**Social participation and psychosocial outcomes of young adults with chronic physical conditions: Comparing disability benefit recipients and non-recipients**

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**Abstract**

**Objective**

To identify predictors during adolescence for receiving disability benefits in young adulthood, and to compare benefit recipients’ and non-recipients’ social participation, and psychosocial outcomes in young adulthood. By doing so, insights for future policy and rehabilitation care could be provided.

**Methods**

Follow-up study of 18 to 25 year olds with various chronic conditions who at adolescent age completed a web-based survey (n=518). Outcome measure was receiving disability benefits (yes or no). Associations with background characteristics, social participation, and impact of the chronic condition were explored with stepwise multivariate modelling, using T0-variables. Differences between recipients and non-recipients were explored using Chi-Square tests and t-tests.

**Results**

Greater extent of physical disability, receiving special education, absenteeism at school/work, and lower health-related quality of life during adolescence were associated with receiving disability benefits in young adulthood. In young adulthood, benefit recipients reported higher perceived impact of the chronic condition on their school/work career and lower quality of life compared to non-recipients. Social participation varied across domains.

**Conclusion**

This study provides important insights into the characteristics of a vulnerable subgroup of young people with chronic physical conditions. Disability benefit recipients experienced more impact of their chronic condition and reported a lower health-related quality of life over time. Rehabilitation professionals are encouraged to use patient-reported outcomes to address the lived experiences and screen the need for psychosocial support of this vulnerable subgroup of young people with chronic physical conditions.

**Key words**

Chronic conditions; Physical disabilities; Adolescent; Psychosocial development; Social Participation; Quality of life;

**Introduction**

Employment fosters the acquirement of life skills and autonomy needed to participate in society [1]. It increases people’s sense of control over their own lives, helps to develop their self-identity, and positively influences income levels and occupational achievements during the lifespan [1, 2]. Starting a work career is, therefore, an important developmental milestone for young adults. Finding and maintaining employment, however, is a major challenge for young adults with chronic physical conditions [3, 4]. Compared to healthy peers, their work participation rate is lower [4-6]. While reported employment rates vary, rates of about 30% are common both in Europe and the USA [7, 8]. In the Netherlands, 39-45% of the young adults with chronic physical conditions are employed [8, 9] compared to 64-72% of their healthy peers [7, 9]. Reported barriers for employment include limited accessibility of work places, discrimination, inadequate possibilities of transportation, and lack of social support [3, 4, 10, 11]. Unemployment, in turn, negatively influences their financial situation, psychological well-being, social interactions, and quality of life [3, 4].

Rehabilitation healthcare teams have taken steps to foster work participation of young adults with chronic physical conditions [12, 13, 14]. Also on macro-level, policies aimed at improving their work participation and quality of life have been implemented. In the Netherlands, young adults who are partially or fully incapable of working due to a childhood onset of chronic condition may be entitled to a benefit under the scheme for young disabled persons: Wajong (the Disablement Assistance Act for Handicapped Young Persons) [15]. Someone may apply for Wajong if he/she is at least 25% occupationally disabled before the 17th birthday or became occupationally disabled during education. The disability benefit consists of (supplementary) income support, and those who are fit to work are supported in finding and sustaining employment [15, 16].

The National Employee Insurance Agency assessed young adults’ work ability and capacity. The number of benefit recipients rose from 147,000 in 2005 to 249,000 in 2015 [15, 17]. Around 25% of the benefit recipients were employed, while 60% of all recipients were found fit to work [18]. In other countries the number of disability benefit claims has also risen in recent years, with lower employment rates reported for benefit recipients [8].

Recent studies among young adults receiving disability benefits emphasized that they have a less favourable developmental trajectory while growing up compared to healthy age-mates [16, 19, 20].In young adulthood, they report lower health-related quality of life (HRQoL) and are at higher risk for anxiety and depression [19, 21]. Psychosocial support during childhood and adolescence is therefore recommended [20]. Still, little is known about the possible differences between young people with chronic physical conditions who apply for disability benefits and those who do not [21]. This study aims to explore the association between characteristics during adolescence and the likelihood of receiving disability benefits in young adulthood among a cohort of young people with chronic physical conditions. In addition, the differences between benefit recipients and non-recipients on participation and psychosocial outcomes in young adulthood are studied. By doing so, insights for future policy and rehabilitation care could be provided.

