



Original article

## Lagging Behind or Not? Four Distinctive Social Participation Patterns Among Young Adults With Chronic Conditions

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### A B S T R A C T

**Purpose:** Typical childhood and adolescent development and acquiring self-management skills are crucial for a satisfying adult life and autonomy in social participation. The aims of this study were to identify patterns of autonomy in social participation and to explore differences between these patterns.

**Methods:** Adolescents with various chronic conditions participating in a survey in 2006 (T0) were re-invited for a follow-up study (T1) in 2012. The young adults (18–25 years of age) assessed self-management skills, their condition's impact on school or work, health-related quality of life (HRQoL), and social participation in various domains. Patterns were identified through cluster analysis. Differences between patterns were analyzed in bivariate and multivariate analyses.

**Results:** Compared with healthy age-mates, our sample (n = 483) generally lagged behind in social participation. Four patterns emerged: typical developers, financially secure laggards, slow developers, and outgoing laggards. The patterns differed regarding gender, educational level, attending special education, having disability benefits, and degree of physical limitations. Groups with a higher level of autonomy in social participation did not necessarily have higher HRQoL but did report higher self-efficacy and independence at both measurements.

**Conclusions:** Autonomy in some participation domains can coincide with a lack of autonomy in others. In addition, better social participation does not necessarily correlate with higher HRQoL, or vice versa. Yet, more social participation was associated with more self-efficacy and independence. Our results emphasize that there is no standardized approach. Clinicians should take care to address all life areas in clinical practice to screen patients' lived experiences and the need for social and self-management support.

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### IMPLICATIONS AND CONTRIBUTION

Young adults with chronic conditions generally lag behind in social participation. However, distinct patterns exist, and some do even better than healthy peers. Better social participation does not necessarily correlate with higher health-related quality of life, but is associated with more self-efficacy and independence. Specialized support for these young adults is important.

The vast majority of children with chronic conditions live into adulthood [1]. Children who reach adulthood involve a role shift for both parents and health care professionals, who are

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expected to move from controlling the child's life to helping develop the young adult's self-management and social participation skills [2]. The importance of this new role is increasingly acknowledged, because a chronic condition may interfere with gaining autonomy, which is a main developmental task for young people [3]. Achieving developmental milestones and growing up into a self-efficacious individual—but also acquiring self-management skills—are crucial for a satisfying adult life

and successful fulfillment of social roles [3,4]. In turn, successful social participation positively affects one's health and well-being [4,5].

The International Classification of Functioning, Disability and Health defines social participation as a person's involvement in life situations [6] in domains of social functioning such as education, employment, leisure, and sexuality. Young adults (YAs) with chronic conditions often lag behind in social participation compared with their healthy peers [7]. In this regard, a variety of chronic conditions and physical disabilities have been associated with reduced work participation or school participation [8–10], as well as with delayed courtship, sexuality, and independent living [11–13]. To strengthen self-management and social participation skills, several interventions aimed at children, adolescents, and YAs with chronic conditions have been developed (e.g., [14–17]).

Becoming an adult involves a transition that does not occur simultaneously in all domains of functioning [18]. This is why researchers often focus on separate domains, or measure multiple domains and provide sum scores of subdomains (e.g., Life-H [19]) to describe participation and associative factors. However, this approach carries the risk of missing important information on patterns of participation in several life areas that together constitute reality for YAs. The present study aimed to identify different patterns of autonomy in social participation, and to explore how they differ with respect to self-management skills and health-related quality of life (HRQoL) of young adults now and during adolescence, as well as the impact of the chronic condition on current education or vocational participation.

