

# Controlled evaluation of a transition clinic for Dutch young people with cystic fibrosis

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## Abstract

**Background:** Transition clinics (TCs) are advocated as best practice to support young people with cystic fibrosis (CF) during transition to adulthood and adult care. We aimed to research the functioning of a TC for young people with CF compared with direct hand-over care and to evaluate whether those treated at the TC have better transfer experiences and outcomes compared with the control group.

**Methods:** Mixed-methods retrospective controlled design, including interviews with professionals, observations of clinics, chart reviews (at four measurement moments), and patient surveys. Qualitative data analysis focused on organization and daily routines, and barriers and facilitators experienced. Young people's transfer experiences, self-management, health care use, and clinical outcomes were assessed quantitatively.

**Results:** The most notable feature distinguishing the TC and direct hand-over care comprised joint consultations between pediatric and adult care professionals in the former. A transition coordinator was considered essential for the success of the TC. The main barriers were lack of time, planning, and reimbursement issues. Young people treated at the TC tended to have better transfer experiences and were more satisfied. They reported significantly more trust in their adult care professionals. Their self-management-related outcomes were less favorable.

**Conclusions:** The TC had several perceived benefits and showed positive trends in transfer experiences and satisfaction, but no differences in health-related outcomes. Structured preparation of young people, joint consultations with pediatric and adult care professionals, and better coordination were perceived as facilitating elements. Further improvement demands solutions for organizational and financial barriers, and better embedding of self-management interventions in CF care.

## KEYWORDS

adolescents, mixed-methods, transfer, transitional care

## 1 | INTRODUCTION

In the Netherlands, around 1500 people live with cystic fibrosis (CF) and more than half are over 18 years of age.<sup>1</sup> Their life expectancy has improved and is likely to improve further with the advent of CF transmembrane conductance regulator modulator therapies.<sup>1,2</sup> CF care in the Netherlands has been concentrated in seven centers, each with an adult and a pediatric department. Although treatment protocols are standardized across these centers,<sup>3</sup> differences in the organization of care continue to exist.

Young people with CF may experience difficulty entering into adulthood as developmental milestones can clash with the demands of the disease.<sup>4</sup> Independence and autonomy are compromised by frequent pulmonary exacerbations and may accentuate the feeling of being different from healthy peers.<sup>5</sup> Patients should be made aware early on in life of fertility concerns, genetic implications of CF, and short life expectancy.<sup>5</sup> Young people with CF also need to prepare for the transfer from pediatric to adult-oriented health care, which means bridging the gap between these settings.<sup>6-8</sup> Because this coincides with physical and psychosocial changes, therapy adherence may be threatened with risk of loss of pulmonary function, lowering of body mass index (BMI), and hospitalizations.<sup>9-11</sup> It is widely acknowledged that young people with CF should receive the appropriate support during the transitional phase.<sup>7,9,12,13</sup>

A transition clinic (TC) is often advocated as best practice for this type of support.<sup>14,15</sup> Although there is no shared model, the TC's core principle is that professionals from both pediatric care (PC) and adult care (AC) deliver outpatient care in preparation for the upcoming transfer.<sup>14</sup> Studies evaluating TCs in CF care have reported improved health status, self-care and self-advocacy skills, and more independence.<sup>2,11,12,16-18</sup> However, most studies did not include a controlled pre-post outcome evaluation, and the body of evidence for effects is still small. Also, daily routines and protocols differ considerably between TCs.<sup>9,14</sup> Despite the expected positive impact, the contributions of the different components and the experiences of young people and professionals are still unclear.<sup>12</sup> This study aimed to evaluate the functioning and outcomes of a TC compared with a control setting with direct hand-over care. Our hypothesis is that young people with CF treated at the TC will have more positive transfer experiences and will show better self-management, health care use, and clinical outcomes around the transfer.

## 2 | MATERIALS AND METHODS

### 2.1 | Setting and design

This study involved a retrospective, controlled mixed-methods evaluation of a TC for young people with CF. Two of the largest CF centers in university hospitals in the Netherlands, each treating 200 to 300 patients a year, participated. One had implemented a TC in 2009; the other served as control setting providing direct hand-over care. The settings were compared on structures and daily routines, health care use, clinical- and self-management outcomes, and experiences

and satisfaction with the transfer. Experienced barriers and facilitators for the functioning of the TC and perceived benefits were also studied. The study protocol has been published elsewhere.<sup>19</sup>

### 2.2 | Participants

Health care professionals (HCPs) from relevant disciplines in both settings were interviewed. All young people who transferred between 2010 and 2013 (2-4 years before data collection) were included in a chart review and were asked to fill out a survey. Those with known intellectual disabilities or psychiatric conditions were excluded.

