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The added value of transition programs in Dutch diabetes care: A controlled evaluation study

Mariëlle A.C. Peeters, MSc^{a,b,*}, Jane N.T. Sattoe, PhD^{a,b}, Madelon B. Bronner, PhD^{a,1}, Roland A. Bal, PhD^b, AnneLoes van Staa, PhD MA MD RN^{a,b}

^a Rotterdam University of Applied Sciences, Research Center Innovations in Care, P.O. Box 25035, 3001 HA Rotterdam, the Netherlands

^b Erasmus University Rotterdam, Erasmus School of Health Policy & Management, P.O. Box 1738, 3000 DR Rotterdam, the Netherlands

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ABSTRACT

Purpose: The desirability of evaluating transition programs is widely acknowledged. This study aimed to explore the added value of transitional care investments for young adults with type 1 diabetes mellitus.

Design and methods: Based on qualitative data, two groups of diabetes teams were created through cluster analysis: paying more (HI-ATT) versus less attention (LO-ATT) to transitional care. Retrospective controlled evaluation included chart reviews on healthcare use and clinical outcomes; and a survey on young adults' experiences, satisfaction with care, and self-management skills.

Results: Data from 320 patients in fifteen diabetes teams were collected; 123 young adults (38.4%) completed a questionnaire. Self-reported outcomes showed that young adults treated by a HI-ATT team felt better prepared for transfer ($p < .05$). Self-management outcomes did not differ between groups. HI-ATT teams had more scheduled consultations in the year after transfer ($p < .05$); only 10.6% of all measurements had reached targeted HbA1c scores.

Conclusions: Current transitional care investments in Dutch diabetes care did not lead to notable improvements in experiences and outcomes, except for preparation for transfer. The period after transfer, however, is just as important. Attention is required for parent involvement.

Practice implications: Transitional care investments should extend beyond the transfer. By educating young adults about the importance of regular clinic attendance and introducing additional person-centered consultations in adult care, nurses may help ensure continuity of care. Nurses could also introduce support programs for parents to prepare for the transition and their change in role, taking into account their continuing partnership.

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Introduction

Health prospects of young adults with chronic conditions have improved, especially regarding type 1 diabetes mellitus (T1DM) (Michaud et al., 2018; Zhou et al., 2016). Still, T1DM patients' transition from adolescence to adulthood – referring to the process of moving from being a child to becoming a young adult including the transfer from pediatric to adult healthcare – is characterized by risk and vulnerability (Cameron et al., 2018; White et al., 2018). These young adults have to take up responsibility for self-management of the disease in the context of competing developmental tasks, such as changing social

relationships, shifting roles between them and their parents, and academic and career demands (Agarwal et al., 2017). The transition period has been associated with less outpatient hospital clinic attendance and more dropout or disengagement from specialist services (White et al., 2017). Psychosocial issues are common in this phase, and young T1DM patients have significantly higher rates of diabetes-related distress than other age groups (Iyengar et al., 2019). These issues could lead to deterioration of glycosylated hemoglobin (HbA1c) levels with an associated increase in acute and even chronic complications such as ketoacidosis or microvascular problems (Burns et al., 2018; Clements et al., 2016; Farrell et al., 2018; Gray et al., 2018).

Both national (Dutch Diabetes Federation, 2020) and international (DiMeglio et al., 2018; National Institute for Health and Care Excellence, 2016) healthcare standards and consensus guidelines acknowledge the importance of and the need to improve transitional care. Still, many young patients experience large care gaps when transitioning from pediatric to adult settings, causing discomfort, confusion and high rates of loss to follow-up (Agarwal et al., 2017; Goralski et al., 2017;

* Corresponding author at: Rotterdam University of Applied Sciences, Research Centre Innovations in Care, P.O. Box 25035, 3001 HA Rotterdam, the Netherlands.

E-mail addresses: m.a.c.peeters@hr.nl (M.A.C. Peeters), j.n.t.sattoe@hr.nl (J.N.T. Sattoe), r.bal@eshpm.eur.nl (R.A. Bal), a.van.staa@hr.nl (A. van Staa).

¹ Present address: Erasmus University Medical Center, Department of Dermatology, P.O. Box 2040, 3000 CA Rotterdam, the Netherlands

Van Staa et al., 2011; Zhou et al., 2016). From a professional viewpoint, treatment of patients in the transition phase is also challenging, as pediatric and adult care providers have their own working ways (e.g., with regard to consultation and the use of electronic medical record systems) and clinical guidelines (e.g., about monitoring glycemic control).

Several interventions have been developed and implemented to bridge the gap between pediatric and adult care, and to support young adults and healthcare professionals; from educational programs and skills training to appointing transition coordinators and setting up transition clinics (Crowley et al., 2011). Various interventions have shown promising benefits for young adults with T1DM, but evaluation of multifactorial transition programs remains complex (Le Roux et al., 2017). It is not feasible to implement all interventions at every center, and generalizability is often limited due to differing study designs and outcome measures (Campbell et al., 2016; White et al., 2017). As a result, factors that effectively influence the transition process are still poorly understood (Betz et al., 2018; Chu et al., 2015; Colver et al., 2018; Gray et al., 2018; Schultz & Smaldone, 2017; Sheehan et al., 2015). Consensus on the definition of transition success is lacking, and little high-quality evidence on which to base transition practice is available (Campbell et al., 2016; White et al., 2017).

