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## Readiness to Transfer to Adult Care of Adolescents with Chronic Conditions: Exploration of Associated Factors

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### A B S T R A C T

**Purpose:** To explore associations between adolescents' perception of their readiness to transfer to adult care and socio-demographic and disease-related characteristics, effect of the condition, self-management ability, and attitude toward transition.

**Methods:** A cross-sectional study was conducted in a Dutch university hospital, where all adolescents (12–19 years) with somatic chronic conditions (n = 3,648) were invited to participate in a web-based questionnaire. Invitations were issued to those without an intellectual disability and who had been under treatment for at least 3 years.

**Results:** In all, 30% (n = 1,087) of the adolescents responded; 954 assessed their perception of readiness for transfer. The majority (56%) felt that they were ready for transfer. Logistic regression analyses showed that 48% of the total variance in transfer readiness (TR) could be explained. Feeling more self-efficacious in skills for independent hospital visits and a greater perceived independence during consultations were found to be most strongly associated with being ready to transfer. Higher TR was associated with older age, but age did not prove to be the most important explaining variable. Adolescents with a more positive attitude toward transition and those who reported more discussions related to future transfer also felt more ready. Disease-related factors and effect of the condition including quality of life were only weakly associated with higher TR.

**Conclusions:** Adolescents' attitude to transition and their level of self-efficacy in managing self-care seem to be the keystones to TR. This study suggests that individual transition plans and readiness assessments might prove to be beneficial. Strengthening adolescents' independence and self-management competencies, combined with early preparation and repeated discussions on transition, seem to be useful strategies to increase adolescents' readiness for transfer to adult care.

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Transition of care for adolescents with chronic conditions has been much discussed, but rarely studied [1]. Blum et al. [2] define transition as “a multi-faceted, active process that attends to the medical, psychosocial and educational and vocational needs of

adolescents as they move from child-focused to the adult-focused health-care system.” Ideally, it is a purposeful, planned process, as has been advocated repeatedly in policy documents [3,4], clinical guidelines, and journal editorials [5]. However, daily clinical practice is somewhat relentless, and Viner [6] therefore aptly concluded that a major cultural shift in staff attitudes is needed as well as training. Some authors concluded that the evidence on which to build appropriate interventions is weak [7,8]. Others, however, identified essential elements for a transition program [9,10], such as having reached a certain age

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and the availability of developmentally appropriate services, early start of preparation, coordination of care, and appointment of a specific key worker [10]. One of the most important elements is that young patients need to be trained and empowered to become effective partners in their own care [6].

The term “transition” refers to the process before and after the event of “transfer”, that is, the actual shift from pediatric to adult health care [11]. For the transfer to be successful, all partners involved need to be “ready”. The process of “getting ready” then encompasses the specific decisions made and actions taken for building the capacity of the adolescent, the parents, and the providers to prepare for, to begin, to continue, and to finish the process of transition. There is no consensus on age limits for these stages. Chronological age, however, is not a sufficient criterion for transfer because physical and psychological criteria should be met as well [7,12]. A developmental perspective on adolescence provides a conceptual framework to better understand the young adult’s readiness to engage in medical therapy [13]. However, concepts such as “developmental readiness” and “social maturity” are difficult to operationalize. Only a few empirical studies have explored the factors which are indicative of readiness for transfer and the method by which readiness could be assessed [14–16].

The Pediatrics Consensus statement [3] proposes that the timing of the transfer should depend on developmental readiness, complexity of health problems, characteristics of the adolescent and family, and the availability of skilled adult health providers. Practitioners have elaborated on this, suggesting that patients should be able to self-manage care as well as understand their disease process [11,17]. Self-care responsibility may be a better predictor of readiness to transfer as compared with level of knowledge or age [12]. Therefore, one’s socio-demographic characteristics, severity and effect of the chronic condition, ability to self-manage the condition, and attitude toward the transition process are potentially relevant for transfer readiness (TR). Good self-management in chronic care requires a high level of self-efficacy [18]. Bandura [19] defines self-efficacy as one’s belief in their own capabilities to organize and execute the courses of action required to produce the given attainments.