## Methods

### Participants

Participants of a Web-based survey in 2006 (T0) [20] were re-invited for a similar survey 6 years later (T1). In 2006, they were adolescents aged 12–18 years had been under treatment in the Erasmus Medical Centre–Sophia's Children's Hospital Rotterdam for more than 3 years. Contact information and death notices were retrieved from the hospital's electronic patient registry. Eligible YAs received an invitation letter providing relevant information and a unique password to log in on a secured Web site. Those who did not respond within a month were sent a reminder by mail. After another month, nonresponders were reminded through a phone call. Respondents were entered in a lottery to win one of 25 cookbooks, two smart phones, or an iPad. The Medical Ethical Committee of the Erasmus Medical Centre approved the study.

### Measures

The Web-based follow-up questionnaire assessed four dimensions: (1) social participation; (2) background characteristics (including age, gender, and physical limitations); (3) aspects of self-managing the chronic condition (e.g., self-efficacy), and (4) HRQoL and the impact of the condition on school or work career. The questionnaire was based on a literature review and the previous questionnaire [21]. It was pilot-tested in face-to-face ( $n = 7$ ) and telephone ( $n = 3$ ) interviews with young people with chronic conditions, who then were not included in the final sample.

**Social participation.** Level of autonomy in social participation was classified using the Rotterdam Transition Profile (RTP) [18]. 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. Furthermore 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 behavior. Young persons in Phase 2 experiment with adult behavior or orient to it. Phase 3 refers to full autonomy in participation. Because we were interested in a successful transition to adulthood, we dichotomized the phases as follows: 0 = Phases 0–2, and 1 = Phase 3. Reference data from Dutch age-mates were extracted from the database of Statistics Netherlands (StatLine) [22] and from a report on sexual health of Dutch youths aged 15–25 years [23]. Reference data for transportation and leisure were not available, however.

**Background characteristics.** At T0, physical limitations in mobility had been assessed through a 10-item scale (Cronbach  $\alpha = .90$ ) [24]. Also, the codes from the International Classification of Diseases available in the hospital's database were used. At T1, the following sociodemographic characteristics were addressed: gender (1 = female; 2 = male), age, ethnicity (1 = Dutch surname; 2 = non-Dutch surname), level of education (1 = low [junior vocational or secondary general low]; 2 = medium [secondary general high or senior vocational]; and 3 = high [higher educational institutions or university]), and type of education followed in the past (1 = mainstream education; 2 = special education). Respondents were also asked whether they were benefit recipients within the framework of the Wajong, the Dutch Income Provision Act for Disabled Young People (1 = yes; 2 = no). Young people who are partly unable to work because of their chronic condition may be eligible to receiving these benefits [8].

**Self-efficacy and independence during hospital consultations.** Self-efficacy was measured by the On Your Own Feet Self-Efficacy Scale (OYOF-SES) using a 4-point Likert scale for every item (1 = no, definitely not; 2 = no, probably not; 3 = yes, probably; 4 = yes, certainly) [25]. It consists of three domains: coping with the condition (four items, Cronbach  $\alpha = .82$ ), knowledge about the condition (six items, Cronbach  $\alpha = .78$ ) and competencies during consultations (six items, Cronbach  $\alpha = .85$ ). The OYOF-SES is based on self-report and was included at both T0 and T1. The higher the sum score is on the OYOF-SES, the higher the self-efficacy is of the YAs. Finally, in both questionnaires, YAs rated their general independence during hospital consultations on a visual analog scale [1–10]. The higher the score was, the more independent the YA was.

**Health-related quality of life and impact of the condition on school or work career.** The HRQoL was assessed using the self-report versions of the DISABKIDS questionnaire, originally designed for children and adolescents. The T0 questionnaire presented the short form measure (DCGM-10) [26], and scores had been transformed to a scale of 0–100. At T1, five domains of HRQoL were measured with the DCGM-37 [27] on a 5-point Likert scale (1 = often; 2 = quite often; 3 = sometimes; 4 = almost never; and 5 = never): Independence (six items, Cronbach  $\alpha = .86$ ), Physical (six items, Cronbach  $\alpha = .84$ ), Emotion (seven items,

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