**Material and methods**

**Study design and participants**

A longitudinal survey study was conducted in which participants of a web-based survey in 2006 (T0) were re-invited for a similar survey six years later (T1) [22]. The web-based follow-up questionnaire was basically the same as the previous questionnaire, except that questions on social participation and source of income were added. It was pilot tested in face-to-face (n=7) and telephone (n=3) interviews with young university students with a chronic physical condition, who were not included in the final sample. Based on the pilot-test, some questions were rephrased or deleted in order to reduce the response time.

In 2006, participants were adolescents aged 12 to 18 years who had been under treatment at the Erasmus MC – Sophia’s Children’s Hospital Rotterdam for more than three years. They had a variety of chronic physical conditions. Those with intellectual disabilities were excluded. In 2012, contact addresses and death notices were retrieved from the hospital’s electronic patient records. Eligible young adults were sent a patient information letter and a unique password to log in on a secured website. Included was a postcard on which they could state they did not want to participate. Those who did not respond within one month were sent a reminder by mail. After another month, non-responders were reminded through a phone call. Respondents were entered in a lottery to win one of twenty-five cookbooks, two smart phones, or an iPad provided by local suppliers. The Erasmus MC medical ethical review board approved the study (MEC 2012-022) and all data was processed anonymously. Participants electronically provided consent for their participation in the study.

**Measures and study outcomes**

Main outcome

*Disability benefit claim***.** At T1, respondents were asked if they were benefit recipients within the framework of the Wajong Act (1= yes; 2 = no) [16].

Independent variables

*Background characteristics.* Age, medical diagnosis (classified according to International Statistical Classification of Diseases and Related Health Problems [ICD-10]), educational level (1 = low or medium (primary school, secondary general vocation or lower vocational education); 2 = high (higher educational institutions or university)), and type of education followed in the past (1=mainstream; 2=special education) were recorded at both T0 and T1, while data from the T0 questionnaire served to establish gender (1 = female; 2 = male), and age at onset of the chronic condition (1 = congenital; 2 = 1-5 years; 3 = 6-12; 4 = >12 years). The extent of physical disability had been measured at T0 using ten items scored on a 4-point Likert scale (1 = no physical limitations; 2= some difficulty; 3 = with great difficulty; 4= I cannot do it) [23]. A total score was computed by summing the scores (Cronbach’s alpha = .91) [23]. At T0, data on medical diagnosis and onset of the chronic condition was verified in patients’ medical records.

*Self-management,*as reflected by disease-related self-efficacy, was measured at T0 with the On Your Own Feet Self-Efficacy Scale (OYOF-SES) using a 4-point Likert scale (from 1=‘no, definitely not’ to 4=‘yes certainly’) [24]. The OYOF-SES consists of three domains: coping with the condition (four items, Cronbach’s alpha = .82), knowledge about the condition (six items, Cronbach’s alpha = .78) and competencies during consultations (six items, Cronbach’s alpha = .85).

*Perceived impact of the condition*was measured at T0 in different ways.Adolescents reported the visibility of their chronic physical condition and absenteeism at school or work due to their condition using 3-point Likert scales (both 1 = never; 2 = sometimes; 3 = frequently to always). The experienced burden of visibility of the chronic physical condition was measured using two items scored on a 5-point Likert scale (1 = no burden at all; 2 = no burden; 3 = little burden; 4 = burden; 5 = much burden). These two items were summed up (Cronbach’s alpha = .80). The self-report short form measure of DISABKIDS questionnaire (DCGM-10) was used to assess HRQoL at T0 (Cronbach’s alpha = .80) [25].

Outcome measures at T1

*Level of autonomy in social participation* was classified using the Rotterdam Transition Profile (RTP) [26]. The RTP describes participation in seven life areas defined in the

International Classification of Functioning, Disability, and Health: 1) Finances; 2) Employment and education; 3) Housing; 4) Intimate relationships; 5) Sexuality; 6) Transportation; and 7) Leisure. It distinguishes four transition phases (0-3). Young persons in phases 0 and 1 are still fully dependent on adults (e.g. parents) or display typical child behaviour. Young persons in phase 2 experiment with or orient to adult behaviour. Phase 3 refers to full autonomy in participation. Because we were interested in a successful transition to adulthood, we dichotomised the phases as follows: 0 = phases 0-2; 1 = phase 3 [22].

