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

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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. 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. This, in turn, leads to a variety of economic, social and quality of life problems.

Several studies among people with chronic somatic diseases show lower income levels, lower Health Related Quality of Life (HRQoL), worse mental health such as more anxiety and depression 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. 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. 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
labour market. 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\textsuperscript{19, 20}. It is essential to gain insight into factors affecting the vocational success of people with a Wajong benefit in order to be able to develop strategies to support this vulnerable population towards employment and adulthood independence.

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\textsuperscript{15, 21-23}. However, these studies focussed on specific disease categories or examined both physical and mental conditions. 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\textsuperscript{24, 25}. 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 workforce 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\textsuperscript{26, 24}. Non-working patients were more likely to have maladaptive illness perceptions. Maybe these factors are also important for work participation of young adults with disability benefits 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\(^{28}\) 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 present in the respondent. The ICQ has strong internal consistency and reliability, and good construct and predictive validity across chronic conditions\(^{28,29}\). Cronbach’s alpha in the present study was 0.85 for helplessness, 0.89 for acceptance, and 0.87 for perceived benefits.

**Work motivation**
The 'work involvement scale' of the Work and Life Attitudes Survey\(^{30}\) was used to measure the degree to which respondents want to be engaged in work. This scale consists of 6 items assessed on a four-point scale from 1 = definitely disagree to 4 = definitely agree. Examples of work motivation questions are: 'Even if I won a great deal of money on the pools I would continue to work somewhere'.
Getting to work: factors associated with work participation

'Having a job is very important to me', 'I should hate to be on the dole'. Scale ranges from 6-24. 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. High scores represent high work motivation. In the present study, Cronbach’s alpha of the 'work involvement scale' was 0.78.

Attitude of parents regarding work for the young adult was measured by one question “Do your parent(s) find it important that you have a paid job?” (yes/no).

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>
<thead>
<tr>
<th>Condition/illness</th>
<th>Unsuccessful employment</th>
<th>Successful employment</th>
<th>Total (N=353)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visually impaired/blind</td>
<td>32</td>
<td>65.3</td>
<td>17</td>
</tr>
<tr>
<td>Spasm</td>
<td>26</td>
<td>65.0</td>
<td>14</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>26</td>
<td>63.4</td>
<td>15</td>
</tr>
<tr>
<td>CFS/migraine</td>
<td>22</td>
<td>64.7</td>
<td>12</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>15</td>
<td>50.0</td>
<td>15</td>
</tr>
<tr>
<td>Arthritis</td>
<td>10</td>
<td>62.5</td>
<td>6</td>
</tr>
<tr>
<td>Back complaints</td>
<td>16</td>
<td>61.5</td>
<td>10</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>17</td>
<td>68.0</td>
<td>8</td>
</tr>
</tbody>
</table>
### TABLE 1: Continued

<table>
<thead>
<tr>
<th>Disease characteristics</th>
<th>Unsuccessful employment N=218 (61.8%)</th>
<th>Successful employment N=135 (38.2%)</th>
<th>Total (N =353)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Hearing impaired/deaf</td>
<td>16</td>
<td>66.7</td>
<td>8</td>
</tr>
<tr>
<td>Intestinal complaints</td>
<td>13</td>
<td>61.9</td>
<td>8</td>
</tr>
<tr>
<td>Lung complaints</td>
<td>14</td>
<td>73.7</td>
<td>5</td>
</tr>
<tr>
<td>Paralysis</td>
<td>12</td>
<td>63.2</td>
<td>7</td>
</tr>
<tr>
<td>Cancer</td>
<td>9</td>
<td>47.4</td>
<td>10</td>
</tr>
<tr>
<td>Accident damage</td>
<td>12</td>
<td>75.0</td>
<td>4</td>
</tr>
<tr>
<td>Kidney disease</td>
<td>12</td>
<td>80.0</td>
<td>3</td>
</tr>
<tr>
<td>Skin disease</td>
<td>5</td>
<td>62.5</td>
<td>3</td>
</tr>
<tr>
<td>Heart disease</td>
<td>6</td>
<td>85.7</td>
<td>1</td>
</tr>
<tr>
<td>Liver disease</td>
<td>4</td>
<td>80.0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>70</td>
<td>64.2</td>
<td>39</td>
</tr>
</tbody>
</table>