This study, part of a national quality improvement initiative (called 'Better Transition in Diabetes') to advance transitional care in diabetes (Van Staa et al., 2020), was designed to explore the added value of transitional care investments for young adults (aged 16–30 years) with T1DM in the Netherlands. In this context, transitional care investments are all efforts made by diabetes care providers aimed at improving the quality of transitional care. The final aim was to provide additional insight into the benefits of transitional care investments with regard to transfer experiences and satisfaction, self-management-related outcomes, healthcare use and clinical outcomes.

Methods

Study aim and design

We performed a retrospective, controlled evaluation of process, clinical and patient-reported outcomes – based on the original study design of Sattoe et al. (2016). Using a mixed methods approach, this evaluation focuses on the expected added value of transitional care investments containing different elements. Qualitative data were collected through observing healthcare professionals' consultations with young adults with T1DM and semi-structured interviews with healthcare professionals, and served as input for categorizing the participating diabetes teams into two groups for quantitative comparison. The quantitative evaluation included medical chart reviews and an online questionnaire among young adults with T1DM (Table 1).

Setting and participants

All medical centers in the Netherlands providing care to young adults with T1DM were invited for participation in the project, conducted between 2016 and 2018. Representation of the multidisciplinary teams of professionals from both pediatric and adult diabetes care was required, as well as the intention to further improve transitional care arrangements. Fifteen hospitals signed up for participation. A consultant (JH/AvS) and a researcher (MP/JS) visited each team to further explain the project, answer questions and arrange start of the data collection. These intake interviews also served to map the centers' organization of the outpatient care for young adults with T1DM.

One hospital withdrew during the project due to staff shortages; two other hospitals did not participate in the research part because they could not comply with the study protocol, leaving twelve hospitals

participating. Three had recently merged and provided care at multiple locations with different teams of healthcare providers and different transitional pathways. In total, fifteen multidisciplinary teams of diabetes care providers from both pediatric and adult care were included, such as diabetes specialist nurses, nurse practitioners, pediatricians, endocrinologists, dieticians, and psychologists. We evaluated data of all patients who had a confirmed diagnosis of T1DM (irrespective of the time elapsed since diagnosis), had made the transfer to adult services in the 2012–2014 period, had no cognitive impairment, and were able to speak and read Dutch.

Data collection

Previously, a general survey among Dutch professionals working in pediatric and young adult diabetes care revealed large differences in the design and execution of transitional care (Van Staa et al., 2020). This was confirmed during the intake interviews in the participating teams. We inventoried the transitional care arrangements in each diabetes team at the start of the program using various methods, following the original study design (Sattoe et al., 2016). Input came from the intake interviews at the start of the program, semi-structured interviews with professionals from both pediatric and adult care ($n = 41$), and observations of health professionals' consultations with young adults in both settings ($n = 57$). Themes addressed were organization, structure and working ways, content of transitional care arrangements, and experienced barriers and facilitators. The quality of care of each team was rated on the eight core elements of the 'On Your Own Feet' transitional care framework (Fig. 1) (Van Staa et al., 2020).

For the quantitative evaluation, we collected a set of background, process and outcome variables. Data from the chart reviews ($n = 320$) included, among other things, no-show (primary process outcome), scheduled consultations, emergency department visits, hospital admissions, and HbA1c levels. These data were collected at four measurement moments: T1, two years before transfer; T2, the year before transfer; T3, the year after transfer; and T4, two years after transfer. For practical and ethical reasons, T3 and T4 data were only available for young adults who had transferred to adult care within the same hospital ($n = 293$). All 320 young adults were invited to fill out an online questionnaire about their transfer experiences (primary patient-reported outcome), containing the following aspects: reception in adult care, alliance between pediatric and adult care, preparation for the transfer, readiness to transfer, and youth involvement (Van Staa & Sattoe, 2014). Trust in care providers and coping with T1DM were also explored in the questionnaire. Reminders were sent after two and four weeks. Table 1 provides an overview of the operationalization and data collection method per variable.

Data analysis

Qualitative part

On the basis of our rich qualitative data set, we established detailed reports on each participating diabetes team, in which we described their setting, composition of the team, and their organization of transitional care. A member check was conducted to assess the accuracy with which these reports represented the team's actuality. The eight core elements of good transitional care were leading in our thick descriptions; the elements were divided into three categories of interventions: 1) interventions to improve the organization of care; 2) interventions to stimulate independence and self-management of young adults; and 3) collaboration with young adults and within the multidisciplinary team of professionals representing both pediatric care and adult care (Van Staa et al., 2020). A detailed description of the eight elements is presented in Appendix A.