Most studies aimed at improving transitional services focus on specific diseases, disregarding the common challenges that adolescents with all kinds of chronic conditions face [20,21]. Moreover, the prevailing perspective is that of health care providers [7]; young people’s voices on what facilitates successful transition are largely absent, with some exceptions [22–24].

The present study was concerned with the adolescents’ personal views on their own self-management competencies and their readiness to transfer. In a large sample of adolescents with all kinds of chronic conditions, we explored the associations between adolescents’ perception of their TR and the following factors: (a) socio-demographic characteristics, (b) disease-related factors, (c) effect of the condition, (d) self-management ability, and (e) attitude toward transition.

## Methods

### Participants

The target group was selected from the hospital database, which consisted of all adolescents who were aged 12–19 years and who in mid-2006 were under active long-term treatment for a somatic chronic condition either in the Department of Pediatrics or

the Department of Pediatric Surgery at the Erasmus MC-Sophia Children’s Hospital. Inclusion criteria included the following:

- Before July 1, 2006, the adolescent should have been under treatment for >3 years;
- The adolescent should have made outpatient visits and/or should have been hospitalized for at least three times in these 3 years.

Adolescents were excluded in cases where transfer to adult care had already been performed or when they had a documented diagnosis of intellectual impairment.

At the time of the research (between October and December, 2006), no transitional programs were conducted in the hospital, except for hemophilia patients. Preparation for transition and collaboration with adult health care was virtually nonexistent. Transfer usually took place at approximately 18 years of age.

Ethical approval for the study was obtained from the Erasmus MC Medical Ethics Review Board. Participants were assured of confidentiality and the data were processed anonymously. The researchers had no access to the medical records of the participants. Eligible adolescents and their parents received written information regarding the study and the adolescents were invited to complete a web-based questionnaire, which was accessible for 3 months using a unique code on a secured Internet site.

Response postcards were included to encourage adolescents to state the reasons because of which they did not qualify for the study, if this should be the case, or to provide an explanation as why they did not wish to participate in the study. All adolescents received a reminder after 3 weeks. There was no financial remuneration; however, the participants were involved in a lottery for two iPods and a cell phone.

### Measures

The questionnaire measured the following five domains: socio-demographic characteristics, variables related to disease and health care, effect of the chronic condition (including quality of life), self-management, and attitude toward transition. Table 1 shows variable descriptions, data sources, and number of items. The questionnaire was built on findings from a literature review, extensive data-analysis of our previously conducted interviews with chronically ill youth [25], and pilot tests of the draft questionnaire in face-to-face interviews with five adolescents and four parents.

### Outcome variable

Adolescents’ perception of TR was assessed by a single question “Do you think that you are ready to transfer to adult care?” (range: 1 = no, definitely not; 2 = no, probably not; 3 = yes, probably; 4 = yes, definitely).

### Socio-demographic characteristics

Data of the participants’ age, gender, and medical diagnosis (International Statistical Classification of Diseases and Related Health Problems [ICD-9 CM]) were retrieved from the hospital database. Because ethnicity is not recorded there, two researchers [A.v.S.; H.v.d.S.] classified the family names into Dutch versus non-Dutch using the Dutch Databank of Surnames. Educational level and type of education (regular vs. special education for the physically-disabled) were obtained through the questionnaire.