*Perceived impact of the chronic condition on current education/vocational participation*was measured at T1 with a newly constructed 5-item scale. The items were derived from relevant literature and from interviews with young adults with chronic physical conditions, and are reported elsewhere [22]. The impact was rated on a 5-point Likert scale (1 = totally disagree; 2 = disagree; 3 = neutral, 4 = agree; 5 = totally agree). The items were summed (Cronbach’s alpha = .88).

*HRQoL* was assessed at T1 using the self-report DISABKIDS questionnaire (DCGM-37) [27]. It consists of five domains: Independence (6 items, Cronbach’s alpha = .86); Physical (6 items, Cronbach’s alpha = .84); Emotion (7 items, Cronbach’s alpha = .91); Social exclusion (6 items, Cronbach’s alpha = .81); Social inclusion (6 items, Cronbach’s alpha = .83). Responses are given on a 5-point Likert scale (1 = often; 2 = quite often; 3 = sometimes; 4 = almost never; 5 = never). A general score was computed by combining all items (Cronbach’s alpha = .95). HRQoL scores were transformed to a 0 - 100 scale.

**Statistical analysis**

Backward logistic analysis was used to detect selective response; determinants of study non-response were expressed in Odds Ratios (ORs) with the 95% Confidence Intervals (95% CI), and Nagelkerke R2 indicated the proportion of explained variance. Model fit was tested with the Hosmer and Lemeshow test. The study sample was described using descriptive statistics. Differences between benefit recipients’ and non-recipients’ background characteristics were tested using t-tests (continuous variables) and chi-square tests (nominal variables). Associations between the likelihood of a disability benefit claim and other variables (Cramer’s V and Phi for ordinal or nominal variables; and Pearson's r for interval variables) were established to determine which variables should be included in the regression analyses. Only variables significantly correlated (p<.05) with the outcome variables were included in the regression model. Stepwise multivariate linear regression analyses were performed to identify factors associated with the likelihood of a disability benefit claim: starting with background variables, and subsequently the T0 variables. Multicollinearity was checked by calculating the Variance Inflation Factor (VIF). Chi-Square tests were used to study differences between recipients and non-recipients on autonomy in social participation (T1). Lastly, independent T-tests were applied to detect differences between benefit recipients and non-recipients on HRQoL and perceived impact of the chronic physical condition on school and work career (T1). Data were analysed with SPSS 20.

**Results**

**Response**

Of the 1,039 participants in the original study, 13 had died and 25 could not be traced. Consequently, 1,001 were invited for participation in this study, 88 of whom returned a postcard stating that they declined to participate further. Eventually, 518 young adults (net response: 51.8%) submitted the survey. Backward logistic regression analysis showed that nonresponse was associated with male gender (OR, .57; 95% CI, .43 - .74), and non-Dutch ethnicity (OR, .49; 95% CI, .33 - .74) (χ2 = 29.0, degrees of freedom = 2; *p* < .001; R2 = .04; Hosmer and Lemeshow test, *p* = .773). Six respondents (1.2%) did not report if they received social security benefits and were excluded from the analysis. Hence, the final sample numbered 512, of which 101 respondents received a disability benefit. The characteristics of the study sample are presented in Table 1. With respect to diagnosis, congenital malformations, deformations and chromosomal abnormalities were most frequent, followed by neoplasms, endocrine, nutritional, and metabolic diseases, diseases of the eye and adnexa, and the ear and mastoid process, diseases of the musculoskeletal system and connective tissue, and diseases of the digestive system.