Table 1
Operationalization of background characteristics, process and outcome measures.^a

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review) ^b or measurement tool used (survey)
Background characteristics	Gender	Male/female	Chart review	
	Date of birth	dd/mm/yyyy	Chart review	
	Transferred to Age at transfer	Intern/extern In years	Chart review Chart review	T3 T3
Process outcomes Medical follow-up	Last appointment pediatric care	dd/mm/yyyy	Chart review	T2
	First appointment adult care	dd/mm/yyyy	Chart review	T3
	No-show at first appointment in adult care	Yes/no/unknown	Chart review	T3
	Scheduled physical consultations	Number per year	Chart review	T1; T2; T3; T4
	Missed 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	Number per year	Chart review	T1; T2; T3; T4
Outcome measures Clinical	HbA1c	All observed values per year	Chart review	T1; T2; T3; T4
	Healthcare-related	Transfer experiences	Survey	On Your Own Feet – Transfer Experiences Scale (OYOF-TES) (validated 20-item scale with 5-point Likert scales, $\alpha = 0.64-0.86$) (Van Staa & Sattoe, 2014)
Satisfaction with transition		Satisfaction with the overall process of transfer to adult care	Survey	Self-reported satisfaction on a 1–10 scale
Self-management-related	Trust in healthcare providers	Trust in pediatric and adult care providers	Survey	Self-reported trust on a 1–10 scale
	Self-management skills	Self-management of chronic condition	Survey	Partners in Health Scale (PIH) (validated 12-item scale with 9-point Likert scales, $\alpha = 0.82$) (Petkov et al., 2010)
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	PedsQL 4.0 adult version (validated 23-item scale with 5-point Likert scales, $\alpha = 0.77-0.94$) (Limperg et al., 2014)

^a Based on study protocol published elsewhere (Sattoe et al., 2016).

^b T1: second year before transfer; T2: year before transfer; T3: year after transfer; and T4: second year after transfer.

Three researchers independently scored each team on the eight elements. Scores ranged from 1 – indicating ‘minimal transitional care’ – to 4 – indicating ‘excellent transitional care’. Teams that used systematic interventions for transitional care – i.e., concrete tools or instruments to arrange transitional care – received higher scores. Examples of interventions are multidisciplinary team consultation meetings, independent consultations with young adults (without parents), transition protocols, transition coordinators, and individual transition plans (Van Staa et al., 2020). Kendall's *W* was calculated to measure concordance of raters' scores on the eight core elements (0 = no agreement among raters; 1 = complete agreement among raters). The mean Kendall's *W* coefficient was 0.579, indicating moderate agreement. Consensus on the scores was established in a research team meeting. The scores for each element were then summed up (minimum = 8; maximum = 32), resulting in a highest score of 26 and a lowest of 10.

Quantitative part

To enable further quantitative analysis, an exploratory hierarchical cluster analysis using the within-groups linkage method was performed to cluster teams (Mooi & Sarstedt, 2011). The summed consensus scores served as input for the cluster analysis. Two distinctive groups were derived from the dendrogram resulting from the hierarchical cluster analysis. Subsequently, K-means clustering with two clusters resulted in a group of five teams with a final cluster center of 13.8, indicating less attention for transitional care (LO-ATT), versus ten teams with a final

cluster center of 21.3, indicating more attention for transitional care (HI-ATT) ($p < .01$).

The resulting format was used to compare consensus-based mean scores on the eight core elements and the presence of transition interventions between both groups of diabetes teams. Process, clinical and patient-reported outcomes were also compared between the two groups. Independent samples *t*-tests and Pearson chi-square tests served to compare chart review and survey outcomes. Effect sizes were calculated to measure the magnitude of the differences between both groups (Cohen's $d = 0.2$ small effect, 0.5 medium and 0.8 large). Overall within-group differences over the four years of measurement were tested with paired samples *t*-tests; correlations were examined with Pearson's and Spearman's tests. To investigate differences and interactions on transfer experiences and transition satisfaction, healthcare use, and HbA1c levels, mixed repeated measures analyses of variance (ANOVA) were performed using measurement moment (T1-T4) as within-factor and group of teams (HI-ATT versus LO-ATT) as between-factor. SPSS 26.0 was used to perform the statistical analyses.

Ethics approval and consent to participate

The Ethics Review Board of Erasmus MC approved the original study protocol (Sattoe et al., 2016) as well as the updated protocol in which diabetes specific outcomes were described. Ethical approval was also obtained from all local hospital review boards. Teams and young adults were informed about the goals of the research orally and in writing, and