**Table 1**  
Overview of measurement instruments per variable and domain (n = 938)

Variable	Source <sup>a</sup>	No. of items	Cronbach's $\alpha$	Theoretical range <sup>b</sup>	Actual range	Mean (SD)
<b>Disease-related factors</b>						
Hospital admissions in past 3 years	DB	1			0–138	4.5 (9.2)
Outpatient visits in past 3 years	DB	1		$\geq 3$	3–146	16.9 (15.7)
Number of different outpatient departments visited in past 3 years	DB	1			1–15	3.1 (2.2)
Prescribed medications, diet, or exercise	Q	1		0–1	0–1	.6 (.5)
Diagnosis after age of 6	Q	1		0–1	0–1	.3 (.5)
Presence of physical limitations (AVO-99)	Q	10	.90	10–40	10–34	11.0 (3.2)
<b>Effect of condition</b>						
School/work absenteeism due to illness	Q	1		1–5	1–5	1.9 (.9)
Burden of visibility of condition	Q	2	.81	2–10	2–10	4.6 (2.1)
General Health score	Q	1		1–5	1–5	3.6 (1.0)
KIDSCREEN-10 (General health-related quality of life)	Q	10	.83	0–100	15–100	77.0 (16.3)
DISABKIDS-Short Form (impact of disease on well-being)	Q	10	.80	0–100	16–100	80.3 (15.9)
<b>Self-management</b>						
Self-efficacy in coping with condition	Q	8	.77	8–32	8–32	26.8 (4.0)
Self-efficacy in knowledge about condition	Q	10	.77	10–40	13–40	32.5 (4.8)
Self-efficacy in skills for independent hospital visits	Q	11	.88	11–44	11–44	35.1 (6.0)
Independent behavior during last consultation	Q	7	.56	0–7	0–7	2.5 (1.5)
General score of independence during consultations	Q	1		1–10	1–10	7.1 (2.0)
<b>Attitude toward transition</b>						
Attitude toward transition	Q	4	.70	4–20	4–20	12.0 (3.5)
Transition of care often discussed during consultations	Q	1		1–5	1–5	1.6 (1.0)
Importance of discussing transitional care during consultations	Q	1		1–5	1–5	3.2 (1.2)

<sup>a</sup> DB = electronic hospital database; Q = questionnaire.

<sup>b</sup> Scores are arranged so that a higher score on each variable indicates a better outcome or more absenteeism, self-efficacy, quality of life, etc.

#### Disease-related factors

Numbers of outpatient visits, hospital admissions, and the various outpatient departments visited between July 1, 2003 and June 30, 2006 were retrieved from the hospital database. Adolescents provided information related to any prescribed medication, diet, or exercises. They were also asked to assess the presence of physical limitations in mobility including independence in activities of daily living. The original 10-item scale (AVO-99 [26]) was dichotomized and in cases where any physical limitations were present, it was recorded as one.

#### Effect of the chronic condition

General health status, absenteeism from school or work because of illness in the past year, and the burden of the visibility of their condition were rated using 5-point Likert scales. Health-related quality of life was assessed by using the self-report versions of KIDSCREEN [27] and DISABKIDS [28]. The KIDSCREEN-10 Index provides a one-dimensional global health-related quality of life index with good internal consistency ( $\alpha = .82$ ) and good test-retest reliability ( $r = .73$ ; intraclass correlation coefficient [ICC] = .72) [27]. DISABKIDS Short-Form measures general quality of life and the level of distress caused by a chronic disease (impact on well-being). It consists of twelve 5-point Likert-scaled items which were assigned to the following three domains: mental, social, and physical. Two items related to the impact of medication use were excluded in the present analysis because not all respondents had a medication regimen. The remaining 10 items were combined to produce a total score and this scale was found to have good internal consistency ( $\alpha = .84$ ) [28].

#### Ability for self-management

Ability for self-management was measured through assessing self-efficacy and independent behaviors. Validated instruments measuring self-efficacy in adolescents with a variety of chronic conditions were not available. Instead, items from available self-efficacy instruments for diabetes [29], arthritis, [30] and sickle

cell disease were selected [31]. These items were supplemented with items from readiness assessments available on the Internet in 2006, such as the California Healthy and Ready To Work (CHRTW) Transition Assessment Tool [32]. Bandura's Guide was used for framing of the self-efficacy questions (How confident are you that you could successfully perform this task?) [33]. After preliminary testing of the formulations and response categories in face-to-face interviews, a final self-efficacy instrument was constructed to measure the following three nondisease-specific domains (Table 2): (1) coping with the condition (8 items), (2) knowledge of the condition (10 items), and (3) skills for independent hospital visits (11 items). Adolescents rated their self-efficacy on a 4-point Likert scale (1 = no, certainly not; 4 = yes, certainly).

Adolescents rated their general independence during hospital consultations using a visual analogue scale (range: 1–10). They assessed independent behaviors (such as actively participating in treatment decisions, talking to the doctor on your own) during their last consultation using a dichotomous 7-item scale.

