and work experiences than their peers during high school. Early experiences with different kind of tasks can help to identify preferences and impossibilities as well as needed adjustments in the workplace. Third, they need support to develop skills to find work. Some key challenges for young people with a chronic condition or disability include disclosing their condition to employers and asking for accommodations at work 94. Training programs, job search assistance and job placement could increase the likelihood of obtaining employment for young adults with chronic conditions 102-103. If these vocational preparatory efforts are not made, the child may not develop the skills, confidence and motivation to be effective in work environments 65. Health care providers, school supervisors, transition counsellors and employers should have knowledge about resources and vocational services available to young persons with chronic conditions or disabilities and their parents. SAVTI (Successful Academic and Vocational Transition Initiative) of the Pediatric Oncology Group of Ontario (POGO) and Emma@work (job mediation for youth with a somatic disease, see appendix) of different children’s hospitals in the Netherlands are examples of valuable programs 102.

On another level, employers play an important role in improving job availability, job retention and re-integration for young people with disability benefits because of chronic health problems. It are the employers who can create real work opportunities. Employers should be aware that in today’s world with adaptive equipment and high technology electronic support systems, per-
KEYMESSAGES

- Growing up with a chronic illness and/or disabilities in childhood and adolescence has consequences for the transition to adulthood and beyond.
- Young adults with disability benefits with a chronic condition demonstrate delayed developmental trajectories across the transition to adolescence and adulthood. It is important to pay continuous attention to their developmental trajectory and emotional well-being.
- More consistent, early and rigorous monitoring of psychosocial outcomes in a lifespan perspective is needed.
- Health care providers’ awareness of the effect of childhood illness and disability on the whole family is essential.
- Pediatric and adult health care professionals need an optimal blend of knowledge, skill, attitudes, and experience in the medical and social issues of persons growing up with a childhood condition.
- The treatment and support must focus on meaningful and satisfying participation in society.
- It is important to stimulate young people with disabilities to be active in work. Preparation for employment at an early age is warranted.
- Achieving linkages between the organisations of health care, education, vocational community and social services is recommended.
- Our society needs to ensure that adequate resources and support are made available to all youths with chronic conditions and their families to maximize social participation.

persons with physical limitations can be effective workers in many environments. In addition, it is important that employers realize that the motivated and dedicated attitude of employees with physical impairments can have positive effects on the attitudes and commitment of co-workers as well as on the productivity. However, employers often have misplaced concerns about possible problems and costs of employees with physical impairments and fail to recognize the potential benefits. Possibly the most impeding factor is the misplaced belief that a person with an illness or disability is not a capable person. This stigmatization has prejudiced and restricted the vocational opportunities that are available to young persons with a chronic condition and can become a self-fulfilling prophesy. This is especially difficult in the economic current climate. There is evidence of discrimination against individuals with chronic illness and disability when applying for a job and in the workplace in general. Despite governmental incentives, activation policies have not yet proven to be effective in improving the employment prospects to people on disability benefits in the Netherlands. This shows that the social and occupational integration of chronically ill or disabled young people into society can never be enforced by incentives and regulations alone. Real integration ultimately depends on attitudes, inspired by human values of solidarity. Employment of youth with chronic impairments can bring – next to financial benefits as a result of schemes from the government – enthusiasm in the company and a positive image. Clearly, the economic situation is influencing the work participation of young adults too. Although youth unemployment in the Netherlands is relatively low from a European perspective, the youth unemployment rate has risen in the Netherlands as well. In the Netherlands, the unemployment rate of young adults in general (15-25 years) has risen from 9.3% in 2008 to 15.5% in 2013 (www.cbs.nl). Young adults with chronic conditions need protection and support to prevent exclusion in this tight labour market. Therefore, it is of utmost importance that employers, municipalities and the government provide suitable employment for young adults with chronic conditions to give them a rightful place in society.
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Development of Wajong benefits
DEVELOPMENT OF WAJONG BENEFITS

1. Old Wajong
2. New Wajong
3. Participation Act

1. THE DISABLEMENT ASSISTANCE (YOUNG PERSONS) ACT; ‘OLD’ WAJONG
The General Disablement Act was abolished in 1997, and on 1 January 1998 a new Act came into force for young people and students who have become disabled at an early age and therefore do not qualify for wage-related benefits: the Disablement Assistance (Young Persons) Act, known as ‘Wajong’ in Dutch. This Act provides (supplementary) income support as well as support to find employment and if necessary support at the work place. The benefit is not obligatory or automatically including all young adults with disabilities: the initiative for application lies with the individual and his/her social environment. A Wajong benefit is payable not earlier than the 18th birthday, for as long as the inability to work lasts and ends when the recipient reaches the age of 65. The Employee Insurance Agency (UWV) implements the Act and is also responsible for determining the level of benefit paid. The level of benefit received under the terms of the Act depends on age and the amount someone can earn from a job; Wajong income support is a supplementary payment on top of what a young person with a chronic disease or handicap is able to earn from work. The UWV insurance physicians assess the work ability of the claimant considering the medical history and prognosis and describe the limitations for work. Based on the limitations assessed by the insurance physician, employment specialists investigate what jobs the claimant could perform on the labour market despite these limitations and what work opportunities are available. Depending upon the question whether or not the young disabled can theoretically earn a minimum wage with a job, a disability pension will be refused or awarded [46]. A part of those who receive a Wajong benefit is potentially (partially) capable to work. The other part is declared fully unfit for work.

2. THE WORK AND EMPLOYMENT SUPPORT (YOUNG DISABLED PERSONS) ACT: ‘NEW’ WAJONG
The previous Wajong Act has been superseded for new entrants as of 1 January 2010 by the Work and Employment Support (Young Disabled Persons) Act and is called the ‘new’ Wajong. In the face of growing numbers of young people with health problems or disabilities registering for disability benefit, the government postponed the age of eligibility from 18 to 27 years for those that are considered
to have, or be able to, develop earning capacities. This new measure includes
a first claimant assessment at the age of 18 and a final reassessment at the age
of 27. This new Wajong Act covers only those who, at the age of 18, have hardly
any productive capacity. The others have to improve their educational level
and search for a job or they will lose their financial support. Subsequently the new
Act is split into:

- a benefit measure providing a minimum income for those who are unfit
  for work;
- an employment measure with the right to receive all necessary support
to prepare for and find labour, which involves a first claimant assessment
at the age of 18 and a final reassessment at the age of 27 years;
- a study measure for those who stay at school or start a programme of
study after age 18 years with a (reduced) income support.

So the emphasis in the new Wajong Act is on what people with Wajong benefits
can do rather than what they cannot do with the aim of getting people into reg-
ular employment and removing some of the inherent disincentives to find work.
For example, claimants are no longer assessed for lifelong disability at such a
young age and there is increased flexibility in relation to earnings from work-
ing and the maintenance of benefits. The main idea behind the new law is that
most young people are still developing at the age of 18. This is also true of their
possibilities for performing work. Contrary to the old Wajong, those who find
employment under the new Wajong Act will receive a higher income because
of the new payment method. The employment measure gives the young people
with disabilities who can work the right to receive all necessary support from
the UWV to prepare for and find employment. Young adults with the ability to
work in competitive employment are subsequently referred to a reintegration
consultancy for further training, if necessary, and job placement.