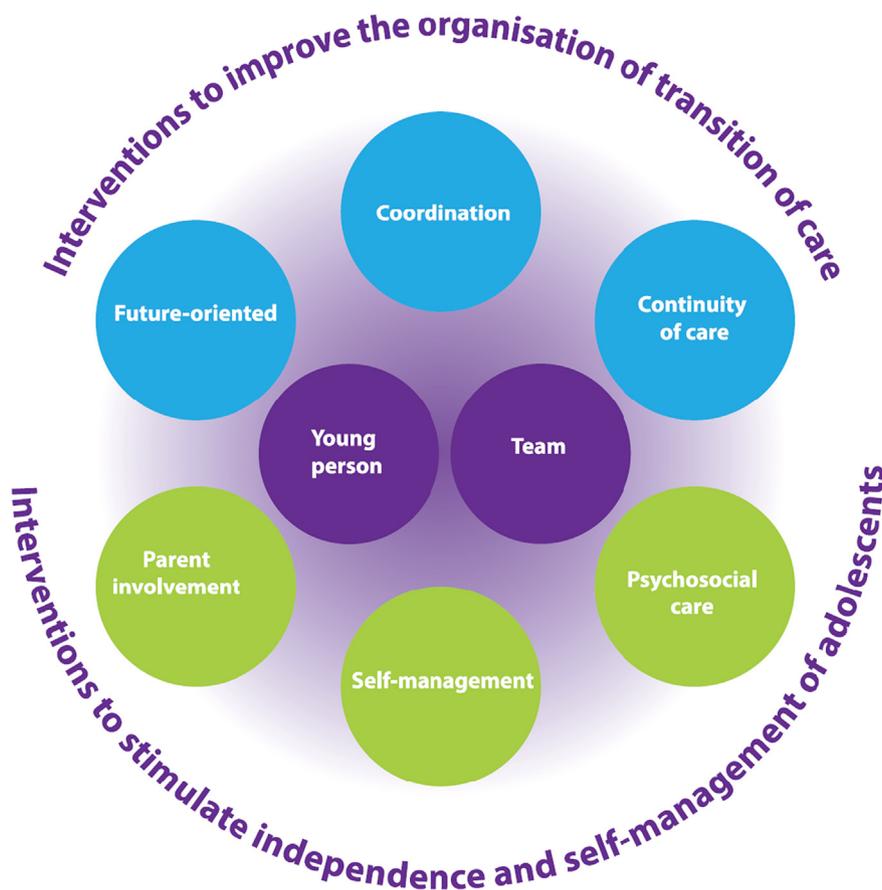


Fig. 1. Transitional care framework 'On Your Own Feet' (Van Staa et al., 2020).

they were ensured complete confidentiality and anonymity. All young adults gave consent; to enhance participation, every third respondent to the online questionnaire received a €20 gift voucher.

Results

Response and background characteristics

Table 2 provides a description of the total study sample of 320 young adults with T1DM who were included in the chart review; 38.4% (n = 123) responded to the online questionnaire. The non-responders (n = 197) did not differ from the responders in age (23.6 ± 1.38 versus 23.9 ± 1.51; p = .106), but they were more often male (62.9% versus 40.7%; p = .000). Five teams also invited patients who had made the transfer in 2015 and 2016 to complete the online questionnaire, which resulted in 19 additional responses on the self-reported outcomes.

Table 2
Total study sample of young adults with type 1 diabetes (n = 320).

	LO-ATT teams (n = 130)	HI-ATT teams (n = 190)	p-value ^a
Gender (male)	66 (50.8%)	108 (56.8%)	0.284
Age	23.71 (±1.42)	23.71 (±1.44)	0.988
Age at transfer ^b	18.64 (±1.77)	18.62 (±1.11)	0.905
Transfer within the same hospital ^c	118 (92.9%)	175 (92.6%)	0.914
Response to online survey	53 (40.8%)	70 (36.8%)	0.478

^a Independent Samples t-test or Pearson Chi-Square Test (p < .05).
^b n = 128 in the LO-ATT group and n = 184 in the HI-ATT group.
^c n = 127 in the LO-ATT group and n = 189 in the HI-ATT group; the other patients have become lost to follow-up after transfer to adult care.

In both groups of teams, more than 90% of the young adults (118/130 in LO-ATT teams and 175/190 in HI-ATT teams) transferred to adult services within the same hospital. There were no statistically significant differences in the background characteristics of young adults between the two groups. Regarding the core elements of the 'On Your Own Feet' framework, HI-ATT teams scored significantly higher on all eight elements except for parent involvement (p < .05) (Table 3). The effect sizes for all eight core elements are large (d > 0.82). Regarding the use of specific transitional care interventions, only one notable difference was found. All HI-ATT teams organized joint consultation sessions (i.e., transition clinics) wherein young people are seen by professionals from both pediatric and adult care at the same time, in contrast to only two of the LO-ATT teams (100% versus 40%; p = .022).

