

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

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Abstract

Background 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. **Methods** On the basis of 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; 142 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 participants had reached targeted HbA1c scores. **Conclusions** The attention being paid to transition in Dutch diabetes care does 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. Considering actual implementation and adaptation of interventions is recommended for future evaluation studies.

1 Background

Health prospects of young adults with chronic conditions have improved, especially regarding type 1 diabetes mellitus (T1DM) [1, 2]. Still, T1DM patients' transition from adolescence to adulthood – including the transfer from pediatric to adult healthcare – is characterized by risk and vulnerability [3, 4]. 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 [5]. The transition period has been associated with less outpatient hospital clinic attendance and more dropout or disengagement from specialist services [6]. Psychosocial issues are common in this phase, and young T1DM patients have significantly higher rates of diabetes-related distress than other age groups [7]. 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 [8–11].

Both national [12] and international [13, 14] 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 [2, 5, 15, 16]. 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 [17]. Various interventions have shown promising benefits for young adults with T1DM, but evaluation of multifactorial transition programs remains complex [18]. It is not feasible to implement all interventions at every center, and generalizability is often limited due to differing study designs and outcome measures [6, 19]. As a result, factors that effectively influence the transition process are still poorly understood [11, 20–24]. Consensus on the definition of transition success is lacking, and little high-quality evidence on which to base transition practice is available [6, 19].

This study, part of a national quality improvement initiative (called ‘Better Transition in Diabetes’) to advance transitional care in diabetes [25], was designed to explore the added value of transitional care investments for young adults with T1DM in the Netherlands. 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.

2 Methods

2.1 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 and colleagues [26]. 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).

Table 1

Operationalization of background characteristics, process and outcome measures[†]

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review) [‡] or measurement tool used (survey)
<i>Background characteristics</i>				
	Gender	Male/female	Chart review	
	Date of birth	dd/mm/yyyy	Chart review	
	Transferred to	Intern/extern	Chart review	T3
	Age at transfer	In years	Chart review	T3
<i>Process outcomes</i>				
Medical follow-up	Last appointment pediatric care	dd/mm/yyyy	Chart review	T2
		dd/mm/yyyy		T3
	First appointment adult care	Yes/no/unknown	Chart review	T3
			Chart review	
	No-show at first appointment in adult care			
	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

[†] Based on study protocol published elsewhere [24].

[‡] T1: second year before transfer; T2: year before transfer; T3: year after transfer; and T4: second year after transfer.

Theme	Variable	Operationalization	Method of data collection	Measurement moment (chart review) [‡] or measurement tool used (survey)
<i>Outcome measures</i>				
Clinical	HbA1c	All observed values per year	Chart review	T1; T2; T3; T4
Healthcare-related	Transfer experiences	Experiences on five subscales: 1) reception in adult care, 2) alliance between pediatric and adult care, 3) preparation for the transfer, 4) readiness to transfer, and 5) youth involvement	Survey	On Your Own Feet – Transfer Experiences Scale (OYOF- TES) (validated 20-item scale with 5-point Likert scales, $\alpha = 0.64-0.86$) [27]
	Satisfaction with transition	Satisfaction with the overall process of transfer to adult care	Survey	Self-reported satisfaction on a 1–10 scale
	Trust in healthcare providers	Trust in pediatric and adult care providers	Survey	Self-reported trust on a 1–10 scale
Self-management-related	Self-management skills	Self-management of chronic condition	Survey	Partners in Health Scale (PIH) (validated 12-item scale with 9-point Likert scales, $\alpha = 0,82$) [28]
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, $\alpha = 0.77-0.94$) [29]
† Based on study protocol published elsewhere [24].				
‡ T1: second year before transfer; T2: year before transfer; T3: year after transfer; and T4: second year after transfer.				

< INSERT Table 1 >

2.2 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 sometimes 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.

2.3 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 [25]. 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 [26]. 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' Framework [25].

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), trust in care providers, and their coping with T1DM.

Reminders were sent after two and four weeks. Table 1 provides an overview of the operationalization and data collection method per variable.

2.4 Data analysis

2.4.1 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 [25]. 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 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 [25]. 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 .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.

2.4.2 Quantitative part

To enable further quantitative analysis, an exploratory hierarchical cluster analysis using the within-groups linkage method was performed to cluster teams [30]. 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.

3 Results

3.1 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% responded to the online questionnaire. The non-responders 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*
Gender (male)	66 (50.8%)	108 (56.8%)	.284
Age	23.71 (± 1.42)	23.71 (± 1.44)	.988
Age at transfer [†]	18.64 (± 1.77)	18.62 (± 1.11)	.905
Transfer within the same hospital [‡]	118 (92.9%)	175 (92.6%)	.914
Response to online survey	53 (40.8%)	70 (36.8%)	.478
* Independent Samples T-test or Pearson Chi-Square Test ($p < .05$)			
[†] n = 128 in the LO-ATT group and n = 184 in the HI-ATT group.			
[‡] 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 transferred to adult services within the same hospital. There were no statistically significant differences in the background characteristics of young people 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 ($d > .82$). 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%; $p = .022$).

