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Original article

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

Q1 Marjolijn I. Bal^{a,b,*}, Jane N.T. Sattoe^a, Harald S. Miedema^a, AnneLoes van Staa^{a,c}

Q2^a Rotterdam University of Applied Sciences, Research Centre Innovations in Care, Rotterdam, The Netherlands

^b Erasmus MC University Medical Center Rotterdam, Department of Rehabilitation Medicine, Rotterdam, The Netherlands

^c Erasmus University Rotterdam, Institute of Health Policy & Management, Rotterdam, The Netherlands

ARTICLE INFO

Article history:

Received 18 May 2017

Accepted 9 December 2017

Keywords:

Chronic conditions

Physical disabilities

Adolescent

Psychosocial development

Social Participation

Quality of life

ABSTRACT

Background: Little is known about any differences between young people with chronic physical conditions who do and do not apply for disability benefits in young adulthood for providing insights for future policy and rehabilitation care.

Objective: We aimed to identify predictors during adolescence of receiving disability benefits in young adulthood and to compare recipients and non-recipients of benefits in social participation and psychosocial outcomes in young adulthood.

Methods: Follow-up study of 18 to 25 year olds with various chronic conditions who at adolescent age completed a web-based survey ($n = 518$; T0). The outcome 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.

Results: Receiving disability benefits in young adulthood was associated with greater extent of physical disability, receiving less special education, absenteeism at school/work, and low health-related quality of life during adolescence. In young adulthood, recipients of benefits reported higher perceived impact of the chronic condition on their school/work career and lower quality of life than 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 than non-recipients. 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.

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1. 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 develop their self-identity, and positively influences income levels and occupational achievements during the lifespan [1,2]. Therefore, starting a work career is an important developmental milestone for young adults. However, finding and maintaining employment is a major challenge for young adults with chronic physical conditions

[3,4]. As compared with healthy peers, non-healthy young adults show lower work participation rate [4-6]. Reported employment rates vary, but rates of about 30% are common in both Europe and the United States [7,8]. In The Netherlands, 39% to 45% of young adults with chronic physical conditions are employed [8,9] versus 64% to 72% of their healthy peers [7,9]. Reported barriers to employment include limited accessibility of work places, discrimination, inadequate possibilities for transportation, and lack of social support [3,4,10,11]. Unemployment in turn negatively affects the financial situation, psychological well-being, social interactions, and quality of life of such people [3,4].

Rehabilitation healthcare teams have taken steps to foster the work participation of young adults with chronic physical conditions [12-14]. Also, on the macro level, policies aimed at

* Corresponding author. P.O. Box 25035, 3001 HA Rotterdam, The Netherlands.
E-mail address: m.i.bal@hr.nl (M.I. Bal).

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 childhood onset of a chronic condition may be entitled to a benefit under the scheme for young disabled persons: Wajong Act (the Disablement Assistance Act for Handicapped Young Persons) [15]. People may apply for Wajong if they are at least 25% occupationally disabled before their 17th birthday or became occupationally disabled during their 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 Netherlands National Employee Insurance Agency has assessed young adults' work ability and capacity. The number of benefit recipients rose from 147000 in 2005 to 249000 in 2015 [15,17]. About 25% of the recipients of benefits were employed, whereas 60% of all recipients were found fit to work [18]. In other countries, the number of disability benefit claims has risen in recent years, with lower employment rates reported for benefit recipients [8].

Recent studies of young adults receiving disability benefits emphasized that they had a less favourable developmental trajectory while growing up as compared with healthy age-mates [16,19,20]. In young adulthood, they report lower health-related quality of life (HRQoL) and are at increased risk for anxiety and depression [19,21]. Therefore, psychosocial support during childhood and adolescence is recommended [20]. Still, little is known about any differences between young people with chronic physical conditions who apply for disability benefits and those who do not [21].

This study explored 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, we studied the differences between recipients and non-recipients of benefits on participation and psychosocial outcomes in young adulthood. Our aim was to provide insights for future policy and rehabilitation care.

2. Material and methods

2.1. Study design and participants

A longitudinal survey study was conducted whereby 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. From the pilot test, some questions were rephrased or deleted 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 3 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 into a secured website. Included was a postcard on which they could state they did not want to participate. Patients who did not respond within one month were sent a reminder by mail. After another month, non-responders were reminded by a phone call. Respondents were entered in a lottery to win one of 25 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 were processed anonymously. Participants electronically provided consent for their participation in the study.

2.2. Measures and study outcomes

2.2.1. Main outcome

At T1, respondents were asked if they were recipients of benefits within the framework of the Wajong Act (yes, no) [16].

2.2.2. Independent variables

Age, medical diagnosis (classified according to International Statistical Classification of Diseases and Related Health Problems [ICD-10]), educational level [low or medium (primary school, secondary general vocation or lower vocational education); high (higher educational institutions or university)], and type of education followed in the past (mainstream, special education) were recorded at both T0 and T1; data from the T0 questionnaire established gender (female, male) and age at onset of the chronic condition (congenital and 1-5, 6-12, > 12 years). The extent of physical disability had been measured at T0 with 10 items scored on a 4-point Likert scale (1 = no physical limitations; 2 = some difficulty; 3 = great difficulty; 4 = I cannot do it) [23]. A total score was computed by summing the scores (Cronbach's $\alpha = 0.91$) [23]. At T0, data on medical diagnosis and onset of the chronic condition was verified in patient 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) by 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 $\alpha = 0.82$), knowledge about the condition (six items, Cronbach's $\alpha = 0.78$) and competencies during consultations (six items, Cronbach's $\alpha = 0.85$).

Perceived impact of the condition was measured at T0 in different ways. Adolescents reported the visibility of their chronic physical condition as well as absenteeism at school or work due to their condition by using a 3-point Likert scale (1 = never; 2 = sometimes; 3 = frequently to always). The experienced burden of visibility of the chronic physical condition was measured by 2 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 (Cronbach's $\alpha = 0.80$). The self-reporting short-form DISABKIDS questionnaire (DCGM-10) was used to assess HRQoL at T0 (Cronbach's $\alpha = 0.80$) [25].

2.2.3. Outcome measures at T1

Level of autonomy in social participation was classified by 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: finances, employment and education, housing, intimate relationships, sexuality, transportation, and leisure. It distinguishes four transition phases (0-3). Young people in phases 0 and 1 are still fully dependent on adults (e.g., parents) or display typical child behaviour. Young people 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 five-item scale. The items were derived from the 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;

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