Transfer experiences, satisfaction, self-management and quality of life outcomes

Regarding young adults' transfer experiences, no significant differences were found between HI-ATT and LO-ATT teams, except for the subscale 'Preparation for the transfer' (Table 4). Those treated by a HI-ATT team felt better prepared for transfer to adult care than those treated by a LO-ATT team (3.16 ± 0.86 versus 2.83 ± 0.99, p = .042). Moreover, Spearman's test showed a moderate positive correlation of preparation for transfer with overall satisfaction with transition (r_s = 0.517; p = .000). Individual item analysis of the Transfer Experiences Scale revealed that the young adults in the HI-ATT group had more often met their new healthcare providers before the transfer (p = .044), and more often felt having received enough information about the transfer (p = .016). Additionally, they more often judged the timing of the transfer to be just about right (p = .012). Those treated by a LO-

Table 3
Overview of transitional care interventions and consensus-based mean scores on the eight core elements.^a

	LO-ATT teams (n = 5)	HI-ATT teams (n = 10)	Effect size ^b	p-value ^c
<i>Consensus-based mean scores on the eight core elements (1 = minimal transitional care; 4 = excellent transitional care)</i>				
Future-oriented	1.60 (±0.55)	2.50 (±0.58)	1.55	0.029*
Coordination	1.60 (±0.89)	2.90 (±0.88)	1.46	0.028*
Continuity of care	2.20 (±0.84)	3.30 (±0.82)	1.31	0.042*
Parent involvement	1.60 (±0.55)	2.40 (±0.97)	0.82	0.063
Self-management	1.60 (±0.55)	2.60 (±0.52)	1.82	0.010*
Psychosocial care	2.20 (±0.45)	2.80 (±0.42)	1.33	0.038*
Youth participation	1.40 (±0.55)	2.30 (±0.68)	1.32	0.020*
Team collaboration	2.00 (±0.00)	2.50 (±0.53)	0.94	0.015*
<i>Transitional care interventions</i>				
Transition coordinator	2 (40%)	6 (60%)	NA	0.608
Transition protocol (in use)	0 (0%)	2 (20%)	NA	0.524
Multidisciplinary team consultation meetings with pediatric and adult care providers	1 (20%)	4 (40%)	NA	0.600
Joint consultation	2 (40%)	10 (100%)	NA	0.022*
Structural support for parents	1 (20%)	2 (20%)	NA	1.000
Structural use of a quality of life questionnaire	1 (20%)	7 (70%)	NA	0.119
Structural use of an individual transition plan	0 (0%)	3 (30%)	NA	0.505
Independent consultations with young adults (without parents)	1 (20%)	4 (40%)	NA	0.600

^a Based on the transitional care framework 'On Your Own Feet' (Van Staa et al., 2020).

^b Cohen's *d* (based on largest SD).

^c Independent Samples *t*-test or Fisher's Exact Test.

* Significant at $p < .05$.

ATT team more often reported that the new care providers were well informed about them and their condition ($p = .040$).

Overall satisfaction with transition was scored with a mean of 7.01 (± 1.53 , $n = 167$), and was strongly correlated with the transfer experiences sum score ($r_s = 0.737$; $p = .000$). In this regard, there was no significant difference between the groups of teams ($p = .856$). The young adults, on average, showed significantly more trust in their pediatric healthcare providers than in their adult healthcare providers (8.24 ± 1.73 versus 7.54 ± 1.77 , $p = .001$; $n = 168$). Trust in healthcare providers was not significantly different between the HI-ATT and LO-ATT groups, and neither were health-related self-management and quality of life outcomes (Table 4). Spearman's test showed a weak correlation between the transfer experiences sum score and trust in pediatric healthcare providers ($r_s = 0.170$; $p = .028$) and a moderate correlation between the transfer experiences sum score and trust in adult healthcare providers ($r_s = 0.492$; $p = .000$).

Healthcare use

Overall, young adults had significantly more scheduled consultations in pediatric care than in adult care (14.77 ± 11.35 versus 11.67 ± 7.51 , $p = .000$). The number of missed consultations had significantly increased after transfer (0.66 ± 1.44 versus 1.14 ± 1.98 , $p = .000$). In the two years before transfer, 30.1% ($n = 94$) of the young adults had missed at least one scheduled consultation, compared to 42.0% ($n = 123$) in the two years after transfer.

Looking at the differences between HI-ATT and LO-ATT teams (Table 5), we found that the HI-ATT teams had more scheduled consultations in the year after transfer (7.38 ± 4.49 versus 5.97 ± 4.24 , $p = .006$). Mixed repeated measures analyses showed a significant interaction effect between the measurement moment (T) and the group of teams on the number of scheduled consultations ($p = .014$). In the LO-ATT teams, the decrease in the number of scheduled consultations

Table 4
Differences in transfer experiences, satisfaction with transition and self-management skills.

	LO-ATT teams (n = 56)	HI-ATT teams (n = 85)	Effect size ^a	p-value ^b
<i>Mean scores on OYOF-TES subscales (1 = strongly disagree; 5 = strongly agree)</i>				
Reception in adult care ($\alpha = 0.861$)	4.03 (±0.72)	3.88 (±0.89) ^c	0.17	0.295
Alliance between pediatric and adult care ($\alpha = 0.832$)	3.18 (±0.96)	3.16 (±0.83)	0.02	0.909
Preparation for the transfer ($\alpha = 0.637$)	2.83 (±0.99)	3.16 (±0.86)	-0.33	0.042*
Readiness to transfer ($\alpha = 0.796$)	3.93 (±0.71)	4.11 (±0.63)	-0.25	0.102
Youth involvement ($\alpha = 0.671$)	3.32 (±0.98)	3.26 (±1.00)	0.06	0.740
Total score	70.68 (±13.30)	72.01 (±12.15)	-0.10	0.540
<i>Overall satisfaction and trust (0–10 scale)</i>				
Overall satisfaction with transition	7.11 (±1.57)	7.15 (±1.49) ^d	-0.03	0.856
Trust in pediatric healthcare providers	8.05 (±1.74)	8.48 (±1.51)	-0.25	0.123
Trust in adult healthcare providers	7.82 (±1.42)	7.38 (±2.04)	0.22	0.129
<i>Self-management and quality of life outcomes</i>				
Self-management skills (PIH)	80.84 (±7.98)	79.60 (±9.25) ^d	0.13	0.412
Health-related quality of life (PedsQL-YA)	79.55 (±13.29) ^e	78.23 (±16.02) ^d	0.08	0.613