### 2.3 | Data collection

#### 2.3.1 | Qualitative part

In semistructured interviews, HCPs were encouraged to share their experiences and expectations regarding transitional care. Topics addressed were organization and structure, facilitators and barriers, content of consultations, use of interventions, and potential improvements. HCPs working at the TC were also asked about perceived benefits.

Nonparticipant observations of outpatient consultations between young people, their parents (if present), and HCPs were conducted at both settings. Two observations of 4 hours each were performed at the TC and two observations of, respectively, 3 and 2 hours in the control setting. In addition, a multidisciplinary meeting of pediatric and adult HCPs at the TC was observed, in which they discussed the patients' psychosocial status. In the control setting, a regular multidisciplinary meeting of pediatric HCPs was observed. The observers focused on coordination of the transition process, structure and content of consultations, interaction between involved parties, and use of interventions.

#### 2.3.2 | Quantitative part

A set of background, process, and outcome variables was selected that previously had been found essential for a successful transition.<sup>19</sup> Table 1 provides an overview of our operationalization and data collection method per variable. Patient data from four measurement moments were collected: T1, the 2 years before transfer; T2, the 1 year before transfer; T3, the 1 year after transfer; and T4, the 2 years after transfer. The young people who provided consent for the chart review were invited to fill out an online survey. A reminder was sent to nonresponders after 2 weeks, followed by a telephone call after 4 weeks.

### 2.4 | Data analysis

#### 2.4.1 | Qualitative part

Interviews were audio-recorded and transcribed ad verbatim; observation field notes were recorded in narratives. Atlas.ti 7.0 was used for data analysis. Two researchers (MP and JS) independently

**TABLE 1** Operationalization of background characteristics, process, and outcome measures<sup>a</sup>

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review) <sup>b</sup> or measurement tool used (survey)
<i>Background characteristics</i>				
	Gender	Male/female	Chart review	
	Ethnicity	Caucasian/mixed/African American	Chart review	
	Date of birth	dd/mm/yyyy	Chart review	
	Date of transfer	dd/mm/yyyy	Chart review	T3
	Transferred to	Internal/external	Chart review	T3
<i>Process outcomes</i>				
Health care use	No-show at first appointment in adult-care	Yes/no	Chart review	T3
	Scheduled consultations	Number per year	Chart review	T1, T2, T3, T4
	Hospitalizations related to condition	Number per year	Chart review	T1, T2, T3, T4
	Emergency department visits related to condition	Number per year	Chart review	T1, T2, T3, T4
<i>Outcome measures</i>				
Clinical	Height	Value (cm)	Chart review	T1, T2, T3, T4
	Weight	Value (kg)	Chart review	T1, T2, T3, T4
	BMI	Value	Chart review	T1, T2, T3, T4
	Pulmonary functioning <sup>c</sup>	FEV1 value (L)	Chart review	T1, T2, T3, T4
	Acute pulmonary exacerbations	Use of antibiotics (yes/no, frequency per year)	Chart review	T1, T2, T3, T4
Health care-related	Transition experiences and satisfaction with transfer	Experiences on two domains: (1) organization of health care related to transition and (2) satisfaction with preparation to transfer	Survey	On Your Own Feet Transfer Experiences Scale (OYOF-TES) <sup>28</sup> (validated 18-item scale with 5-point Likert scales, $\alpha = .93$ ) + self-reported satisfaction on a 1-10 scale
	Trust in health care providers	Trust in pediatric and adult care providers	Survey	Self-reported trust on a 1-10 scale
	Perceived patient-centeredness of care	Patient-centeredness of adult care providers	Survey	Subscale "patient-centeredness" of the American Consumer Assessment of Health Plan Surveys <sup>28,29</sup> (validated 5-item scale with 4-point Likert scales ( $\alpha = .90$ ))
Self-management-related	Self-management	Chronic condition self-management	Survey	Partners in Health Scale (PIH) <sup>30</sup> (validated 12-item scale with 9-point Likert scales, $\alpha = .82$ )
	Independence during consultations	Self-reported independent behavior during consultations with health care providers	Survey	Independent Behaviors During Consultations (IBDCS) <sup>28</sup> (validated 7-item scale with 5-point Likert Scales, $\alpha = .79$ ) + self-reported independence on a 1-10 scale
	Self-efficacy	Disease-related self-efficacy on four domains: (1) knowledge about the condition, (2) coping, (3) competencies during consultations, and (4) medication	Survey	On Your Own Feet Self-Efficacy Scale (OYOF-SES) <sup>31</sup> (validated 16-item scale with 4-point Likert scales, $\alpha = .85$ )
	Adherence	Self-reported adherence to medical treatment	Survey	Medication Adherence Rating Scale (MARS-5) <sup>32</sup> (validated 5-item scale with 5-point Likert scales, $\alpha = .77$ ) + self-reported adherence on a 1-10 scale
Quality of life	Health-related quality of life	Health-related quality of life on four domains: (1) physical, (2) emotional, (3) social, and (4) school/work	Survey	Pediatric Quality of Life Inventory Young Adult (PedsQL-YA) <sup>33</sup> (validated 23-item scale with 5-point Likert scales, $\alpha = .93$ )