3. THE PARTICIPATION ACT
The Participation Act will enter into force on 1 January 2015. The purpose of this
Act is to get more people, also the persons with an occupational impairment, to
the work. With the entry into force of the Participation Act, the municipalities
will be responsible for people with an occupational impairment and for people
who need assistance in finding work. The Participation Act will replace the three
regulations that are currently in force: the Social Assistance Act (Wet werk en
bijstand, WWB), the Sheltered Employment Act (Wet sociale werkvoorziening,
WSW), and the Invalidity Insurance (Young Disabled Persons) Act (Wet Werk en
Arbeidsziektemaatschappij Jonggehandicapten, WAJONG). The House of Represen-
tatives has already adopted the legislation for the Participation Act.

With respect to this new target group, the municipalities have the same tasks
as for people receiving social assistance benefits, namely providing support
aimed at integration into the workforce and, where necessary, income support.
For the purpose of reintegration support, the municipalities will have a com-
bined reintegration budget and more tools at their disposal. Based on the needs
of their clients, the municipalities will decide who will qualify for what type of
tailor-made support. The municipalities shall cooperate at the regional level
with the Netherlands Employees Insurance Agency (UWV), employers, and em-
ployees in regional branches of UWV WERKbedrijf (the work placement branch
of the UWV) to place people who are not able to earn the statutory minimum
 wage in jobs which will be made available by employers. As from 1 January 2015,
the benefits under the Wajong will only be accessible to young disabled persons
who permanently lack the ability to work. The UWV decides whether a person
qualifies for such a benefit.

The group of persons currently receiving Wajong benefit payments (everyone
admitted before 1 January 2015) will be assessed on their ability to work. This will
also be decided by the UWV. Persons receiving Wajong benefit payments who
do not have the ability to work will keep their benefit payments of 75 percent
of the statutory minimum wage (SMW). Persons receiving Wajong benefit payments
with the ability to work will be confronted with a reduction in the benefit pay-
ment to 70 percent of the SMW as from 1 January 2018. In order to assist this
group in finding a job, additional funds will be made available for the UWV as
from 2015. These persons receiving Wajong benefit payments will continue to be
entitled to a Wajong benefit payment. The UWV will continue to be responsible
for reintegration and the provision of the benefit payments.

The agreements in the Social Agreement imply that everyone will earn at least
the minimum wage, also those people who are not able to do so due to impair-
ment. In these cases, the employers pay the minimum wage (or, where applica-
table, the negotiated wage), but they get the difference between the minimum
wage and the actual production of this employee reimbursed through the wage
cost subsidy. The employers have agreed in the Social Agreement to guarantee
additional jobs for people with an occupational impairment. In the period up to
2026, the employers have committed themselves to gradually create 100,000
additional jobs for this target group, and the government will add 25,000 jobs
to this number. These agreements are not without obligations. The number of
jobs that have been added for people with an occupational impairment will be
counted from year to year. If the parties fail to meet their commitments, a quota
scheme will enter into force.
Summary
GENERAL INTRODUCTION

In the past, most childhood diseases were fatal for the majority of children. As a result of improved medical knowledge, technology and practices, pediatricians were able to change the natural course of numerous diseases. This resulted on the one hand in higher survival rates for many diseases, but on the other hand, in an increased number of children growing up with chronic health problems and morbidities since these children have been treated but have not been cured. In addition, the prevalence of some diseases has increased as well.

With the increased rates of successful treatment and its positive effect on life expectancy, additional challenges have emerged. Children and adolescents with chronic conditions are expected to pass through similar developmental stages as their nondisabled peers, to leave home, develop psychosocially, and define a role for themselves in the community through employment or other activities. However, a chronic condition and its treatment can have a profound influence on aspects of development during the transition into adulthood. Concern has risen about the implications of growing up with a chronic condition. They live longer, they mature, but what does it mean to grow up with a chronic illness for later societal participation as an adult in our society?

WORK

An important way to participate in social life is work. Besides money, employment offers a lot of other additional immaterial benefits like the possibility for further self-development, social relationships, development of skills, daily rhythms, and often, self-esteem and meaning in life. However, having a chronic disease or disability often negatively affects the capacity to participate in gainful employment. The labour market position of people with a chronic disease or disability is found to be problematic, with regard to getting a job as well as job continuation.

In the Netherlands, young people who are (partially) unable to work because of a chronic disease or disability since childhood may be eligible for benefit under the scheme for young disabled persons: known as ‘Wajong’ in Dutch. The numbers claiming benefits under the Wajong scheme rose from 40,000 in 1976 to 127,400 in 2000 and 238,700 in 2013. Although some of the young adults with Wajong benefits were unable to work in any way because of their limitations, others could and were willing to work. However, those young adults with a Wajong benefit who were able to work remain under-represented in the labour market.
RESEARCH QUESTIONS
The purpose of this EMWAjong study was to evaluate the psychosocial functioning, the emotional well-being and the factors affecting the vocational success and well-being in young adults with a Wajong benefit for a childhood-onset chronic somatic condition while growing up. The study was aimed at young adults with a disability benefit as a result of a somatic illness or condition. The primary research questions of this study are as follows:

1. How does the psychosocial developmental trajectory (course of life) of young adults with disability benefits as a result of a somatic condition compare to that of a reference group?
2. How does the Health Related Quality of Life (HRQoL) and anxiety and depression of young adults with disability benefits as a result of a somatic condition compare to that of reference groups?
3. What are the Illness Cognitions (IC) of young adults with disability benefits as a result of a somatic condition? Is there an association of IC with HRQoL, anxiety and depression in this study population?
4. Is there a difference in the psychosocial development trajectory of young adults with and without a disability benefit?
5. What are the disease characteristics, work characteristics, and work motivation of young adults with disability benefits as a result of chronic conditions and the association of those factors and IC with the likelihood of being employed?

METHODS
The EMWAjong study is a large cross-sectional study. All young adults between 22 and 31 years of age who claimed a Wajong benefit in the year 2003 or 2004 for a chronic somatic condition were invited to fill in an online questionnaire via a letter. The target group is a heterogeneous group with different types of health conditions and different abilities and limitations. Those with no sustainable work opportunities (classified as fully incapable for work) and serious cognitive impairment or psychiatric conditions were excluded. In total, 2,046 persons were invited to take part in the study: 415 young adults participated (response rate 20.1%). Work participation was defined in conformity with Statistics Netherlands (CBS), as performance of paid work for at least 12 hours per week for an uninterrupted period of 6 months.

RESULTS
In chapter 2, the achievement of developmental milestones while growing up is evaluated among young adult beneficiaries with somatic limitations (N=415) and compared with that of peers from the general Dutch population. The fulfilment of developmental tasks and achievement of developmental milestones while growing up, referred to as the ‘course of life’, are generally recognised to be of great importance to adjustment in adult life. The course of life of the young adult beneficiaries was found to be delayed since they proved to have achieved fewer milestones in all domains (social, autonomy and psychosexual development, substance use and gambling, anti-social behaviour), or to have achieved the milestones when they were older than their peers. The differences between the EMWAjong group and the peers were substantial.