**Course of disease**

- Variable/Negative: 108 (49.5%), 42 (31.1%), 150 (42.5%)
- Stable/Positive: 110 (50.5%), 93 (68.9%), 203 (57.5%)

**Visible disability**

- Yes: 119 (54.6%), 46 (34.1%), 145 (41.1%)
- No: 99 (45.4%), 89 (65.9%), 208 (58.9%)

**Congenital disorder**

- Yes: 113 (51.8%), 75 (55.6%), 188 (46.7%)
- No: 105 (48.2%), 60 (44.4%), 165 (53.3%)

**Daily medicine use**

- Yes: 122 (56.0%), 68 (50.4%), 190 (53.8%)
- No: 96 (44.0%), 67 (49.6%), 163 (46.2%)

**Medical devices**

- Yes: 116 (53.2%), 52 (38.5%), 168 (47.6%)
- No: 102 (46.8%), 83 (61.5%), 185 (52.4%)

**Limitations of sight**

- Yes: 59 (27.1%), 28 (20.7%), 87 (24.6%)
- No: 159 (72.9%), 107 (79.3%), 266 (75.4%)

**Limitation of hearing**

- Yes: 19 (8.7%), 9 (6.7%), 28 (7.9%)
- No: 199 (91.3%), 126 (93.3%), 325 (92.1%)

**Limitations to stand half an hour**

- Yes: 107 (49.1%), 40 (29.6%), 147 (41.6%)
- No: 111 (53.9%), 95 (70.4%), 206 (58.4%)
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>Requirements for work participation (N=347)</th>
<th>Unsuccessful employment</th>
<th>Successful employment1</th>
<th>Total (N=353)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjusted working hours</td>
<td>97 45.5 150 43.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted work place</td>
<td>72 33.8 113 32.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transport to work</td>
<td>62 29.1 104 30.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted tasks</td>
<td>49 23.0 72 20.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support at work*</td>
<td>46 21.6 89 25.5</td>
<td></td>
<td></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 beneficially 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.
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=0.0001, 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>Age</td>
<td>0.11</td>
<td>0.07</td>
<td>1.12</td>
<td>0.98</td>
<td>1.28</td>
</tr>
<tr>
<td>Gender</td>
<td>-0.06</td>
<td>0.29</td>
<td>0.94</td>
<td>0.53</td>
<td>1.66</td>
</tr>
<tr>
<td>Level of education</td>
<td>0.29</td>
<td>0.30</td>
<td>1.34</td>
<td>0.74</td>
<td>2.41</td>
</tr>
<tr>
<td>Disease characteristics</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>2.43</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>
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<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>
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<td>0.32</td>
<td>0.60</td>
<td>0.32</td>
<td>1.13</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>
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<td>0.29</td>
<td>1.49</td>
<td>0.84</td>
<td>2.62</td>
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<tr>
<td>Requirements for work participation</td>
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<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>0.65</td>
<td>2.21</td>
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<tr>
<td>Adjusted working hours</td>
<td>-0.13</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>
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<tr>
<td>Support at work</td>
<td>0.46</td>
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<td>1.58</td>
<td>0.85</td>
<td>2.93</td>
</tr>
<tr>
<td>Job during high school</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>Illness cognitions</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</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>Work motivation</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 fulfil 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
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 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. 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
economic factors relevant for work participation in young adults with chronic conditions. Other factors that were not examined in this study might influence occupational outcomes as well, for example, coping skills, personality and the amount of received support. Also, more insight in the influence and the role of parents of a child with a chronic condition is important. Also, we did control for some disease characteristics in this present study, but these characteristics merit greater attention as potentially mediating variables in predicting successful work participation.

Third, our measurements had some limitations which need to be taken into account. To fill in the questionnaire, some level of self-insight was required. Some young adults with disabilities may have had difficulties with this kind of self-report. Also, we used only one scale of the Work and Life Attitudes Survey. To measure work motivation in more detail, more questions are required. Fourth, it is important to realise that the Wajong Act 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. Another limitation is the response rate of 20%, though this is an average response rate among young adults with a disability.

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 participating successful on the labour market 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. 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. Finally, 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. It is also unknown how the group of young adults with a chronic somatic condition who apply for disability benefits compares to the group that does not apply.

Therefore, the generalizability of our findings to the whole group of young adults with a chronic somatic condition 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 accu-
rate 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.
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