Abbreviations: BMI, body mass index.

<sup>a</sup>Based on previously published study protocol (Sattoe et al, 2016).<sup>b</sup>T1: 2 years before transfer; T2: 1 year before transfer; T3: 1 year after transfer; and T4: 2 years after transfer.<sup>c</sup>FEV1% predicted was calculated based on age, gender, ethnicity, height and FEV1 value by using the calculator of the Global Lung Function Initiative (<http://glistransfer.org.au/calcs/spiro.html>).

analyzed the data by using the framework approach, whereby themes addressed during the interviews and observations were leading in the coding process. If applicable, subthemes were derived from the data.

## 2.4.2 | Quantitative part

Analysis of variance tests were used to investigate within-group differences on clinical outcomes and health care use over the four measurement moments. Independent samples *t*-tests and Pearson's  $\chi^2$ -tests were performed to compare the TC and control setting on chart review and survey outcomes. Effect sizes were calculated to indicate the magnitude of the observed effects, as they are not affected by the sample sizes, unlike *P*-values (Cohen's *d* = 0.2 small effect, 0.5 medium, and 0.8 large). Spearman's tests were used to examine correlations. Statistical analyses were performed with IBM SPSS 26.0.

## 2.5 | Ethical considerations

All young people provided written consent for the different study parts in which they were included after they received the appropriate information. Quantitative data were processed anonymously, and pseudonyms were used in the interview transcripts and observation narratives. The Medical Ethics Review Board of Erasmus Medical Center approved the study protocol (MEC-2014-246).

## 3 | RESULTS

### 3.1 | Response

Ten HCPs were interviewed in the TC setting and 18 in the control setting. Table 2 provides a description of the study sample.

## 3.2 | Structure and organization

In the TC setting, young people were invited for a final visit to the pediatric clinic, including joint consultations with: (a) their current pediatric pulmonologist and their future adultcare pulmonologist, and (b) the nurses from both settings. This one-time visit was additional to the regularly scheduled multidisciplinary outpatient visits (four times a year). In the control setting, no special transition arrangements were arranged apart from these regular visits. Here, young persons and their parents said farewell during the final consultation with the pediatric pulmonologist. In the period between the last appointment in PC and the first appointment in AC, the pediatric pulmonologist was in charge of treatment decisions in case of unforeseen circumstances. This was the case in both the TC and control setting. Table 3 provides more detailed information on the characteristics of care provision of these two centers and their pediatric and adult clinics, and presents the differences in structures and daily routines between both settings.

## 3.3 | Interview results

### 3.3.1 | Perceived benefits of a TC

Professionals at the TC perceived several benefits. In PC, HCPs appreciated the planned farewell moment. They found that preparation for transfer had improved:

*"It really helps to prepare children. [...] Now they know that something is going to happen which could have a high impact on them. That was not the case before, when it was abrupt and we got a lot of reactions afterwards. [...] So, it is much better organized and less stressful for the patients than before." (TC; pulmonologist PC)*

**TABLE 2** Description of the total study sample

	TC	Direct hand-over care	P-value <sup>a</sup>
Professionals interviewed	n = 10 Pediatric pulmonologists (3); pediatric nurses (2); pediatric psychologist; pediatric psychotherapist; pulmonologist adult care; nurse adult care; psychologist adult care	n = 18 Pediatric pulmonologists (4); pediatric gastroenterologists (2); pediatric nurses (2); pediatric social workers (2); pediatric psychologist; pediatric dieticians (2); pediatric physiotherapists (2); pulmonologist adult care; nurses adult care (2)	NA
Young people with CF	n = 27	n = 19	
Gender (male)	13 (48.1%)	10 (52.6%)	.765
Age	22.56 ( $\pm 1.22$ )	22.26 ( $\pm 1.33$ )	.444
Age at transfer <sup>b</sup>	18.31 ( $\pm 0.618$ )	18.36 ( $\pm 0.633$ )	.812
Department to which young person transferred is recorded/known (yes)	27 (100%)	18 (94.7%)	.413

Abbreviations: TC, transition clinic.