^a Cohen's *d* (based on largest SD).

^b Independent Samples *t*-test.

^c $n = 86$.

^d $n = 84$.

^e $n = 55$.

* Significant at $p < .05$.

in the years before transfer, from T1 to T2, was significantly bigger than in the HI-ATT teams ($F(1, 288) = 5.38, p = .021$).

Clinical outcomes

Mean HbA1c scores did not change over time ($p = .836$); they were elevated across the whole study period with no significant differences between pediatric and adult care (71.04 ± 14.52 versus $70.72 \pm 14.48, p = .683; n = 261$). The mean HbA1c scores also did not differ between the LO-ATT and HI-ATT teams, and the development of glycemic control over time was not significantly different between both groups ($p = .358$).

Considering the International Society of Pediatric and Adolescent Diabetes (ISPAD) Clinical Practice Consensus Guidelines (DiMeglio et al., 2018), only 10.6% of our T1-T4 measurements ($n = 114$) met targeted HbA1c scores of ≤ 53 mmol/mol (for children, adolescents and young adults until the age of 25 years); 14.6% of the measurements ($n = 157$) scored very high (≥ 86 mmol/mol). HbA1c measurements were carried out more often in pediatric than in adult care (5.64 ± 2.44 versus $4.40 \pm 2.10, p = .000; n = 261$). Moreover, those with higher HbA1c scores were seen more often in pediatric care than in adult care ($r = 0.187, p = .001$).

Discussion

This study compared two groups of healthcare teams that differed in their investments in transitional care for young adults with T1DM, i.e., teams with more attention for transitional care (HI-ATT) versus teams with less attention in this regard (LO-ATT). Only a few gradual results in favor of the HI-ATT teams were found.

Young adults treated by the HI-ATT teams felt better prepared for transfer to adult care than those treated by the LO-ATT teams; they especially valued the possibility to meet their new healthcare providers

before the transfer. This is one of the three key features of transitional care associated with improved outcomes identified in the five-year transition research program by Colver et al. (2020). Furthermore, the young adults in our study found receiving enough information about the transfer important. Feeling well prepared for transfer was positively correlated with one's overall satisfaction with the transition process. However, being offered transitional care interventions did not prove to be decisive factor for this satisfaction. Our results suggest that interventions were still not systematically used; even not in the HI-ATT teams, although those teams had offered more joint consultations. Accordingly, the presence or absence of specific transitional care interventions did not appear to be a good indicator for the outcomes of transitional care. This is unexpected, but confirms the complexity of evaluating transitional care, which is still characterized by large differences and inconsistencies in implementation of interventions (Campbell et al., 2016; Le Roux et al., 2017). An example is the structural use of quality of life questionnaires. Regularly addressing psychosocial issues is highly recommended for young adults with T1DM, many of whom experience psychosocial problems and diabetes-related distress (Bronner et al., 2020; Iyengar et al., 2019; Van Staa et al., 2020). However, we do not know if and how the teams that use quality of life questionnaires bring up quality of life issues during consultations.

A general point of attention appearing from our results is the overall lack of structured support for parents. Colver et al. (2020) identified appropriate parental involvement with the child with a chronic health condition as the second key feature of transitional care associated with improved outcomes, as it would help achieve maximal service uptake. The pediatric-to-adult care transition phase necessitates a role shift away from a child's dependence on parents to manage a disease such as T1DM towards independently manage the disease. However, during this phase young adults' lives are still characterized by interdependencies, which facilitate their diabetes management (Allen et al.,

Table 5 Differences in healthcare use and clinical outcomes.