#### Attitude toward transition

Four quotes, taken from adolescents' interviews [25], were presented to assess attitude toward transition: "It is a normal part of growing up"; "I am very concerned about having to leave Sophia Children's Hospital"; "I am rather looking forward to leave the Children's Hospital"; and "I do not really care where I am being treated." Responses were scored on a 5-point Likert scale (1 = totally disagree; 5 = totally agree), a higher score indicating a more positive attitude. Adolescents also stated on a 5-point Likert scale how often transition of care was being discussed during consultations and how important they considered it to be.

#### Data analysis

Data were analyzed using SPSS 17.0 (SPSS Inc., Chicago, IL). Descriptive statistics were applied. Reliability (Cronbach's alpha)

**Table 2**  
Self-efficacy scales used in the study (n = 954)

	Mean (SD)	Cronbach's $\alpha$
Self-efficacy in coping with condition		.77
I am convinced that		
I could manage to tell new classmates or friends about my condition	3.36 (.87)	
I could manage to explain my teacher or boss about my condition	3.49 (.76)	
I could manage to tell my parents or friends about being bullied	3.37 (.76)	
I could manage to tell my teacher or boss if I would be bullied	3.23 (.81)	
I could handle the fact that people may treat me "differently"	2.86 (.96)	
I can live with the knowledge that I will have my illness or disability for the rest of my life	3.31 (.88)	
I can accomplish as much as other people with the same illness or disability	3.62 (.68)	
I can accomplish as much as other people without an illness or disability	3.51 (.77)	
Self-efficacy in knowledge of condition		.77
I am convinced that		
I can clearly describe the future consequences of my illness or disability	3.16 (.81)	
I know how to reach the doctor or nurse, if necessary	3.20 (.85)	
I can tell which doctor or nurse at Sophia's takes care of me	3.36 (.87)	
I know which regimen the doctor has prescribed me (e.g., medications, diet or other lifestyle advice)	3.47 (.79)	
I could explain precisely what my regimen is for	3.39 (.75)	
I realize the future and present consequences of not adhering to my regimen now	3.31 (.85)	
I am capable of looking for information about my illness or disability myself (books, Internet, leaflets)	3.43 (.84)	
I would recognize signs of health decline or of complications of my illness or disability	3.21 (.86)	
I know at what intervals I must go back to the hospital for check-ups	3.51 (.75)	
I know what happens when I will transfer to adult care	2.46 (1.03)	
Self-efficacy in skills for independent hospital visits		.88
I am convinced that		
I could talk with the doctor on my own	3.27 (.81)	
I could make hospital appointments on my own	2.98 (.95)	
I could manage to travel to the hospital on my own	2.58 (1.14)	
I could explain the doctor how I feel and what my needs are	3.48 (.66)	
I could answer all questions of the doctor myself	3.38 (.69)	
I would dare ask the doctor anything, even about my private matters	3.06 (.86)	
I would dare ask the doctor explain things until I understand it all	3.39 (.72)	
I would dare confess to the doctor that I did not stick to my regimen or hospital appointments	3.20 (.74)	
I could deal with it if the doctor should criticize me	3.19 (.77)	
I would dare tell the doctor if I should disagree with her or him	3.23 (.76)	
I could explain to others what we discussed in the consultation room	3.29 (.77)	

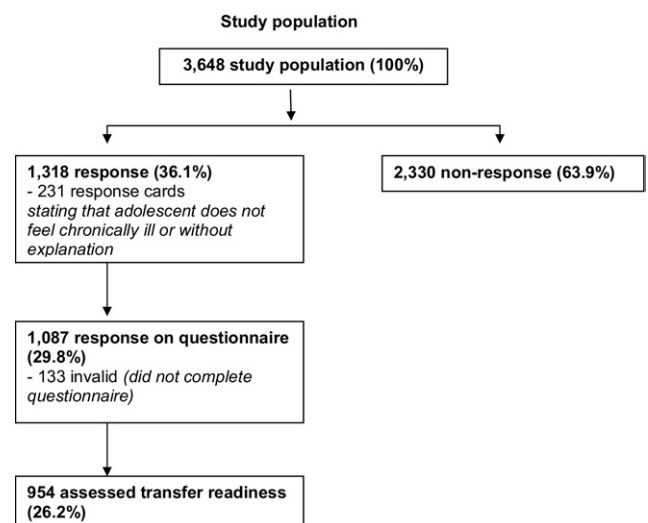
of scales was calculated. All tests were two-tailed, and *p* values of <.05 were considered to be statistically significant. Next, univariate odds ratios were calculated to explore which measures in the domains were significantly associated with the outcome variable: an adolescent's TR (0 = definitively or probably not ready; 1 = definitively or probably ready). All variables were then entered into multivariate logistic regression analyses. Odds ratios and 95% confidence intervals were calculated for all models. Nagelkerke *R*<sup>2</sup> was used to express the explained variance in each domain. The regression models analyzed the five domains separately. In the final combined model, only significant variables (*p* < .05) were included. Finally, multicollinearity was checked calculating the Variance Inflation Factor (VIF) by means of multivariate analysis.