<sup>a</sup>Independent samples *T*-test or the Pearson's  $\chi^2$ -test/Fischer's exact test.

<sup>b</sup>N = 26 in the TC group and n = 14 in the control setting because, respectively, n = 1 and n = 5 respondents did not give permission for chart review.

**TABLE 3** Differences in structures and daily routines between TC setting and control setting

Characteristics of care	TC setting	Control setting
Location	Pediatric and adult clinic are colocated on the same campus.	Pediatric clinic is located on two different campuses in the city, adult clinic is centralized on one of these campuses.
Electronic medical record system (EMR)	Pediatric and adult clinic use the same EMR.	Pediatric and adult clinic that are colocated on the same campus use the same EMR; the other pediatric clinic (located on a different campus) uses paper charts.
<i>Transition</i>		
Team of professionals	Pediatric pulmonologists, pediatric nurses, pediatric psychologist, pediatric psychotherapist, pulmonologist AC, nurse AC, and psychologist AC.	Pediatric pulmonologists, pediatric gastroenterologists, pediatric nurses, pediatric social workers, pediatric psychologist, pediatric dieticians, pediatric physiotherapists, pulmonologists AC, and nurses AC.
Start of the transition phase	From 12 y by using the Individual Transition Plan.	Stimulating self-management skills from 12 y, specific attention for transfer from around 16 or 17 y.
Use of self-management interventions	Knowledge tool, Cystic Fibrosis Questionnaire (CFQ), Individual Transition Plan, independent consultations with young people (without parents present).	Knowledge tool, Cystic Fibrosis Questionnaire (CFQ), KLIK PROfile (a web-based application for the use of patient reported outcomes), independent consultations with young people (without parents).
<i>Transfer</i>		
Setting of effectuation	Pediatric clinic.	Pediatric clinic (one of the two locations).
Visitors	Young people with CF aged 17 or 18 y, with or without their parents.	Young people with CF until age of 18 y, with or without their parents.
Working ways	TC with joint consultations, written transfer (EMR).	Written transfer (EMR or paper chart), multidisciplinary CF team meeting with professionals from PC and AC (doctors, nurses and paramedics; every month; alternately on each of the two campuses).
Structure and organization	<ol style="list-style-type: none"> <li>1. Joint consultation with pediatric pulmonologist and adult pulmonologist. Just before the young person enters the consultation room, the pulmonologists briefly talk about the patient's situation.</li> <li>2. Joint consultation with pediatric nurse and adult nurse.</li> </ol>	<ol style="list-style-type: none"> <li>1. Multidisciplinary pediatric CF team meeting.</li> <li>2. Consultation of pediatric pulmonologist with young person.</li> </ol>
Topics discussed (content)	<i>During preliminary discussion between pulmonologists:</i> Pediatric pulmonologist informs the adult pulmonologist about the young person and his/her situation. Themes addressed are the medical situation, independent behavior, and (relation with) parents.	<i>During multidisciplinary team meeting:</i> Discussion of the most striking issues regarding patients' current situation and relevant historical occurrences, such as therapy adherence and clinical outcomes, hospital admissions, self-management skills, risk behavior, and school situation. Not only about transferring patients but about all children who are planned for an outpatient visit that day.
	<i>During joint consultation of pediatric and adultcare pulmonologist with young person (with or without parents present):</i> Young persons are asked about their disease and therapy adherence, and a physical examination is performed. Subsequently, the adult pulmonologist explains about structures and routines in AC (ie, the outpatient clinic and the team of professionals) and differences with PC are discussed. Attention is paid to young people's responsibility regarding therapy adherence and to social participation (eg, sport, driving license, school, and work).	<i>During individual consultation of pediatric pulmonologist with young person (with or without parents present):</i> Attention is paid to medical subjects (ie, symptoms, treatment, and adherence) and nonmedical subjects (ie, study, work, sport, transition in care, and the importance of independent behavior). Sometimes other relevant professionals—like a physiotherapist or a psychologist—participate in the care process, dependent on the young person's individual situation and needs. The overall care trajectory is coordinated by the pediatric nurse specialist.
	<i>During joint consultation of pediatric and adultcare nurse with young person (with or without parents present):</i> Focus is on preparing young persons and their parents for the transfer to AC. Practical things are discussed, such as the way outpatient visits are organized, logistics, and attainability. Attention is also paid to differences with PC; young people receive an information bulletin about the AC setting. Moreover,	