	LO-ATT teams		HI-ATT teams		Effect size ^a	p-value ^b
<i>No. of scheduled consultations (mean; SD)</i>						
T1	n = 130	8.56 (±5.58)	n = 185	7.85 (±6.47)	0.11	0.309
T2	n = 130	6.31 (±5.11)	n = 185	6.91 (±7.69)	-0.08	0.437
T3	n = 128	5.97 (±4.24)	n = 177	7.38 (±4.49)	-0.31	0.006*
T4 ^c	n = 124	4.55 (±3.29)	n = 172	5.01 (±4.70)	-0.10	0.353
<i>No-show at first appointment in adult care (N; %)</i>						
	n = 119	17 (14.3%)	n = 174	19 (10.9%)	NA	0.389
<i>No. of missed consultations (mean; SD)</i>						
T1	n = 129	0.33 (±0.90)	n = 185	0.38 (±0.95)	-0.05	0.637
T2	n = 129	0.33 (±0.75)	n = 185	0.35 (±0.81)	-0.02	0.889
T3	n = 126	0.71 (±1.49)	n = 177	0.67 (±1.42)	0.03	0.778
T4	n = 122	0.48 (±0.84)	n = 172	0.45 (±0.94)	0.03	0.794
<i>No. of hospital admissions (mean; SD)</i>						
T1	n = 130	0.21 (±0.46)	n = 188	0.22 (±0.64)	-0.02	0.810
T2	n = 130	0.16 (±0.50)	n = 189	0.19 (±0.67)	-0.04	0.676
T3	n = 128	0.20 (±0.77)	n = 176	0.25 (±0.87)	-0.06	0.570
T4	n = 124	0.22 (±0.69)	n = 170	0.11 (±0.48)	0.16	0.144
<i>No. of emergency department visits (mean; SD)</i>						
T1	n = 130	0.18 (±0.40)	n = 187	0.18 (±0.42)	0.00	0.992
T2	n = 130	0.10 (±0.39)	n = 187	0.16 (±0.49)	-0.12	0.267
T3	n = 128	0.21 (±0.57)	n = 176	0.25 (±0.71)	-0.06	0.609
T4	n = 124	0.27 (±0.71)	n = 169	0.19 (±0.65)	0.11	0.340
<i>HbA1c (mean NGSP, IFCC; SD)</i>						
T1	n = 121	8.6% (71; ±14.10)	n = 171	8.7% (72; ±16.49)	-0.04	0.750
T2	n = 120	8.6% (71; ±13.69)	n = 179	8.6% (71; ±15.88)	-0.02	0.893
T3	n = 95	8.6% (70; ±13.42)	n = 153	8.6% (71; ±15.83)	-0.05	0.667
T4	n = 91	8.6% (71; ±13.57)	n = 141	8.6% (70; ±15.34)	0.10	0.436

^a Cohen's d (based on largest SD).

^b Independent Samples T-test or Pearson Chi-Square Test.

^c T1: second year before transfer; T2: year before transfer; T3: year after transfer; T4: second year after transfer.

* Significant at $p < .05$.

2011). These interdependencies are not always reflected in healthcare policy and practice. Therefore, it would be worthwhile to develop a service structure that recognizes the continuing role of parents in a young adult's diabetes care and that support parents in adjusting to a new existence (Allen et al., 2011; Betz et al., 2015; Coyne & Hallowell, 2020). A systematic review of studies of parents' perceptions of their role in transition made clear that parents could be key facilitators of the child's healthcare transition by supporting him or her to become an expert in self-management (Heath et al., 2017).

From a clinical perspective, adolescents and young adults generally have the worst HbA1c scores among T1DM patients (Iyengar et al., 2019). In a previous study, only 17% of young adults with T1DM (18–25 years) met the ISPAD goal of less than 7.0% (≤ 53 mmol/mol) (Beck et al., 2012), which is even better than the 10.6% proportion of the HbA1c measurements in our study. Although recent registry data of the American Diabetes Association indicate that glycemic control is still not improving, despite advances in technology and newer insulins (Beck et al., 2019), research suggests that transition interventions may be effective in maintaining glycemic control after transfer to adult care (Farrell et al., 2018; Schultz & Smaldone, 2017). Our study showed a decreasing trend in the number of HbA1c measurements and scheduled consultations after transfer, while poor glycemic control persisted in adult care. This observation emphasizes the need for more attention for young adults in the adult care setting.

Clinic attendance is crucial to promote self-care (i.e., self-monitoring and taking care of one's own health) and – from the broader perspective – self-management (i.e., the ability to integrate the chronic condition in daily life), and consequently diabetes control (Farrell et al., 2018). Strengthening young adults' confidence in self-management is the third key feature of transitional care associated with improved outcomes, mentioned by Colver et al. (2020). Ideally, self-management support is provided all the way from pediatric into adult care, since competency building and evaluation of self-management skills continues after rapport with the new care providers has been established (Iyengar et al., 2019; Van Staa et al., 2020). Therefore, in our 'Better Transition in Diabetes' innovation program, Dutch versions of the Ready Steady Go instruments (Nagra et al., 2015) have been implemented to help young adults gain knowledge and skills to manage T1DM. In the present study, we found that the HI-ATT teams had more scheduled consultations than the LO-ATT teams in the year after transfer. This might indicate that HI-ATT teams were better able to remain in touch with the young adults after transfer. Nevertheless, the number of scheduled consultations decreased in both groups in the second year after transfer, and there were fewer HbA1c measurements after transfer.