**Results**

*Study population*

Of the original sample of 3,861, a total of 213 subjects were not included in the study because they either met the exclusion criteria (179 intellectual disabilities; four already transferred) or inadvertently did not receive the letter (n = 30). Therefore, a total of 3,648 formed the study population (Figure 1). A response was received from 1,318 adolescents (36.1%). However, 231 of them returned the response card explaining why they could not participate in the study: of these, 144 (62.3%) claimed they were

not chronically ill. Of the 1,087 questionnaires received from the adolescents (29.8%), 133 were excluded because they were incomplete, leading to a total of 954 valid questionnaires. The number of nonresponders was 2,330 (63.9%). Analyses revealed that nonresponders were more frequently males and



**Figure 1.** Study population.

**Table 3**  
Adolescents' socio-demographic and disease-related characteristics (n = 954, unless indicated)

	Source <sup>a</sup>	n	%
<b>Socio-demographic characteristics</b>			
Gender	DB		
Girls		536	56.2
Boys		418	43.8
Age	DB		
12–15 yrs		585	61.3
16–19 yrs		369	38.7
Ethnicity	DB		
Dutch surname		827	86.7
Non-Dutch surname		127	13.3
Level of education (n = 942)	Q		
Lower/middle		526	55.8
Higher		416	44.2
Type of education (n = 946)	Q		
Mainstream		852	90.1
Special		94	9.9
<b>Disease-related factors</b>			
Hospital admissions in past 3 years	DB		
0		233	24.4
1–5		510	53.5
>6		211	22.1
Outpatient visits in past 3 years	DB		
<12		484	50.7
13–24		275	28.8
>25		195	20.4
Number of different outpatient departments visited in past 3 years	DB		
1		254	26.6
2–5		569	59.6
>6		131	13.8
Prescribed medications, diet, or exercise	Q		
Yes		602	63.1
No		352	36.9
Diagnosis after age of 6	Q		
Yes (i.e. diagnosed between age 6–16)		290	30.4
No (i.e. diagnosed at birth/during first 5 years)		664	69.6
Presence of physical limitations (AVO-99)	Q		
Yes		271	28.4
No		683	71.6

<sup>a</sup> DB = electronic hospital database; Q = questionnaire.

had non-Dutch surnames, in addition, they were older and were less frequent visitors at the hospital (outpatient department and hospital admissions) as compared with responders ( $p < .05$ ).

Table 3 presents participants' characteristics. Mean age was 15.5 years (SD: 1.9); females predominated in this study; 13.3% of the participants had a non-Dutch surname. Over 90% of them lived with their parents or guardians. In all, 45% of them attended higher levels of education and 9.9% received special education for the physically disabled.

Congenital anomalies and conditions originating in the perinatal period (26.7%); neoplasms (12.7%), endocrine, nutritional, metabolic diseases, and immunity disorders (11.8%); diseases of the nervous system and sense organs (11.4%); and diseases of the musculoskeletal system and connective tissue (10.2%) were the five largest diagnostic categories (ICD-classification) in the sample.

#### Transfer readiness

About 56% of the 954 respondents perceived themselves to be "probably" (38.1%) or "definitely" (18.1%) ready to transfer to adult care (mean: 2.6; SD: .9). Univariate associations between TR and variables in the five domains are presented in Table 4.

With respect to socio-demographic variables, TR was found to be positively associated with age: the older the adolescent, the higher the TR, and regarding gender boys exhibited more readiness than girls. Twelve-year-olds scored TR with a mean of 2.0 (SD: .9); the 18-year-olds with 3.2 (SD: .8). However, 25.7% of those aged 16–19 years felt not yet ready to transfer as compared with 55.2% of those aged 12–15 years.