(Continues)

**TABLE 3** (Continued)

Characteristics of care	TC setting	Control setting
	the nurses suggest a guided tour to become familiar with the new setting. After providing information and instructions, the nurses inquire young people about their attitude toward the upcoming transfer. They are asked about their transfer readiness (possibly also of their parents), their experiences with taking up responsibility and self-management, for instance in self-care, therapy adherence, and social participation (school/work and future plans). The pediatric nurse also asks if the young person agrees with transferring the Individual Transition Plan to AC.	
Follow-up after transfer within the same hospital	By an adult pulmonologist, the same who was involved in the TC.	By an adult pulmonologist, the same who was involved in monthly meetings and discussions about the CF patients.

Abbreviations: AC, adult care; EMR, electronic medical record system; PC, pediatric care; TC, transition clinic.

*"Professionals from adult care say: 'We see different young people and parents transferring.' That is nice to hear. I hear nurses and the doctor say that things went better last years. They see changes and the transfer goes more smoothly." (TC; nurse PC)*

The joint consultations provided HCPs from AC with a more holistic view of the transferring patient. The pulmonologist explained: "It is no longer the case that you just hand over the person. Instead, 'This is the patient as a whole: this is his disease, this is his personality and these are goals or concerns.' I think that's the secret of a good transition, that you know all these facets."

Moreover, using an Individual Transition Plan (ITP) from around the age of 12 creates structure and continuity in the preparation for transfer. "The ITPs are also transferred at the TC, so that we are fully aware of the young persons' preparation and information so far, and things that need special attention from us" (TC; nurse AC).

The TC also facilitates finetuning of the care trajectory between PC and AC: "Two distinct worlds have to communicate with each other, two settings. [...] It is, of course, paramount that this runs smoothly and that we know what our colleagues from PC have done and how we can best continue" (TC; psychologist AC). HCPs in the control setting miss such joint care arrangements: "A transition clinic, where young people are seen by the pulmonologists and the nurses from PC and AC, would be really valuable [...]. Such a transition process, with more intensive consultation between pediatric and adult professionals, would improve [the quality of] care" (control; nurse AC).

### 3.3.2 | Facilitators and barriers for transitional care

Professionals in the TC setting considered intrinsic motivation and commitment as prerequisites for a successful TC.

*"It is all about the willingness and the effort of a group of people to work together." (TC; psychotherapist PC)*

*"Everyone is convinced that it is better to do it this way. Despite the busy schedules [...], it's everyone's intention to make time for transition." (TC; pulmonologist AC)*

Starting paying attention to transition at an early stage is essential according to professionals from both settings. This helps to better prepare young people and their parents for their final visit to the pediatric clinic. Also, flexibility in the moment of transfer is required.

*"We start at the age of 12: 'Listen, from now on you are going to manage your medication by yourself [...] because when you reach 18, you should be able to do it on your own.' So, we emphasize that very often and it is no longer a surprise. I think it is important to announce [the transfer] far in advance and repeat it over and over." (TC; pulmonologist PC)*

*"I think we need to be more alert. We only wake up when the date of transfer comes really close. Now it is like: 'Oh, he or she is 17, we have to get started with a number of things.' That should be earlier." (Control; pulmonologist PC)*

Several professionals pointed out that it helps when a member of the care team takes up a coordinating role in this process, preferably "a dedicated nurse specialist". This transition coordinator is not only important for logistics, but also to ensure an early start, to serve as a spokesperson for young people and parents, and to create a sense of urgency for adequate transitional care in both teams.

*"The nurse is often easily accessible; patients dare to tell more to their nurse than to their doctor, also about*

nonmedical issues. Nurses can act as a link between the patient and other professionals; so that a more holistic view of the patient can be established." (Control; pulmonologist AC)

Professionals also reported several barriers to the organization and functioning of the TC. First, lack of time; their work schedules hardly left any room for extra or longer consultations or additional team meetings. Presently, the TC only involved one moment of joint care, which was not always enough.

"Time is always limited while the [transition] consultation has two goals, as we also use it for regular follow-up [next to preparation for the transfer]." (TC; pulmonologist PC)

"Nowadays, everyone is too busy. [...] I think that our collaboration suffers from that. Because there is just too little time to think about things quietly and to align or fine-tune things." (Control; social worker PC)

Lack of financial support is another important barrier as transitional care is not reimbursed. One of the TC pediatric pulmonologists illustrates this: "At regular consultation hours you see ten children and at the transition clinic only four." Potential barriers may also lie within a setting's culture, policy, and ways of working.