Chapter 3 describes the HQoL, anxiety and depression of 377 young adults receiving disability benefits because of somatic conditions compared to reference groups from the general Dutch population and the factors related to their HRQoL, anxiety and depression. The young adults claiming disability benefits report worse HRQoL than the reference group from the general population. The differences in HRQoL were substantial, especially in the physical and social domains. This study also points out that young adults with disability benefits scored significantly worse on feelings of anxiety as well as depression in comparison with the reference group. Almost double the proportion of the young adults with Wajong benefits was at risk of an anxiety disorder, and for a depressive disorder the proportion is almost threefold. Better HRQoL and lower levels of anxiety and depression were associated with a positive course of the illness and the use of medical devices.

Chapter 4 reports on the HRQoL and the psychosocial developmental trajectory in 43 young female beneficiaries with Juvenile Idiopathic Arthritis (JIA). A significant impairment of HRQoL in almost all domains in young females with JIA with Wajong benefits was found. This study also shows that the psychosocial developmental trajectory of young females with JIA is delayed. These young adults achieve fewer psychosocial milestones, or achieve the milestones at an older age than the peer group. During primary school, children with JIA seem to be able to keep up with peers, as is shown by the items about the primary school, but at middle or high school it seems to be more difficult to keep up with healthy peers.

In chapter 5, the way 377 young adult beneficiaries give meaning to their illness/disability was investigated. When patients are diagnosed with an illness they generally develop an organised pattern of beliefs about their condition. These illness perceptions or cognitive representations directly influence the in-
In chapter 7, a study is presented in which the disease characteristics, work of applying for disability benefits in young adulthood. Though causality is not of job participation in adulthood. More specifically, social activities with peers of the psychosocial impact of a somatic condition in childhood on psychological some long-term beneficially consequences of their long term conditions. Helplessness in contrast, a cognition with a substantial negative impact, was present in a considerable part of the respondents. This indicates that the young adult beneficiaries in this study feel an inability to control a particular situation and emphasizes the negative aspects of their condition in daily functioning. Several disease-characteristics were associated with the illness cognitions, particularly those with a positive/stable course of illness scored higher on acceptance and lower on helplessness. Furthermore, the findings indicate that the illness cognitions of young adult beneficiaries are relevant for their psychological functioning. The illness cognitions acceptance and helplessness were associated with HRQoL as well as with feelings of anxiety and depression in young adults with a disability benefit because of a chronic somatic condition. With the recognition of the psychosocial impact of a somatic condition in childhood on psychological well-being in later life comes the growing awareness of the need to develop psychosocial supportive programs. The assessment of generic IC might be a valuable complementary tool for screening of psychological risk factors and tracing patients who may benefit from psychological interventions.

Chapter 6 presents a study about the difference in the psychosocial development trajectory of 53 young adult childhood cancer survivors (CCS) with and 313 CCS without a disability benefit, and 508 peers from the general Dutch population (reference group). The young adults who did not apply for a disability benefit proved to have a more favourable development in terms of developmental milestones than those who had to apply for the disability benefit. These findings indicate that the developmental trajectory while growing up could be predictive of job participation in adulthood. More specifically, social activities with peers and having paid jobs in adolescence were associated with a smaller likelihood of applying for disability benefits in young adulthood. Though causality is not proven between the achievement of milestones while growing up and applying for disability benefits in young adulthood, the fact that the developmental trajectory temporally preceded the disability benefits, gives an indication.

In chapter 7, a study is presented in which the disease characteristics, work characteristics, illness cognitions and work motivation of young adults with disability benefits are studied as well as the association with the likelihood of being employed. In total, 38.2% were successfully employed since they applied for disability benefits. A small minority (46.1%) of the young adults with disability benefits had a paid job during high school.

Many young adults with disability benefits – successful in the work force or not – reported to need work adjustments to be able to participate in the work force. Compared to unsuccessfully employed beneficiaries (N=218), a greater proportion of successful beneficiaries (N=135) reported a need for support at work. Successful beneficiaries reported less feelings of helplessness and had a greater work motivation and a greater proportion of the parents who considered work important for their child. When controlling for socio-demographic and disease characteristics, only the extent to which parents consider work important for their child remained significant in relation to successful employment. The results didn’t give a clear picture of factors associated with successful employment and therefore suggest that there is a complex relationship among demographic factors, treatment, and psychosocial functioning and employment.

**METHODOLOGICAL CONSIDERATIONS AND DIRECTIONS FOR FUTURE**

The results of the EMWajong study must be considered in light of a number of limitations. Limitations concern the study design, the generalizability, the highly heterogeneous study population, the questionnaires used, the measurement of work participation and the use of a self-report measure and a single informant. Based on the limitations, several directions for future research and the development of interventions are suggested. Future research should focus on the very long-term effects of growing up with a chronic somatic condition, whether the disparities between those with and those without a childhood onset somatic condition change when growing older and to identify those most likely to develop difficulties. Other factors that may affect the psychosocial development, the emotional well-being, social participation and labour participation, for example, coping skills, personality, the amount of received support, attitudes towards employment, parental support, should be studied too. Future research should also focus on whether stimulating the achievement of developmental milestones while growing up, including vocational development, will create conditions for a better labour market position and what kind of support is most effective. More consistent, early and rigorous monitoring of the child in a lifespan perspective is needed.
REFLECTIONS

The results of this study add to the understanding of the transition to adulthood and adult experiences and outcomes of young adults with disability benefits as a result of a childhood-onset chronic illness or disability. The psychosocial development, emotional wellbeing and economic position of this group are affected negatively. Three general interpretations in line with the findings may be drawn.

First, our society expects young people to complete school, find satisfying work, develop social networks, contribute to the maintenance and support of households, and participate as citizens in communities, all within a certain timetable. The question is whether this is a realistic expectation for people grown up with a chronic condition, given the fact that we know that these young people develop more slowly or do not reach all developmental milestones. Young people growing up with chronic conditions are mostly gaining their independence but not as quickly as young people without a childhood onset. It is important that our society provide the extra time and appropriate support they need to walk through their steps along their diverging developmental pathways.

Second, the existing view on youth with chronic conditions or disabilities is largely focused on medical optimization and the achievement of indicators of adulthood such as finishing education, starting a career, leaving home. Many of these indicators are normative in nature resulting in disadvantaged or ‘negative’ outcome profiles, or at least a delayed trajectory. Therefore, we need a strength-based approach focused on positive and individualized outcomes such as citizenship and meaningful participation that are significant to all youth with chronic conditions or disabilities and their families.

Third, in order to realise meaningful participation for youth with somatic conditions, we need to focus on person-centred and tailored actions for this vulnerable group.

CLINICAL AND SOCIETAL IMPLICATIONS

In order to maximize opportunities for young people growing up with chronic somatic conditions and to realise meaningful participation in society several adjustments in the care for those with a childhood onset are needed.

PHYSICAL, PSYCHOSOCIAL AND EMOTIONAL CARE IN A LIFESPAN PERSPECTIVE

To achieve optimal support for these young people, healthcare workers should have knowledge about possible gaps in the course of life and the emotional and social wellbeing of their patients. In order to do so, systematic assessment of the ongoing emotional, psychosocial, educational, and vocational needs during the developmental process should be an integral component of the comprehensive care of chronically ill or disabled patients with a childhood-onset. This developmental care should be continued during the health care transition and in adult health care.