Associations between TR and disease-related variables were relatively weak; however, having a physical limitation or a therapeutic regimen, reporting a higher absenteeism from school, and a higher burden of the visibility of the condition were all associated with lower TR. A higher general health score and a higher quality of life (as measured with DISABKIDS) were associated with higher TR. TR scores did not differ between the five major ICD-9 groups.

#### Self-management

The 29-item self-efficacy questionnaire consisted of three factors explaining 41.8% of the variance, and showed good sampling adequacy in confirmative factor analyses (Kaiser-Meyer-Olkin [KMO] .90;  $p < .001$ ). The reliability of the three scales was good,  $\alpha$  ranging from .77 to .88 (Table 2). Among the different scales used in this study, only the scale "Independent behavior during last consultation" had a moderate reliability ( $\alpha = .56$ ) (Table 1). All self-management measures were reported to be strongly associated with TR (Table 4).

Adolescents' general attitude toward transition was found to be moderately positive. Three quarters (75.5%) of the study group responded positively to the statement that transition is "a normal part of growing up." Nonetheless, 70.2% indicated they were not looking forward to the prospect and admitted to being concerned about transition to a little or even a large extent. Only 28.6% stated they were not (at all) concerned about transition. The attitude toward transition scale showed reasonable internal consistency ( $\alpha = .70$ ) and was positively associated with higher TR. The issue of future transfer to adult care was found to be not discussed much during consultations: 65.3% stated it is never discussed, 20.3% sometimes, 6.9% regularly, and only 7.4% claim transfer is discussed (very) often. This factor was found to be associated with age—the older the participant, the more frequently the issue was discussed. Nevertheless, 45.8% of the participants considered discussing this issue as (very) important; 29.0% reported it as not being important (at all). There was a positive association between frequency of discussion and TR.

This was further investigated in the logistic regression analysis.

#### Multivariate associations

Logistic regression analyses (n = 938) explored the influences of all variables in the five domains considered potentially relevant to TR (Table 4). Most of the variance was explained by the socio-demographic characteristics, self-management measures, and the attitude toward transition. Disease-related factors and effect of the condition (including quality of life) contributed minimally to explained variance.

A final combined model that included all statistically significant variables ( $p < .05$ ) explained 48% of all variance (Table 5). Age was an important factor contributing toward "feeling more ready." Among the other socio-demographic variables, only non-Dutch ethnicity contributed significantly toward higher TR. Both the presence of a therapeutic regimen as well as a higher absen-

**Table 4**  
Univariate and multivariate<sup>a</sup> associations of variables in five domains with transfer readiness (n = 938)

Variable	Univariate analysis		Multivariate logistic regression analysis		
	OR	95% CI	OR <sup>b</sup>	95% CI	R <sup>2</sup>
Socio-demographic characteristics					.19***
Gender (male)	1.25	.96–1.62	1.46**	1.10–1.94	
Age	1.49***	1.38–1.61	1.53***	1.42–1.66	
Educational level (high)	1.22	.94–1.58	1.27	.95–1.70	
Type of education (special)	.56**	.36–.86	.51**	.31–.83	
Non-Dutch surname	1.35	.91–2.00	1.72*	1.12–2.62	
Disease-related factors					.03*
Hospital admissions in past 3 years	.99	.97–1.00	.99	.98–1.01	
Outpatient visits in past 3 years	.99	.99–1.00	1.00	.98–1.01	
Number of different outpatient departments visited in past 3 years	.97	.92–1.03	1.02	.94–1.11	
Prescribed medications, diet, or exercise	.63**	.48–.82	.67**	.51–.82	
Diagnosis after age of 6	1.16	.88–1.54	1.21	.91–1.61	
Presence of physical limitations (AVO-99)	.68**	.51–.90	.76	.56–1.02	
Effect of condition					.04***
School/work absenteeism due to illness	.74***	.64–.86	.81**	.69–.94	
Burden of visibility of condition	.88***	.83–.94	.92*	.85–.98	
General health score	1.25**	1.09–1.43	1.12	.96–1.31	
KIDSCREEN-10 (general health-related quality of life)	1.01	1.00–1.01	1.00	.99–1.00	
DISABKIDS-Short Form (impact of disease on well-being)	1.02**	1.01–1.02	1.01	.99–1.02	
Self-management					.24***
Self-efficacy in coping with condition	1.07***	1.04–1.11	1.00	.96–1.04	
Self-efficacy in knowledge of condition	1.16***	1.07–1.13	1.01	.97–1.04	
Self-efficacy in skills for independent hospital visits	1.16***	1.13–1.20	1.11***	1.08–1.15	
Independent behavior during last consultation	1.35***	1.27–1.53	1.05	.94–1.18	
General score of independence during consultations	1.49***	1.38–1.61	1.27***	1.16–1.38	
Attitude toward transition					.30***
Attitude toward transition	1.32***	1.26–1.39	1.35***	1.28–1.42	
Transition of care often discussed during consultations	1.78***	1.51–2.11	1.92***	1.60–2.30	
Importance of discussing transitional care during consultations	1.01	.91–1.13	1.03	.91–1.17	