"We are used to discuss and explain things, and to make shared decisions. In adult care, information is provided, but in the end the patient decides." (TC; nurse PC)

"We always try to make it as easy as possible for our patients. So, when an appointment has to be rescheduled, I schedule a new one. [...] When something is wrong with medication, we call the pharmacy. [...] This is not how it

works in adult care, where patients have to do it all by themselves." (Control; nurse PC)

According to some adult HCPs, PC is made "too attractive," pointing at the high level of involvement and sense of responsibility for young persons' health. They think that this increases the gap and thus impedes the transfer to AC. About content of care at the TC, professionals mentioned lack of uniformity in the preparation trajectory, despite the use of the ITP. A pediatric pulmonologist said: "Regularly I have consultations with youth aged 12 to 18 in which I do not think about transition at all and no one points this out to me." Professionals in the control setting also did not always address transition, thereby leaving the young persons and their parents wondering what to expect from transition and when it was going to happen. Furthermore, professionals from both settings emphasized that their transitional care would benefit from more availability of allied health professionals, more attention for psychosocial aspects, and more independent consultations (without parents).

### 3.4 | Transfer experiences and satisfaction with transition

Analysis revealed a trend of higher scores for transfer experiences among those treated at the TC compared with those treated in direct hand-over care. The difference was not statistically significant; the effect size was medium ( $d = 0.48$ ). The same was the case for reported satisfaction with transition ( $d = 0.68$ ) (Table 4). Looking at individual items of the Transfer Experiences Scale (5-point Likert scales; 1 = strongly disagree, 5 = strongly agree), young people treated at the TC had more often met their adult HCPs before transfer ( $3.73 \pm 1.27$  vs.  $2.14 \pm 1.23$ ,  $P < .01$ ;  $d = 1.25$ ) and reported more trust in their adult HCPs ( $4.73 \pm 0.467$  vs.  $4.21 \pm 0.426$ ,  $P < .01$ ;  $d = 1.11$ ). They assigned higher scores to the experienced alignment in the ways of working and dealings between PC and AC ( $3.45 \pm 1.13$  vs.  $2.93 \pm 0.917$ ). This difference was

**TABLE 4** Differences in health care and self-management related outcomes

	TC (n = 11) <sup>a</sup>	Control setting (n = 14) <sup>b</sup>	Effect size <sup>c</sup>	P-value <sup>d</sup>
<i>Health carerelated</i>				
Transfer experiences (OYOF-TEs)	71.73 ( $\pm 8.84$ )	67.50 ( $\pm 7.83$ )	0.48	.218
Satisfaction with transition (VAS; range 1-10)	8.00 ( $\pm 1.27$ )	7.14 ( $\pm 1.03$ )	0.68	.074
Perceived patient-centeredness of care (CAHPS)	17.60 ( $\pm 2.07$ )	17.57 ( $\pm 2.74$ )	0.01	.978
<i>Self-management related</i>				
Self-management skills (PIH)	78.00 ( $\pm 8.41$ ) <sup>e</sup>	83.29 ( $\pm 6.43$ )	-0.63	.094
Independence during consultations (range 1-10) (IBDCS)	8.67 ( $\pm 0.866$ ) <sup>f</sup>	9.29 ( $\pm 0.914$ )	-0.68	.121
Self-efficacy (OYOF-SES)	57.90 ( $\pm 3.00$ ) <sup>e</sup>	56.00 ( $\pm 10.93$ )	0.17	.600
Adherence to treatment (MARS-5)	21.80 ( $\pm 2.20$ ) <sup>e</sup>	20.00 ( $\pm 3.49$ )	0.52	.165
Health-related quality of life (PedsQL-YA)	72.17 ( $\pm 14.44$ ) <sup>e</sup>	73.84 ( $\pm 18.53$ )	-0.09	.815

Abbreviation: TC, transition clinic.

<sup>a</sup>n = 11 (40.7%) responded to the survey.

<sup>b</sup>n = 14 (73.7%) responded to the survey.

<sup>c</sup>Cohen's  $d$  (based on largest SD).

<sup>d</sup>Independent samples T-test.

<sup>e</sup>n = 10.

<sup>f</sup>n = 9.

not significant; the effect size was medium ( $d = 0.46$ ). There was no difference in perceived patient-centeredness of adult HCPs.

### 3.5 | Self-management related outcomes

There were no significant differences regarding self-management. Still, effect sizes show some trends. Young people in the TC setting tended to report better medication adherence than those in the control setting ( $d = 0.52$ ) (Table 4). However, they also tended to report lower scores on self-management and independence during consultations; effect sizes were medium (respectively  $d = -0.63$  and  $d = -0.68$ ).