THE ROLE OF HEALTHCARE PROVIDERS

Healthcare providers are in a good position to guide their patients in dealing with a childhood onset health condition while aiming at social participation and life satisfaction. Health promotion, healthcare regimen education, peer contact, early vocational awareness, education, alternatives to work, and leisure time use could be topics to discuss. There are also needs for sex education, preparation for parenthood, and genetic counselling. To provide appropriate guidance, healthcare providers should view the patient in the context of his or her life; as an integrated individual in a system of family, friends, school, work and society. There is a need for more effective training of healthcare professionals working with persons growing up with a childhood condition.

HEALTH CARE TRANSITION

The process of health care transition (transfer from pediatrics to adult centred medical care) should start early with a lifespan perspective to development. Also, paying attention to the transfer readiness and individual needs, wishes and aspirations for health care and societal future is very important to provide effective transitional care in an individualized way. Tailored, joint plans are the basis for sound health care planning complemented with a focus on education, social integration, independent living, vocational training, and employment.

FAMILY

Pediatric conditions affect the entire family. In general, families are often overburdened in extending support to children with chronic conditions as they make their way through this extended process of becoming an adult. Many parents are worried about the future of their child. They may have difficulties balancing protection and realistic stimulation of their child. Systematic attention to the effect of living with childhood illness and disability on parents and siblings is essential to healthcare professionals to give the information and support. Also, interventions for parents to effectuate optimal parenting of a child with a chronic condition are needed.
On another level, employers play an important role in improving job availability, job retention and re-integration for young people with disability benefits because of chronic health problems. Young adults with chronic conditions need protection and support to prevent exclusion in this tight labour market. Therefore, it is of utmost importance that employers, municipalities and the government provide suitable employment for young adults with chronic conditions to give them a rightful place in society.

**POLICY**

The Dutch government has a task to create conditions for an inclusive society in which young people with health problems or disabilities can participate in the labour market and in society in general. Certain groups may need support in finding their place in the labour market. To stimulate employment, the government should base the policy and laws on the notion that impaired people must be enabled to participate. The policy and laws have a high symbolic value because it stands for welcome signals from society. The legislation for the group of young people with chronic conditions changed three times in the last seven years. During this period, the indications for benefits have gradually been redefined more strictly and access to support has been tightened. These mixed signals – assigning importance to participation in society along with reducing support for young people with health problems or disabilities at the same time – might indicate that our society does not know how to deal with a group of young people unable to participate in the work force in the common way.

**COOPERATION BETWEEN INSTITUTES**

Any debate about the consequences of the 'pediatric success story' must consider the impact on all different institutes involved in maximising independence and autonomy in youth growing up with chronic conditions. Today’s effective support can only be addressed across systems with a shared long-time perspective. Close collaboration between agencies, a transdisciplinary approach of the professionals involved and the use of key workers can be helpful in meeting the often-changing complex needs of youth with chronic conditions, as well as the needs of their parents. For different institutions to collaborate, not only are political decisions required but also the finances for the co-ordination making sure that the provided services are less fragmented or duplicated and therefore more efficient.

**IMPROVING WORK PARTICIPATION**

This study points out the need for early attention to the achievement of developmental milestones and the development of skills and attitudes that young adults with chronic conditions need for future employment. Young people with impairments are entitled to more support regarding vocational participation. First, they need to be informed about what is possible and feasible for them in the labour market. Second, youth with chronic conditions need to explore their vocational capabilities and interests. Third, they need support to develop skills to find work. Training programs, job search assistance and job placement could increase the likelihood of obtaining employment for young adults with chronic conditions.

- Growing up with a chronic illness and/or disabilities in childhood and adolescence has consequences for the transition to adulthood and beyond.
- Young adults with disability benefits with a chronic condition demonstrate delayed developmental trajectories across the transition to adolescence and adulthood. It is important to pay continuous attention to their developmental trajectory and emotional well-being.
- More consistent, early and rigorous monitoring of psychosocial outcomes in a lifespan perspective is needed.
- Health care providers’ awareness of the effect of childhood illness and disability on the whole family is essential.
- Pediatric and adult health care professionals need an optimal blend of knowledge, skill, attitudes, and experience in the medical and social issues of persons growing up with a childhood condition.
- The treatment and support must focus on meaningful and satisfying participation in society.
- It is important to stimulate young people with disabilities to be active in work. Preparation for employment at an early age is warranted.
- Achieving linkages between the organisations of health care, education, vocational community and social services is recommended.
- Our society needs to ensure that adequate resources and support are made available to all youths with chronic conditions and their families to maximize social participation.
INLEIDING

In het verleden waren de meeste kinderziekten fataal. Als gevolg van verbeterde behandelmogelijkheden binnen de kindergeneeskunde zijn kinderartsen in staat geweest om het natuurlijk beloop van verschillende ziekten, zoals nierziekten, kanker, stofwisselingsziekten, aangeboren hartafwijkingen en taaislijmziekten, te veranderen. Dit heeft geresulteerd in enerzijds hogere overlevingskansen en anderzijds in een toename van het aantal kinderen dat opgroeit met chronische gezondheidsproblemen. Want deze kinderen kunnen weliswaar vaak worden behandeld, maar niet altijd worden genezen. Daarnaast is de prevalentie van bepaalde ziekten, zoals obesitas, astma en ADHD toegenomen.

Door de verbeterde behandelmogelijkheden en het positieve effect op de levensverwachting, zijn nieuwe uitdagingen ontstaan. Voor kinderen met chronische gezondheidsproblemen geldt dat zij dezelfde ontwikkelingsstadia doorlopen als hun gezonde leeftijdgenoten, zoals zelfstandig gaan wonen, zich ontwikkelen op psychosociaal vlak en een plek voor zichzelf creëren in onze maatschappij door middel van werk en andere activiteiten. Een chronische ziekte of aandoening kan grote invloed hebben op aspecten van de ontwikkeling tijdens het opgroeien naar de volwassenheid. Er is bezorgdheid ontstaan over de impact van lichamelijke problemen tijdens de kindertijd en adolescentie. Kinderen met chronische gezondheidsproblemen leven nu langer, ze worden volwassen, maar wat betekent het om op te groeien met een chronische ziekte of aandoening voor hun maatschappelijke participatie als volwassene in onze samenleving?

WERK

Een belangrijke manier om deel te nemen aan het maatschappelijke leven is werk. Naast geld, levert werk vaak een heleboel andere, immateriële voordelen op zoals zelfontplooiing, sociale contacten, ontwikkeling van vaardigheden, een dagelijks ritme, en een gevoel van eigenwaarde en zingeving in het leven. Het hebben van een chronische ziekte of aandoening heeft vaak een negatieve invloed op deelname aan werk. De arbeidsmarktpositie van mensen met een chronische ziekte of handicap is kwetsbaar bij zowel het vinden als het behouden van een baan.