OR = odds ratio; CI = confidence interval; R<sup>2</sup> = explained variance by Nagelkerke R-square test.

\* p < .05

\*\* p < .01

\*\*\* p < .001

<sup>a</sup> The multivariate analyses were conducted for each domain separately. The multivariate models only included the variables listed in each domain.

<sup>b</sup> Adjusted for the variables in the domain only.

teeism because of illness contributed toward lower TR; other disease-related variables did not contribute toward TR. More self-efficacy skills for independent behavior in the hospital and a higher score of general independence during consultations contributed toward a higher TR. Having a more positive attitude toward transition and reporting more discussions about transfer during consultations were also significantly associated with higher TR.

As our analyses involved concepts that may be interrelated, we checked for multi-collinearity. In all models of the multivariate analysis, the VIF was never higher than 2.24. In the combined model, VIF ranged from 1.00 to 1.59, confirming that collinearity is not a problem.

**Discussion**

This study investigated factors that might be associated with perception of being ready to transfer to adult care. Age proved to be an important factor in this sense, whereas other socio-demographic variables and disease-related factors (including quality of life) did not prove to be important. Moreover, adolescents' attitude toward transition and their level of self-efficacy in managing day-to-day self-care and in hospital consultations were strongly associated with TR.

Similar to our study, other studies have also reported that TR is positively influenced after reaching a certain age [3,12]. More-

over, as seen in our study, Lutz Stehl [34] also reported no significant association between other demographic and disease variables and adolescent-rated readiness. McPherson et al. [16], however, found that severity of disease had a negative effect on patients' interest in transition and anticipated difficulty of transfer.

The fact that disease-related variables are not related to TR in our study may support the idea that transition issues are not unique to any disease process, but are instead universal among all those growing up with special health care needs [21]. Similar to other studies, our adolescents were moderately concerned about the forthcoming transition [24,35]. This study also supports the idea that health care professionals may facilitate TR by paying more attention to transition preparation [6,10].

The pivotal importance of adolescents being self-efficacious in managing consultations for TR is in line with other studies [36–38] and recommendations [4]. Because we used general measures to assess self-efficacy, we could not establish correlations between TR and self-efficacy related to treatment regimen, but a study on diabetes found self-efficacy to be an important predictor of self-care behavior and clinical outcomes [13]. Moreover, in a 3-year follow-up study of adolescents with sickle cell disease, self-efficacy in disease management predicted whether the individual would remain in care after transfer to adult care [39]. We expected that self-efficacy related to competencies in everyday self-management would have a strong association with TR.

**Table 5**  
Combined model in logistic regression analysis with transfer readiness; including all variables significant at  $p < .05$  in Table 4 ( $n = 938$ )

Variable	Adjusted <sup>a</sup> OR	95% CI	R <sup>2</sup>
Combined model			.48***
Gender (male)	.78	.55–1.11	
Age	1.43***	1.29–1.59	
Type of education (special)	.84	.46–1.52	
Non-Dutch surname	1.66*	1.01–2.73	
Prescribed medications, diet, or exercise	.70*	.49–1.00	
School/work absenteeism due to illness	.80*	.66–.96	
Burden of visibility of condition	.95	.88–1.03	
Self-efficacy in skills for independent hospital visits	1.07***	1.03–1.10	
General score of independence during consultations	1.25***	1.14–1.38	
Attitude toward transition	1.36***	1.28–1.44	
Transition of care often discussed during consultations	1.56***	1.26–1.92	

OR = odds ratio; CI = confidence interval; R<sup>2</sup> = explained variance by Nagelkerke R<sup>2</sup> test.