### 3.6 | Differences in health care use and clinical outcomes

Young people who received care at the TC were significantly more often admitted to hospital in the two years after transfer than those in direct hand-over care ( $P = .045$ ,  $d = 0.45$ ) (Table 5). This may be related to poorer pulmonary functioning, as they had lower FEV1% predicted over the whole period compared with those in the control setting. Before transfer, these differences were not statistically

significant; effect sizes were medium (T1:  $P = .173$ ,  $d = -0.40$ ; T2:  $P = .145$ ,  $d = -0.49$ ). After transfer, the differences were significant with large effect sizes (T3:  $P = .003$ ,  $d = -1.03$ ; T4:  $P = .007$ ,  $d = -1.06$ ). Within-subject analyses showed a significant linear decrease of FEV1% predicted over the four measurement moments in the TC group ( $F(2.22, 40.03) = 5.89$ ,  $P = .004$ ). There was no significant difference in FEV1% predicted over time within the control group. The correlation between pulmonary functioning and satisfaction with transition was not significant ( $r_s = 0.298$ ,  $P = .203$ ).

## 4 | DISCUSSION

In this study, we found that joint consultations between professionals from PC and AC are generally preferred over direct hand-over transfer, and that having a dedicated transition coordinator is important in transitional care. This is confirmed in several other studies.<sup>20-22</sup> A coordinator at both sites of transition helps to secure organizational and health care related issues, given the array of new services that were to be accessed.<sup>21</sup> For successful transitional care, it also appears essential to address transition and self-management

**TABLE 5** Differences in health care use and clinical outcomes

	TC		Control setting		Effect size <sup>a</sup>	P-value <sup>b</sup>
<i>No-show at first appointment in AC<sup>c</sup></i>						
	n = 26	1 (3.8%)	NA	NA	NA	NA
<i>No. of hospital admissions</i>						
T1	n = 26	0.65 ( $\pm 1.13$ )	n = 14	0.36 ( $\pm 0.842$ )	0.26	.395
T2	n = 26	0.58 ( $\pm 1.10$ )	n = 14	0.43 ( $\pm 1.09$ )	0.14	.686
T3	n = 26	0.54 ( $\pm 0.811$ )	n = 12	0.50 ( $\pm 0.798$ )	0.05	.892
T4 <sup>d</sup>	n = 26	0.54 ( $\pm 1.03$ )	n = 12	0.08 ( $\pm 0.289$ )	0.45	.045
<i>No. of emergency department visits</i>						
T1	n = 26	0.23 ( $\pm 0.815$ )	n = 14	0.07 ( $\pm 0.267$ )	0.19	.484
T2	n = 26	0.31 ( $\pm 1.05$ )	n = 14	0.21 ( $\pm 0.579$ )	0.09	.760
T3	n = 26	0.04 ( $\pm 0.196$ )	n = 12	0.58 ( $\pm 0.996$ )	-0.54	.086
T4	n = 26	0	n = 12	0.08 ( $\pm 0.289$ )	-0.28	.339
<i>FEV1% predicted<sup>e</sup></i>						
T1	n = 25	78.11 ( $\pm 18.54$ )	n = 12	88.41 ( $\pm 25.84$ )	-0.40	.173
T2	n = 23	73.88 ( $\pm 17.28$ )	n = 12	87.55 ( $\pm 28.16$ )	-0.49	.145
T3	n = 24	70.48 ( $\pm 19.07$ )	n = 10	94.89 ( $\pm 23.59$ )	-1.03	.003
T4	n = 22	67.56 ( $\pm 22.51$ )	n = 10	93.08 ( $\pm 24.15$ )	-1.06	.007
<i>No. of acute exacerbations</i>						
T1	n = 27	0.67 ( $\pm 0.832$ )	n = 14	1.29 ( $\pm 1.98$ )	-0.31	.280
T2	n = 23	0.35 ( $\pm 0.775$ )	n = 14	1.86 ( $\pm 2.57$ )	-0.59	.050
T3	n = 25	0.76 ( $\pm 1.27$ )	n = 12	0.75 ( $\pm 1.49$ )	0.01	.983
T4	n = 25	0.72 ( $\pm 1.28$ )	n = 12	0.50 ( $\pm 0.798$ )	0.17	.588
<i>BMI</i>						
T1	n = 25	21.02 ( $\pm 2.14$ )	n = 12	20.45 ( $\pm 2.42$ )	0.24	.473
T2	n = 24	21.22 ( $\pm 2.19$ )	n = 12	20.68 ( $\pm 3.00$ )	0.18	.544
T3	n = 16	20.62 ( $\pm 2.60$ )	n = 6	22.34 ( $\pm 2.84$ )	-0.61	.193
T4	n = 17	20.94 ( $\pm 3.04$ )	n = 6	22.36 ( $\pm 2.62$ )	-0.47	.321

Abbreviations: BMI, body mass index; TC, transition clinic.