In Nederland komen jongvolwassenen die (gedeeltelijk) arbeidsongeschikt zijn vanwege een chronische aandoening sinds de kinderleeftijd in aanmerking voor een uitkering op grond van de regeling voor jonggehandicapten (Wajong). Het aantal aanvragen voor een Wajong uitkering is gestegen van 40.000 in 1976 naar 127.400 in 2000 en 238.700 in 2013. Een deel van deze jongvolwassenen met een Wajong-uitkering is niet in staat om te werken vanwege hun gezondheids-
problemen, maar een groot aantal is dat wel en wil ook graag deelnemen aan de arbeidsmarkt. Toch blijven de jongvolwassenen een Wajong-uitkering die in staat zijn om te werken ondervertegenwoordigd op de arbeidsmarkt.

**ONDERZOEKSVRAGEN**

Het doel van de EMWAjong studie was het in kaart brengen van het psychosociaal functioneren, het emotionele welzijn en de factoren die van invloed zijn op het werk en welzijn van jongvolwassenen met een Wajong-uitkering vanwege een chronisch ziekte of aandoening sinds de kindertijd. Het onderzoek is gericht op jongvolwassenen die een Wajong-uitkering hebben vanwege een somatische ziekte of beperking. De onderzoeksvragen van deze studie:

1. Hoe verhoudt het psychosociale ontwikkelingstraject (levensloop) van jongvolwassenen met een Wajong-uitkering zich tot die van een referentiegroep van leeftijdsgenoten uit de algemene bevolking?

2. Hoe verhouden de gezondheidsgerelateerde kwaliteit van leven (gezondheidsgerelateerde KvL) en de gevoelens van angst en depressie van jongvolwassenen met een Wajong-uitkering zich tot die van referentiegroepen van leeftijdsgenoten uit de algemene bevolking?

3. Wat zijn de ziektecognities van jongvolwassenen met een Wajong-uitkering? Is er een verband tussen de ziektecognities van jongvolwassenen met een Wajong-uitkering en de kwaliteit van leven, en gevoelens van angst en depressie in deze studiepopulatie?

4. Is er een verschil in de levensloop van jongvolwassenen die opgroeiden met chronische gezondheidsproblemen mét en zonder Wajong-uitkering?

5. Wat zijn de ziektekenmerken, de werkkenmerken en de werkmotivatie van jongvolwassenen met een Wajong-uitkering en wat is de associatie tussen deze factoren en hun ziektecognities en de kans op deelname aan de arbeidsmarkt?

**METHODE**

Het EMWAjong-onderzoek is een grote cross-sectionele studie. Alle jongvolwassenen tussen de 22 en 31 jaar die een Wajong uitkering hebben aangevraagd in het jaar 2003 of 2004 vanwege een chronisch somatische ziekte of aandoening zijn via een brief uitgenodigd om mee te doen aan een online vragenlijst. Het betreft een heterogene groep met uiteenlopende ziektes en aandoeningen met verschillende mogelijkheden en beperkingen. De jongvolwassenen die volledig arbeidsongeschikt waren of een ernstige cognitieve stoornis of psychische aandoening hebben, zijn uitgesloten van deelname. In totaal werden 2046 jongvolwassenen met een Wajong-uitkering uitgenodigd om deel te nemen aan het onderzoek; 415 jongvolwassenen hebben meegedaan (respons 20,1%).

Arbeids participatie was, in overeenstemming met de omschrijving van het Centraal Bureau voor de Statistiek (CBS), gedefinieerd als betaald werk voor tenminste 12 uur per week gedurende een onafgebroken periode van 6 maanden.

**RESULTATEN**

In hoofdstuk 2 worden de ontwikkelingsmijlpalen van jongvolwassenen met een Wajong-uitkering vanwege een somatische ziekte of aandoening (N=415) vergeleken met die van leeftijdsgenoten uit de algemene Nederlandse bevolking. Het vervullen van ontwikkelingstaken en het bereiken van mijlpalen, aangeduid als 'levensloop', is van groot belang voor de aanpassing aan het volwassen leven. Jongvolwassenen met een Wajong-uitkering bleken minder ontwikkelingsmijlpalen te hebben bereikt, of op latere leeftijd, dan hun leeftijdsgenoten. Ze scoreden lager in de domeinen van de zelfstandigheidsontwikkeling, sociale en psychosexuele ontwikkeling. Ze vertoonden ook minder risicogedrag dan hun leeftijdsgenoten. De verschillen tussen de EMWAjong groep en de leeftijdsgruppen zijn aanzienlijk.

Hoofdstuk 3 beschrijft zowel de gezondheidsgerelateerde KvL en gevoelens van angst en depressie van 377 jongvolwassenen met een Wajong-uitkering in vergelijking met referentiegroepen uit de algemene Nederlandse bevolking als de factoren die verband houden met hun gezondheidsgerelateerde KvL, angst en depressie. De EMWAjong groep rapporteerde een lagere gezondheidsgerelateerde KvL dan de referentiegroep. De verschillen waren aanzienlijk, met name in de fysieke en sociale domeinen. Deze studie laat ook zien dat de jongvolwassenen met een Wajong-uitkering significant meer gevoelens van angst en depressie hebben in vergelijking met de referentiegroep. Bijna tweemaal zo veel jongvolwassenen met een Wajong-uitkering hebben een verhoogde kans op een angststoornis, en bij een depressieve stoornis was dat bijna het drievoudige. Een hogere gezondheidsgerelateerde KvL en lagere gevoelens van angst en depressie zijn geassocieerd met een positief ziektebeloop en het gebruik van medische hulpmiddelen.

Hoofdstuk 4 bespreekt de gezondheidsgerelateerde KvL en de levensloop van 43 jonge vrouwelijke Wajong-uitkeringsgerechtigden met juveniele idiopathic artritis (JIA; jeugdreuma). Er werd een significant lagere gezondheidsgerelateerde KvL gevonden in vergelijking met de referentiegroep in bijna alle domeinen. Ook het psychosociale ontwikkelingstraject van jonge vrouwen met JIA blijkt vertraagd. Ze bereiken minder psychosociale ontwikkelingsmijlpalen,
Hoofdstuk 6 presenteert een studie over het verschil in de levensloop tussen mensen met en zonder Wajong-uitkering. In hoofdstuk 5 werd bij 377 jongvolwassenen met een Wajong-uitkering onderzocht hoe zij betekenis geven aan hun ziekte of aandoening. Wanneer patiënten worden gediagnosticeerd met een chronische ziekte, ontwikkelen zij over het algemeen een gestructureerd patroon van gedachten/overtuigingen over hun aandoening. Deze ziekteacceptatie of ziektecognities hebben directe invloed op de emotionele reactie van de patiënt op het onomkeerbare karakter van een chronische aandoening; om een gevoel van evenwicht te behouden en om een bevredigende kwaliteit van leven te kunnen bereiken. De ziektecognities van de Wajongers werden onderzocht in relatie tot de ziektekenmerken. Ook werden de associaties tussen de ziektecognities en de gezondheidsgerelateerde KvL en de gevoelens van angst en depressie bekeken. Wanneer patiënten een ziektecognitie met een negatieve invloed - een ziektecognitie met een negatieve invloed - werd in een aanzienlijk deel van de respondenten gevonden. Dit geeft aan dat de ziektecognities relevante zijn voor het psychisch functioneren. Verschillende ziektekenmerken waren geassocieerd met de ziektecognities; met name de respondenten met een positieve ziektecognitie scoorden hoger op acceptatie en lager op hulpeloosheid. Uit de onderzoeksresultaten blijkt ook dat de ziektecognities relevant zijn voor het psychisch functioneren op latere - jongvolwassen - leeftijd. De ziektecognities acceptatie en hulpeloosheid zijn geassocieerd met de gezondheidsgerelateerde KvL, en met de gevoelens van angst en depressie. De toename in kennis en inzicht over de impact van chronische gezondheidsproblemen tijdens de kindertijd op het latere psychosociale welzijn is aandoening van psychosociale ondersteuningsprogramma's te (gaan) ontwikkelen. Het meten van algemene ziektecognities kan een waardevolle aanvulling zijn op de screening van psychologische risicofactoren om patiënten die gebaat zijn bij psychologische interventies op te sporen.