**Associations with receiving a disability benefit**

To determine which variables should be included in the regression analyses, associations were tested (Table 2). The multivariate model for receiving a disability benefit explained 44% of the total variance (χ2 = 307.44, degrees of freedom = 10; *p* < .001; Hosmer and Lemeshow test, *p* = .54) (Table 3).VIF scores varied between 1 and 2, indicating the absence of multicollinearity. The extent of physical disability (OR, 1.28; 95% CI, 1.10-1.48), and having followed special education during adolescence (OR, .15; 95% CI, .07-.33) were positively associated with the likelihood of receiving a disability benefit in young adulthood. Also, more absence from school (OR, 1.54; 95% CI, 1.10-2.10) and a lower HRQoL during adolescence (OR, .97; 95% CI, .95-.99) predicted a disability benefit claim later in life.

**Social participation**

No significant differences between benefit recipients and non-recipients were found on achieved autonomy in the life areas employment (*p* = 1.00), social relationships (*p* = .10), and housing (*p* = .78). Compared to young adults with chronic physical conditions who do not receive a disability benefit, the benefit recipients were less often involved in intimate and sexual relationships (34.7% versus 57.1%; *p*<.001), in independently organizing transportation (75.8% versus 96.4%, *p*<.001) and in attending social events (33.7% versus 59.9%; *p*<.001). As expected, benefit recipients were more often financially self-supporting than non-recipients (100% versus 29.0%; *p*<.001) (Table 4).

**Psychosocial outcomes**

Young adults receiving a disability benefit reported a higher perceived impact of the chronic physical condition on their school and work career (15.12 ±5.13, *p*<.001) compared to young adults with chronic physical conditions who did not receive a disability benefit (8.89 ±4.60, *p*<.001). Also, they experienced a lower general HRQoL (65.92±17.38 versus 80.86 ±14.15, *p*<.001). Note that HRQoL was also lower on each of the subdomains (Table 4).

**Discussion**

We exploredpredictors during adolescence for receiving disability benefits in young adulthood and compare benefit recipients’ and non-recipients’ social participation, and psychosocial outcomes in young adulthood, among a cohort of young people with chronic physical conditions.Our study showed that a greater extent of physical disability, receiving special education during adolescence, a higher perceived impact of their chronic physical condition on their school career, and experiencing lower HRQoL during adolescence predict the likelihood of a disability benefit claim later in life. In young adulthood, benefit recipients perceived a higher impact of their chronic physical condition on their school career and reported a lower HRQoL compared to young people with chronic physical conditions who did not receive a disability benefit. Also, they lagged behind regarding having an intimate relationship, and reported less autonomy in transportation and doing leisure activities.

Our study adds to the literature by defining and characterising a subgroup of young people with chronic physical conditions even more vulnerable for a delay in psychosocial development, and as such underlines the need for a lifespan perspective on care for this group. Roebroeck and colleagues [28] earlier acknowledged the need for incorporating a lifespan perspective throughout pediatric, transition, and adult rehabilitation care. For instance, in England, deployment of Young Adult Teams of health care professionals proved useful in supporting young adults’ social participation [29]. Other options, introduced in the Netherlands, are group-based interventions aimed at single or multiple participation domains, or discussing patient reported outcomes during consultations [12, 30, 31]. The importance of psychosocial support for adolescents and young adults with a chronic physical condition has been noted before [19-21, 32]. Still, these days, transitional care is still mostly focused on medical management issues and less attention is being paid to emotional and social aspects of growing-up with a chronic condition [33]. Yet, identifying and paying attention to adolescents’ lived experiences and needs in the areas of social participation during adolescence is essential for them achieving their full potential and a satisfying adult life [34]. Research for instance showed that not only rates of participation differ from healthy peers [22], but social participation can also be less diverse in young people with chronic condition, e.g., less social or skill-building activities [35]. Therefore, it is strongly recommended to monitor patient-reported outcomes on a regular basis. To this end, specific tools are available, for psychosocial screening, for encouraging independent behaviors (through the use of individual transition plans such as the Skills for Growing Up tool [30]), and for monitoring HRQoL [31] during medical consultations in paediatric and adult rehabilitation care.