<sup>a</sup>Cohen's  $d$  (based on largest SD).

<sup>b</sup>Independent samples  $T$ -test or Pearson's  $\chi^2$ -test.

<sup>c</sup>No data available from the control setting, except that we know that one of the patients was lost to follow-up after transfer.

<sup>d</sup>T1: 2 years before transfer; T2: 1 year before transfer; T3: 1 year after transfer; T4: 2 years after transfer.

<sup>e</sup>Calculation based on guidelines of the Global Lung Function Initiative (<http://gligasttransfer.org.au/calcs/spiro.html>).

skills from an early age on. The interviewed professionals perceived several benefits of the TC, such as obtaining a holistic view of the transferring patient and fine-tuning of care between the settings. Professionals also noted that young people and their parents had more confidence in the transfer since they started seeing them at the TC. Indeed, the young people treated at the TC reported significantly more trust in their adult HCPs than those receiving direct hand-over care. This is probably because the former had met their new HCPs more often before transfer, which is considered one of the most effective mechanisms of transition programs.<sup>12,23</sup>

A contra-intuitive outcome of our study was that young people in the TC group had lower scores on self-management outcomes compared with those in the control group. The qualitative study revealed that self-management interventions (eg, ITPs) are not always used as intended. When embedded in routine, ITPs can facilitate the discussion about patient's and parents' perceptions of transition readiness.<sup>13</sup> Besides this, it is important to provide young people with room for mastering self-management tasks, eg, by organizing independent consultations with young people alone (without parents) more frequently during the transition phase.<sup>24</sup> It remains a misconception, however, that young patients are all on their own when they transfer to AC. Our results showed that pediatric HCPs still take over young people's responsibilities, instead of encouraging them toward more independence. Pediatric HCPs may be projecting their own concerns onto their young patients, thereby hindering patient empowerment.<sup>12,25</sup>

Many professionals mentioned lack of time, planning difficulties, and reimbursement issues as barriers for the organization and functioning of a TC. These organizational barriers are not unique to the CF setting. The need to close the gaps in transitional care delivery and staff support is often mentioned.<sup>26</sup> To optimize the organization and functioning of a TC, the microsystem level (patient, family, and the care team) should receive support from the mesosystem (hospital) and macrosystem level (governance).<sup>27</sup> In current daily practice, this higher-level support seems insufficient.

Looking at health care use and clinical outcomes, we found few significant results. However, most of these are probably not related to having a transition program in place. The lower FEV1% predicted values in the TC group compared with the control group hold for the entire study period, suggesting higher disease severity in the former. This could also explain the higher number of hospital admissions in the TC group in the second year after transfer. Also, other factors outside the scope of this study might have been of influence, such as differences in practice patterns and preferences despite widely utilized protocols.

#### 4.1 | Strengths and limitations

This evaluation study included a unique controlled pre-post design with a reasonably long study period. The mixed-methods approach helped gaining insight into the organization and functioning of the TC and perceived facilitators and barriers.

The relatively small number of participants may have negatively impacted the study's statistical power. Analysis showed some trends toward better transfer experiences in the TC setting, although few findings were statistically significant. Furthermore, the study was conducted in two academic medical centers in the Netherlands, using different electronic medical record systems. Insight into clinic attendance around the time of transfer was limited by the variation in registration of scheduled consultations and the lack of systematic recording of missed consultations. As both centers are following the Dutch Guideline Diagnostics and Treatment Cystic Fibrosis<sup>3</sup> recommending four multidisciplinary consultations a year, differences regarding scheduled consultations are not expected. We initially intended to compare both centers on the primary outcome of no-show after transfer,<sup>19</sup> but unfortunately these data were not available for the control setting. What we do know, however, is that one patient in the control setting was lost to follow-up in the two years after transfer to AC.

## 5 | CONCLUSION

We uncovered some benefits of an outpatient TC for young people with CF, from the perspective of the surveyed young people themselves and that of the interviewed professionals. No notable differences in health-related outcomes were found. Joint consultations in combination with a transition coordinator and an early started and structured process of preparation were considered facilitators for successful transitional care. For further improvement, organizational and financial barriers need to be addressed. This requires support from the meso and macro levels. It would be helpful to embed self-management interventions in routine transitional care.

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## CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

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