Hoofdstuk 6 presenteert een studie over het verschil in de levensloop tussen 53 jongvolwassenen overlevers van jeugdkanker mét en 315 jongvolwassenen overlevers van jeugdkanker zonder Wajong-uitkering, en 508 leeftijdsgenoten uit de algemene Nederlandse bevolking (referentiegroep). De overlevers zonder Wajong-uitkering bleken een gunstigere levensloop te hebben in termen van beheide ontwikkelingsmijlpalen dan de overlevers die wel een Wajong-uitkering hebben aangevraagd. Deze bevindingen duiden erop dat het ontwikkelingsstraject richting de volwassenheid voorspelling kan zijn voor latere deelname aan de arbeidsmarkt. Hoe der er geen oorzakelijk verband tussen het bereiken van de ontwikkelingsmijlpalen en het aanvragen van een Wajong-uitkering is aangetoond, geeft het feit dat het ontwikkelingstraject aan de uitkeringsaanvraag voorafgaat wel een indicatie.

In hoofdstuk 7 wordt een studie beschreven waarin de ziektekenmerken, de ziektecognities en de werkmotivatie van jongvolwassenen met Wajong-uitkering worden onderzocht, evenals de associatie met de kans op werk. In totaal is 38,2% succesvol aan het werk (geweest) vanaf het moment dat er een Wajong-uitkering was aangevraagd. Een kleine minderheid (46,1%) had een betaalde bijslaai tijdens de middelbare school. Veel jongvolwassenen met een Wajong-uitkering - zowel met als zonder werk - rapporteerden aanpassingen in of tijdens het werk nodig hebben om te kunnen deelnemen aan het arbeidspersoneel. In vergelijking met degenen die niet succesvol deelnamen aan de arbeidsmarkt (N = 218) gaf een groter aantal van degenen die wel succesvol waren (N = 135) aan behoefte aan ondersteuning op het werk te hebben. Succesvolle Wajongers rapporteerden minder gevoelens van hulpeloosheid, een hogere werkmotivatie en hadden vaker ouders die werk belangrijk achten voor hun kind. Na de correctie voor socio-demografische kenmerken en de ziektekenmerken, bleek alleen de mate waarin ouders werk belangrijk achtten voor hun kind significant in relatie tot succesvolle deelname aan het werk. De resultaten geven geen duidelijk beeld van factoren die samenhangen met succesvolle deelname aan de arbeidsmarkt. Dit wijst op een complexe relatie tussen socio-demografische factoren, de behandeling, het psychosociaal functioneren en de deelname aan werk.

**METHODOLOGISCHE OVERwegINGEN EN RICHTING VOOR TOEKOMSTIG ONDERZOEK**

De resultaten van het EMWAjong onderzoek moeten worden bezien in het licht van een aantal onderzoeksbeperkingen. Deze hebben betrekking op de
Dutch summary

Ten tweede, de bestaande zorg voor kinderen en jongeren met een chronische aandoening of handicap is grotendeels gericht op medische optimalisatie en op het bereiken van de mijlpalen van de volwassenheid. Veel van deze medische optimalisatie en mijlpalen zijn normatief van aard en resulteren daarmee soms in een ‘negatief’ resultaat. Het is belangrijk dat er een visie en aanpak komt die gericht is op positieve en geïndividualiseerde resultaten, zoals op een eigen manier mee kunnen doen in de maatschappij. Want meedoen aan het maatschappelijke leven is wat van belang is voor alle jongeren met een chronische aandoening of handicap en hun families.

Ten derde, om zinvolle participatie voor jongeren met somatische aandoeningen te realiseren, is het belangrijk dat er maatwerk en persoonlijke aandacht geleverd kan worden in de zorg en ondersteuning voor deze kwetsbare groep.

KLINISCHE EN MAATSCHAPPELIJKE IMPLICATIES

Om zinvolle participatie voor kinderen en jongeren die opgroeien met een chronisch somatische aandoening te realiseren, zijn verschillende aanpassingen in de zorg nodig.

LICHAMELIJKE, PSYCHOSOCIALE EN EMOTIONELE ZORG IN EEN LEVENSPROFIEL PERSPECTIEF

Het is belangrijk dat zorgverleners kennis hebben van mogelijke hiaten in de levensloop en het emotionele en sociale welzijn van hun patiënten. Om dit te realiseren, moet een doorlopende, systematische monitoring van de emotionele, psychosociale en educatieve/werk situatie een integraal onderdeel van de zorg voor chronisch zieke of gehandicapte patiënten worden. Op basis daarvan kan de ontwikkeling gevolgd worden en eventuele ondersteuning worden ingezet. Deze ontwikkelingsgerichte zorg moet tijdens en na de transitie van de kinder- en kinderziekten naar de zorg voor volwassen worden voortgezet.

DE ROL VAN ZORGVERLENERS

Zorgverleners verkennen in een goede positie om hun patiënten te begeleiden in het omgaan met een chronische gezondheidsbeperking met oog voor de maatschappelijke participatie en de kwaliteit van leven. Gezondheidsbevordering, therapietrouw, contact met leeftijdgenoten, vroege aandacht voor (on)mogelijkheden rondom werk of studiekeuzes en vrijetijdsbesteding kunnen onderwerpen zijn om te bespreken. Er moet ook aandacht zijn voor seksuele voorlichting, voorbereiding op eventueel ouderschap en voor genetische aanleg. Om passende begeleiding te kunnen bieden, is het belangrijk dat de zorgverleners de

underzoekspopulatie, de generaliseerbaarheid van de resultaten, de heterogene onderzoekssituatie, de gebruikte vragenlijsten, de manier waarop arbeids participatie is gemeten en het gebruik van zelfrapportage. Op basis van de onderzoeksbeperkingen worden verschillende richtingen voor toekomstig onderzoek genoemd, evenals ideeën voor de ontwikkeling van verschillende interventies. Toekomstig onderzoek moet zich onder meer richten op de lang termijn effecten van het opgroeien met chronische gezondheidsbeperkingen; de verschillen tussen mensen die opgroeien met en zonder gezondheidsbeperkingen veranderen naarmate ze ouder worden en welke jongeren later het meest waarschijnlijk problemen ontwikkelen. Ook andere factoren die van invloed kunnen zijn op de psychosociale ontwikkeling, de emotionele welzijn en de maatschappelijke participatie – zoals coping, persoonlijkheid, de ontvangen steun/support, de houding ten aanzien van werk, de steun voor ouders – moeten worden bestudeerd. Toekomstig onderzoek moet zich bovendien richten op de vraag of het stimuleren van het behalen van de ontwikkelingsmijlpalen tijdens het opgroeien, inclusief de mijlpalen gericht op arbeids participatie, helpend zijn voor een betere positie op de arbeidsmarkt en welke ondersteuning daarbij het meest effectief is. Het grondig, consistent en vroegtijdig monitoren van de psychosociale uitkomsten in een levensloop perspectief wordt aanbevolen.