\*  $p < .05$

\*\*\*  $p < .001$

<sup>a</sup> Adjusted for all variables listed in the table.

### Strengths and limitations

This study gave voice to a large sample of adolescents with a wide range of chronic conditions and yielded valuable information regarding their perceived readiness to transfer of care. The sample was heterogeneous with respect to congenital and acquired conditions, and age. The sample had its origin from the largest university hospital in the Netherlands, which includes all major pediatric subspecialties. However, the very fact that the study sample included adolescents with a wide range of chronic conditions made it impossible to explore relations between TR and specific conditions or disease severity.

The nonresponse rate in this broad sample was fairly high (64%), probably because candidates were approached through an impersonal letter and were asked to access the questionnaire on the Internet. From the returned response postcards, it appeared that many adolescents did not consider themselves as chronically ill. This may be because of knowledge deficits regarding the nature of their condition, but it may also reflect lay views on when you are considered to be “ill” and on the importance of “being normal.” The fact that nonresponders were less frequent hospital visitors than responders may imply that they represent a healthier population, although it may also indicate no-show. The nonresponse analysis revealed that, notably, older adolescents, boys, and adolescents with non-Dutch surnames were underrepresented in the sample. This might have affected the outcomes, considering that TR was associated with age and ethnicity. It is impossible, however, to tell in what way.

Most of the measurement scales were newly designed for the purpose of this study. The internal reliability of each of the new scales was within the range of reasonable to good, but further validation is warranted. Several concepts, including the main outcome variable, were made on the basis of single questions, thereby limiting reliability.

Choosing a nondisease-specific sample limited the inclusion of more specific self-management measures related to self-efficacy and actual self-management of day-to-day therapy, as more than one-third of the total sample did not have a therapeutic regimen.

A generic and a disease-specific approach, each is known to have their own value [20].

Although self-report is useful for collecting information on perceived readiness, this method cannot fully capture the complex range of actual behaviors that characterize self-management and transition readiness. A partial solution could be found in comparing adolescent self-report of readiness with the perspectives of parents or health care providers, and to assess adolescents' actual knowledge of the transitional process. McPherson et al. [16] found that adolescents with sickle cell disease knew little about the basic steps involve in the transition to adult-oriented care.

### Recommendations for further research

The final multivariate model has indicated relevant factors explaining the readiness felt by the adolescents, but it requires further investigation. Future studies should include measures on adolescent development and self-management related to treatment regimen. Also, use of transition readiness assessment instruments deserves scientific evaluation [15], as it is not known whether these have any predictive value for a successful transition.

### Clinical implications

To enhance TR, health care providers should focus on improving adolescents' competency and behavioral skills [12], without failing to enhance and assess adolescents' knowledge of their condition and treatment. Introducing independent visits, that is, without the parents present, when the time is ripe, is a powerful strategy to prepare adolescents for transition and to assess self-management [1,10,37,38]. A timely start and greater attention to transitional care issues during consultations may help to instigate more positive attitudes in young adolescents and parents toward transition and may also increase TR [11,40]. Adolescents may overrate their readiness for transfer, but might later be confident of being ready to transfer after receiving appropriate instruction and support. Formulating self-management assessments and individual transition plans could really make a difference [4,38].

This study also demonstrates that young people with any chronic illness have many aspects in common [21], thereby supporting the implementation of generic transition readiness assessments such as the new Transition Readiness Assessment Questionnaire (TRAQ) [15].

### Conclusion

Apart from age, adolescents' attitude toward transition, and their level of self-efficacy in managing day-to-day self-care and hospital consultations seem to be the keystones to TR. Strengthening adolescents' independence and self-management competencies, combined with early preparation and repeated discussions about the forthcoming transition, seems to be a useful strategy in increasing adolescents' readiness to transfer.

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