Benefits recipients often followed special education during adolescence, were often absent from school or work during adolescence and experienced more barriers in school/work participation in young adulthood, underlining the need to pay attention to and to provide support on school and work participation [3, 36]. Being engaged in mainstream education and doing temporal or seasonal work during adolescence is important for youth with disabilities because it could provide a context for developing life skills, and exploring interests and abilities [11, 36]. In addition, at schools for special education, adolescents receive a great deal of assistance from their parents, friends, and service providers, which could hinder their opportunities to develop skills and to make their own decisions [37]. Thus, being encouraged to develop independent life skills may also be essential, especially for adolescents in special education settings. Such life skills include “psychosocial abilities for adaptive and positive behaviour that enable individuals to deal effectively with the demands and challenges of everyday life” [38].It is important for young people with a childhood onset of chronic condition to make a well-considered decision on the application for disability benefit. A need for financial compensation and support at finding and maintaining employment could be reasons to apply. However, being a benefit applicant could also negatively influence employment opportunities; for example, by reinforcing an employers’ prejudice. Therefore, rehabilitations professionals are recommended to discuss these advantages and disadvantages on time with young people and their parents.

Benefit recipients who are fit to work could get support in finding and sustaining employment. Still, we found that the employment rates of benefit recipients did not differ from employment rates of benefit non-recipients. A low work ability among benefit recipients, could be an explanation of this finding. However, we had no information on the work ability of our respondents and were thus not able to distinguish between benefit recipients who were (partially) able to work or those not able to work. Since we found an association between the extent of physical disability and the likelihood of a benefit claim, this deserves further investigation. To unravel differences in social participation and psychosocial outcomes, subgroups of benefit recipients should be studied. The employment rates of benefit recipients and non-recipients are still lower than the employment rates of healthy age-mates (63.3%) [39], indicating the need for support at finding and maintaining employment for young people with chronic physical conditions. Recently, Dutch legalisations aimed at improving the work participation among young people with chronic physical conditions were amended. Young people with chronic physical conditions who do not have any work ability receive disability payments. In contrast, young people with chronic physical conditions who are (partially) able to work, should be supported by municipalities to find competitive employment. However, nowadays resources for providing support are lessened. Since disability benefit recipients are a vulnerable group, support on this group should be priority.

We also found that benefit recipients were more often financially self-supporting than non-recipients (100% vs. 29%). This suggests that the benefits are substantial, and could in fact be an inducement for the young people with chronic physical conditions to apply for these benefits. Still, people could be motivated for a job for other reasons than income, e.g. psychological well-being, social interactions, and self-development [3, 4]. Therefore, financial support does not necessarily produce a negative influence on work participation.

Our study included a large sample of young persons with a variety of chronic physical conditions. The sample was heterogeneous in terms of congenital and acquired conditions. Yet this heterogeneity made it impossible to explore differences between benefit recipients and non-recipients within all included diagnosis groups. However, we analysed associations between receiving disability benefits and the five most common diagnoses, and found no significant associations. In addition, studying chronic physical conditions in general could be considered as a strength, since all young people growing up with a chronic physical condition face the similar adaptive challenges.

The survey non-response was substantial (48.2%) especially among males and young adults of non-Dutch ethnicity. This may have affected the outcomes, as previous research shows that male gender is a prognostic factor for work participation [40]. Also, we found that gender was related to a disability benefit claim. Last, at T0 we only included the short-version of the HRQoL questionnaire. Therefore, it was not possible to investigate associations between quality of life domains and the likelihood of receiving disability benefits.

Only personal or internal factors were included in our predictive model. But the likelihood of a disability benefit claim also depends on social or external factors, such as national employment options. We can only conclude that providing psychosocial support during childhood may decrease the likelihood of a claim. However, more research is needed to investigate the influence of external factors.

**Conclusion**

In conclusion, this study provides important insights into the development of characteristics of a vulnerable subgroup of young people with chronic physical conditions over time. Adolescents who reported a greater extent of physical disability, followed special education, experienced more impact of their condition on school functioning, and reported lower HRQoL, were more likely to claim a disability benefit in young adulthood. Moreover, we saw that the impact they experienced on vocational functioning and their lower HRQoL persisted over time. In addition, in young adulthood benefit recipients lagged behind in social participation on several domains. Rehabilitation professionals should be aware of this and may make use of various tools to address and screen lived experiences and the need for support on participation, and psychosocial development of this vulnerable subgroup of young people with chronic physical conditions.

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**Declaration of interest statement**

The authors state that they have no potential conflicts of interests to declare, including relevant financial interests, activities, relationships, and affiliations.

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