REFLECTIES

De resultaten van dit onderzoek dragen bij aan de kennis over jongvolwassenen met een Wajong-uitkering die zijn opgegroeid met een somatische ziekte of aandoening sinds de kinderleef tijd. De psychosociale ontwikkeling, de emotionele welzijn en de economische positie van deze groep lijken negatief te worden beïnvloed door het opgroeien met een gezondheidsbeperking. Op basis van de onderzoeksresultaten kunnen drie algemene interpretaties van de resultaten worden geformuleerd.

Ten eerste, onze samenleving verwacht dat alle jongeren hun school afronden, werk vinden, een sociaal netwerk opbouwen, bijdragen aan de maatschappij; dat alles binnen een bepaald tijdschema. Omdat we weten dat kinderen en jongeren die opgroeien met een chronische ziekte of beperking zich langzamer ontwikkelen of niet alle mijlpalen in de ontwikkeling bereiken, is het maar de vraag of dit een realistische verwachting is. Doorgaans lukt het deze jongeren op te groeien tot zelfstandige volwassenen, maar niet in het tempo van jongeren zonder ziekte of aandoening. Het is daarom belangrijk dat onze samenleving de extra tijd en ondersteuning biedt die nodig is om het eigen, specifieke ontwikkelingstraject te doorlopen.

Ten tweede, de bestaande zorg voor kinderen en jongeren met een chronische aandoening of handicap is grotendeels gericht op medische optimalisatie en op het bereiken van de mijlpalen van de volwassenheid. Veel van deze medische optimalisatie en mijlpalen zijn normatief van aard en resulteren daarmee soms in een ‘negatief’ resultaat. Het is belangrijk dat er een visie en aanpak komt die gericht is op positieve en geïndividualiseerde resultaten, zoals op een eigen manier mee kunnen doen in de maatschappij. Want meedoen aan het maatschappelijke leven is wat van belang is voor alle jongeren met een chronische aandoening of handicap en hun families.

Ten derde, om zinvolle participatie voor jongeren met somatische aandoeningen te realiseren, is het belangrijk dat er maatwerk en persoonlijke aandacht geleverd kan worden in de zorg en ondersteuning voor deze kwetsbare groep.

KLINISCHE EN MAATSCHAPPELIJKE IMPLICATIES

Om zinvolle participatie voor kinderen en jongeren die opgroeien met een chronisch somatische aandoening te realiseren, zijn verschillende aanpassingen in de zorg nodig.

LICHAMELIJKE, PSYCHOSOCIALE EN EMOTIONELE ZORG IN EEN LEVENSPROFIEL PERSPECTIEF

Het is belangrijk dat zorgverleners kennis hebben van mogelijke hiaten in de levensloop en het emotionele en sociale welzijn van hun patiënten. Om dit te realiseren, moet een doorlopende, systematische monitoring van de emotionele, psychosociale en educatieve/werk situatie een integraal onderdeel van de zorg voor chronisch zieke of gehandicapte patiënten worden. Op basis daarvan kan de ontwikkeling gevolgd worden en eventuele ondersteuning worden ingezet. Deze ontwikkelingsgerichte zorg moet tijdens en na de transitie van de kinder- en kinderziekten naar de zorg voor volwassen worden voortgezet.

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patiënten in de context van hun leven zien, als een geïntegreerd individu in een systeem van familie, vrienden, school, werk en samenleving. Er is behoefte aan opleiding en training van zorgprofessionals op bovengenoemde aspecten.

**TRANSITIE IN DE GEZONDHEIDSZORG**

Het proces van de overgang van de kindergeneeskunde naar de zorg voor volwassenen moet ruim voor de daadwerkelijke transitie worden ingezet, met aandacht voor het gehele levensloopperspectief. Om de zorg daarbij op een afgepaste en individuele manier te kunnen verlenen, is het belangrijk om na te gaan of een jongere daadwerkelijk toe is aan de overstap naar de volwassenenzorg en opleiding en training van zorgprofessionals op bovengenoemde aspecten. Om de werkgelegenheid te stimuleren, dient de overheid de wet- en regelgeving aan het arbeidsproces de basis voor een gedegen transitie naar de volwassenen zorg en de volwassenheid.

**FAMILIE PERSPECTIEF**

Een zieke of aandoening op de kinderleeftijd heeft invloed op het hele gezin. Over het algemeen zijn gezinnen waar een kind opgroeit overlast als gevolg van de zorg voor en begeleiding van het zieke kind bij het ingewikkeld proces van volwassen worden. Veel ouders maken zich zorgen over de toekomst van hun kind. Zij hebben moeite om een goede balans te vinden tussen het beschermen en het stimuleren van het kind. Om de gezinnen de informatie en ondersteuning te kunnen geven die zij nodig hebben, is het essentieel om systematische aandacht aan het effect van het leven met een kind of broertje of zusje met een aandoening of zieke te besteden. Interventies om ouders te ondersteunen in de begeleiding van hun zieke kind en de rest van hun gezin zijn nodig.

**BELEID, WET- EN REGELGEVING**

De Nederlandse overheid heeft de taak om voorwaarden te scheppen voor een samenleving waarin mensen met gezondheidsproblemen kunnen deelnemen aan de arbeidsmarkt en in de samenleving in het algemeen. Verschillende groepen hebben ondersteuning nodig bij het vinden van hun plek op de arbeidsmarkt. Om de werkgelegenheid te stimuleren, dient de overheid de wet- en regelgeving te baseren op de gedachte dat mensen met een ziekte of beperking in staat worden gesteld om mee te doen. De wet- en regelgeving heeft daarmee een hoge symbolische waarde, omdat deze staat voor de welkomstsignalen vanuit de maatschappij. De wetgeving voor de groep jongeren met chronische aandoeningen is in de afgelopen zeven jaar drie keer veranderd. Tijdens deze periode zijn de indicaties voor het verkrijgen van een Wajong-uitkering geleidelijk strikter gedefinieerd en zijn de mogelijkheid voor ondersteuning bij het vinden en behouden van werk aangescherpt. Deze gemengde signalen - het hechten van belang aan deelnemen aan de samenleving door alle groepen en het verminderen van de steun aan jonge mensen met gezondheidsproblemen - lijken het effect van de maatschappij niet weet hoe een plek te creëren voor een groep jonge mensen die niet in staat is om op de gebruikelijke manier deel te nemen aan het arbeidsproces.