The focus of healthcare providers often is on preparing and organizing a smooth transfer to adult care, while attention for the period afterwards remains underexposed, but is highly needed. The positive correlation we established between the young adults' overall satisfaction with transition and trust in adult healthcare providers emphasizes the importance of building a confidential relationship with young adults after entering adult diabetes services; a study of Klostermann et al. (2005) underlined this. Designating a transition coordinator may help ensure continuity of care and support (Iyengar et al., 2019; Van Staa et al., 2020), especially when the coordinator role is executed on both sides of the transfer – thereby 'bridging the gap' between the settings. Nurses seem excellently positioned to fulfill this role given the relationships they establish with young adults and their parents (Betz & Redcay, 2005; Coyne & Hallowell, 2020; Van Staa et al., 2015).

Practice implications

Additional consultations in the first year after transfer will likely ensure continuity of care, build relationships with the new healthcare

team, and promote young adults' confidence in managing their diabetes. Nurses can also help by creating awareness about the importance of regular clinic attendance among the young adults. Furthermore, nurses can support parents to prepare for the transition and to adjust to their new role, taking into account their continuing partnership. Finally, more consistent use of interventions could perhaps make a difference in transition experiences and outcomes. Future evaluation research of transitional care should also consider the actual implementation and adaptation of interventions used.

Strengths and limitations

This study was unique in its design by evaluating transitional care for young adults with T1DM among fifteen different transition programs in the Netherlands. At the start of the program, we carefully researched each team's arrangements and investigated whether the scope of transitional care investments was related to outcomes in terms of transfer experiences and satisfaction, self-management, healthcare use and clinical results.

Due to the complexity of the various transitional care interventions included in our study, the evolving nature of transitional care, and its multidisciplinary character, a randomized controlled trial was not considered possible (Campbell et al., 2016). We therefore performed a retrospective, controlled pre-post design over a four-year period (of young adults transferred between 2012–2014). The time elapsed between this period and our qualitative evaluation of the transitional care (2016) might have been a source of some recall bias. To minimize the risk of bias, we have asked the teams to provide information about changes in approaches and interventions during the past years. Furthermore, limited data were available for the retrospective study. For instance, HbA1c scores alone do not fully capture diabetes control. Additional information on daily diabetes self-care and significant changes in self-care behavior during the transition period would enable to create a more complete picture (Farrell et al., 2018). Finally, the suboptimal response rate to the questionnaire (38.4%; $n = 123$) might be a limitation of this study, although this is comparable with that in other post-transition diabetes studies (Garvey et al., 2013).

Conclusion

The attention and effort being paid to transition in Dutch diabetes care for young adults does not seem enough to enhance their experiences and outcomes, except for preparation for transfer. Still, investments in transitional care should not only focus on preparing the young adults for and organizing a smooth transfer. The period after transfer – when confidentiality needs to be rebuilt – is as important. Furthermore, the continuing role of parents in light of the shifting responsibilities between parents and young adults should be considered. In our study, almost none of the participating diabetes teams paid special attention to parental involvement.

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Declaration of Competing Interest

The authors declare that there are no conflicts of interest.

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Appendix A. The eight core elements of the *On Your Own Feet* framework explained (Van Staa et al., 2020)

ORGANIZATION OF TRANSITIONAL CARE

<i>Future-oriented</i>	Written protocols and policies are useful to organize planned, developmentally appropriate and holistic transitional care. Early preparation and gradual movement towards more responsibilities and independence for the young person are important elements in this, as well as meeting the new healthcare professionals prior to the transfer.
<i>Coordination</i>	It is recommended to appoint a transition coordinator to monitor the transition process, e.g., the collaboration and communication between pediatric and adult healthcare professionals and the logistics around the transition and transfer. This coordinator should be easy to contact for young persons (and their families) in case of problems or misunderstandings.
<i>Continuity of care</i>	A shared vision on transition, adequate transfer of information (both orally and written) knowing to whom the young person is being transferred, and monitoring and evaluation of follow-up are factors that contribute to continuity of care.

INDEPENDENCE AND SELF-MANAGEMENT

<i>Parent involvement</i>	Parents should be involved in their child's transition process and must be supported in gradually giving their child more control and responsibilities.
<i>Self-management</i>	A person-oriented and holistic approach is important to support young people in their transition. Attention should not only be paid to medical aspects, but also to psychosocial developments and challenges faced by the young people in this phase of life. Young people should be prepared for independence and self-management in adulthood and adult care. Developmentally appropriate care to work on self-efficacy and to achieve transfer readiness is of great importance here.
<i>Psychosocial care</i>	Attention for psychosocial issues is a critical part of transitional care. Timely referral of young people to psychosocial care (e.g., a psychologist, social worker, or dietician) is important to prevent psychosocial problems from escalating. Routine measurement of psychosocial patient-reported outcome measures is helpful in monitoring.

COLLABORATION AND YOUTH INVOLVEMENT

<i>Young person</i>	Transition should be tailored and developmentally appropriate. In addition, young people should be actively involved in their own care. Their wants, needs and preferences must be identified and taken seriously.
<i>Team</i>	Interdisciplinary coordination and alignment between pediatric and adult care professionals, alignment of working methods and procedures (where possible and relevant), and meeting new care professionals prior to the transfer are essential elements for adequate transitional care.

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