**SAMENWERKING TUSSEN VERSCHILLENDE INSTELLINGEN**

De discussie over de gevolgen van het ‘pediatrische succesverhaal’ moet ook ingaan op de impact ervan op alle verschillende instellingen die betrokken zijn, bij het optimaliseren van de onafhankelijkheid van jongeren die opgroei en hebben ondersteuning nodig bij het vinden van hun plek op de arbeidsmarkt. Jongeren met een chronische aandoening en die van hun ouders. Om goed samen te kunnen werken, zijn niet alleen politieke beslissingen nodig, maar moeten ook de financiën behoeve van de coördinatie geregeld worden, zodat de geleverde ondersteuning en zorg minder gefragmenteerd en dubbelop is en daardoor efficiënter.

**HET VERBETEREN VAN DE ARBEIDSPARTICIPATIE**

Deze studie wijst op de noodzaak van vroegtijdige en langdurige aandacht voor het bereiken van ontwikkelingsmijlpalen inclusief de ontwikkeling van vaardigheden en attitudes die jongvolwassenen met chronische aandoeningen nodig hebben voor hun toekomstige deelname aan de arbeidsmarkt. Jongeren met een ziekte of beperking hebben meer ondersteuning nodig voordat ze de stap naar de arbeidsmarkt maken. Ten eerste is het belangrijk dat ze leren wat mogelijk en haalbaar voor hen is op de arbeidsmarkt en ten tweede moeten ze hun eigen mogelijkheden en interesses kunnen verkennen. Ten derde, er is ondersteuning nodig bij het ontwikkelen van vaardigheden om werk te vinden. Trainingsprogramma’s en arbeidsbemiddeling kunnen de kans op het vinden en behouden van werk voor jongvolwassenen met gezondheidsbeperkingen vergroten. Op een ander niveau spelen de werkgevers een belangrijke rol in het verbeteren van de werkplekken, werkplekgaranties en intergratiemogelijkheden voor jongeren met een arbeidsongeschiktheid uitkering vanwege chronische gezondheidsproblemen. Jongvolwassenen met chronische ziekten of aandoeningen hebben
bescherming en ondersteuning nodig om uitsluiting op de krappe arbeidsmarkt te voorkomen. Daarom is het van het grootste belang dat werkgevers, gemeenten en de overheid zorgen voor passende werkgelegenheid voor jongvolwassenen met een chronische aandoening om hen mee te kunnen laten doen in onze maatschappij.

- Opgroeien met een chronische ziekte of handicap tijdens de kindertijd en adolescentie heeft gevolgen voor de overgang naar de volwassenheid en het verdere volwassen leven.
- Jongvolwassenen met een arbeidsongeschiktheidssituering vanwege een chronische ziekte of handicap hebben een vertraagde levensloop tijdens de adolescentie en de overgang naar de (jong)volwassenheid. Het is belangrijk om doorlopend aandacht te besteden aan hun ontwikkelingstraject en emotionele welzijn.
- Het grondig, consistent en vroegtijdig monitoren van de psychosociale uitkomsten in een levensloop perspectief wordt aanbevolen.
- Zorgverleners moeten zich bewust zijn van het effect van een chronische ziekte of handicap tijdens de kindertijd op alle leden van het gezin.
- Kinderartsen en artsen in de volwassenzorg hebben een optimale mix van kennis, vaardigheden en ervaring nodig om hun patiënten die opgroeien met een chronische ziekte of handicap op zowel medisch als de psychosociaal vlak te begeleiden.
- De behandeling en ondersteuning moet gericht zijn op betekenisvolle en bevredigende participatie in de samenleving.
- Het is belangrijk om jonge mensen met een ziekte of handicap te stimuleren deel te nemen aan werk. Een vroege voorbereiding op werk is aanbevolen.
- Het realiseren van verbindingen tussen de gezondheidszorg, het onderwijs, instanties rondom werk en sociale voorzieningen is noodzakelijk.
- Onze maatschappij moet ervoor zorgen dat er voldoende middelen en ondersteuning ter beschikking worden gesteld aan alle jongeren met chronische aandoeningen en hun families om maatschappelijke participatie te optimaliseren.
Portfolio and Publications
Name PhD student: Eefje Verhoof
PhD period: 2008-2015

Name PhD supervisors: Prof.dr. H.S.A. Heymans and Prof.dr. M.A. Grootenhuis

<table>
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<td>• Course of life of young adults with a Wajong-benefit as a result of a somatic disorder since childhood, Emma children’s Hospital symposium, Amsterdam</td>
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<td>• Factors related to successful workforce participation of young adults with disability benefits because of a somatic disorder since childhood, Emma children’s Hospital symposium, Amsterdam</td>
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<td>• Illness cognitions in relation to HRQoL, anxiety and depression in young adults with disability benefits, Emma children’s Hospital symposium, Amsterdam</td>
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<td>• De psychosociale levensloop en kwaliteit van leven van overlevers van jeugdkanker met en zonder Wajong uitkering, Dutch Pediatric Psychology Network conference, Nijmegen</td>
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<td>• De kwaliteit van leven en de psychosociale levensloop van jongvolwassen vrouwen met een Wajong uitkering vanwege JIA, Dutch Pediatric Psychology Network conference, Nijmegen</td>
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<td>• Chronisch ziek als kind, zonder baan als volwassene? Bedrijfsgeneeskundige dagen, Papendal</td>
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<td>• Chronisch ziek als kind, zonder baan als volwassene? Het EMWAjong onderzoek. Symposium Kinderen met een Nierziekte voor professionals, Nierstichting, Driebergen</td>
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<td>• Dutch Pediatric Society Symposium</td>
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Wajongers aan het werk: welke factoren kunnen van belang zijn voor arbeidsparticipatie van jonggehandicapten?
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Verhoof E, Maurice-Stam H, Heymans H, Grootenhuis M
In preparation
Word of thanks
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Lieve Katrijn, wat heerlijk dat we al zo’n lange periode zowel op werkgebied als privé met elkaar delen. Jij bent ongelofelijk belangrijk voor mij! Door onze belangrijkste kopzorgen te reduceren tot (gek genoeg alleen voor ons rake) tegelwijsheden, wordt het leven telkens weer een beetje leuker en simpeler. Want “Rustig aan Jos, we hebben alle tijd, “Het is wat het is”, en “Effe zitten”, zijn natuurlijk onmogelijk relativerend 🙃. Ontzettend dankjewel voor de diepe vriendschap. Ik zeg: ‘start de band’ voor de rest van wat we samen gaan delen!

Lieve Paranimfen, wat bijzonder dat jullie nu naast mij staan! Ik vond het een eer omer bij jullie te mogen staan en ik ben trots op jullie nu aan mijn zijde te hebben.

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Lieve Vief, wat een bijzonder cadeau dat ik aan mijn werkplek in het EKZ een prachtige vriendschap met jou heb overgehouden! Naast alle promotiezaken hebben we ook veel andere levensgebeurtenissen mogen delen en dat is me erg dierbaar. Het is zo waardevol te weten dat je me begrijpt en er voor me bent. Ook sportief gezien zijn we een match, al heb ik momenteel enige twijfel over je vorderingen…:) We wonen nu wat verder uit elkaar, maar deze vriendschap blijft!

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Hey, niet alleen het dankwoord lezen, he? ☺
About the author