Table 3
 Overview of transitional care interventions and consensus-based mean scores on the eight core elements[†]

	LO-ATT teams (n = 5)	HI-ATT teams (n = 10)	Effect size [‡]	p-value*
<i>Consensus-based mean scores on the eight core elements</i> (1 = minimal transitional care; 4 = excellent transitional care)				
Future-oriented	1.60 (± .55)	2.50 (± .58)	1.55	.029
Coordination	1.60 (± .89)	2.90 (± .88)	1.46	.028
Continuity of care	2.20 (± .84)	3.30 (± .82)	1.31	.042
Parent involvement	1.60 (± .55)	2.40 (± .97)	0.82	.063
Self-management	1.60 (± .55)	2.60 (± .52)	1.82	.010
Psychosocial care	2.20 (± .45)	2.80 (± .42)	1.33	.038
Youth participation	1.40 (± .55)	2.30 (± .68)	1.32	.020
Team collaboration	2.00 (± .00)	2.50 (± .53)	0.94	.015
<i>Transitional care interventions</i>				
Transition coordinator	2 (40%)	6 (60%)	NA	.608
Transition protocol (in use)	0 (0%)	2 (20%)	NA	.524
Multidisciplinary team consultation meetings with pediatric and adult care providers	1 (20%)	4 (40%)	NA	.600
Joint consultation	2 (40%)	10 (100%)	NA	.022

[†] Based on the 'On Your Own Feet' Framework [25].

[‡] Cohen's *d* (based on largest SD)

* Independent Samples T-test or Fisher's Exact Test ($p < .05$)

	LO-ATT teams (n = 5)	HI-ATT teams (n = 10)	Effect size [‡]	<i>p</i> - value*
Structural support for parents	1 (20%)	2 (20%)	NA	1.000
Structural use of a quality of life questionnaire	1 (20%)	7 (70%)	NA	.119
Structural use of an individual transition plan	0 (0%)	3 (30%)	NA	.505
Independent consultations with young adults (without parents)	1 (20%)	4 (40%)	NA	.600
† Based on the 'On Your Own Feet' Framework [25].				
‡ Cohen's <i>d</i> (based on largest SD)				
* Independent Samples T-test or Fisher's Exact Test (<i>p</i> < .05)				

3.2 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 ($3.16 \pm .86$ vs. $2.83 \pm .99$, $p = .042$). Moreover, Spearman's test showed a moderate positive correlation of preparation for transfer with overall satisfaction with transition ($r_s = .517$; $p = .000$). 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-ATT team more often reported that the new care providers were well informed about them and their condition ($p = .040$).

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 [†]	p-value*
<i>Mean scores on OYOF-TES subscales (1 = strongly disagree; 5 = strongly agree)</i>				
Reception in adult care (α = .861)	4.03 (± .72)	3.88 (± .89) [‡]	.17	.295
Alliance between pediatric and adult care (α = .832)	3.18 (± .96)	3.16 (± .83)	.02	.909
Preparation for the transfer (α = .637)	2.83 (± .99)	3.16 (± .86)	– .33	.042
Readiness to transfer (α = .796)	3.93 (± .71)	4.11 (± .63)	– .25	.102
Youth involvement (α = .671)	3.32 (± .98)	3.26 (± 1.00)	.06	.740
Total score	70.68 (± 13.30)	72.01 (± 12.15)	– .10	.540
<i>Overall satisfaction and trust (0–10 scale)</i>				
Overall satisfaction with transition	7.11 (± 1.57)	7.15 (± 1.49) [§]	– .03	.856
Trust in pediatric health care providers	8.05 (± 1.74)	8.48 (± 1.51)	– .25	.123
Trust in adult health care providers	7.82 (± 1.42)	7.38 (± 2.04)	.22	.129
<i>Self-management and quality of life outcomes</i>				
Self-management skills (PIH)	80.84 (± 7.98)	79.60 (± 9.25) [§]	.13	.412
Health-related quality of life (PedsQL-YA)	79.55 (± 13.29) [¶]	78.23 (± 16.02) [§]	.08	.613
[†] Cohen's <i>d</i> (based on largest SD)				
* Independent Samples T-test (<i>p</i> < .05)				
[‡] n = 86				
[§] n = 84				
[¶] n = 55				

< INSERT Table 4 >

Overall satisfaction with transition was scored with a mean of 7.01 ($\pm .1.53$, $n = 167$), and was strongly correlated with the transfer experiences sum score ($r_s=.737$; $p = .000$). 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 vs. 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 ($r_s=.170$; $p = .028$) and a moderate correlation between the transfer experiences sum score and trust in adult healthcare providers ($r_s=.492$; $p = .000$).

3.3 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 ($.66 \pm 1.44$ 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 in the years before transfer, from T1 to T2, was significantly bigger than in the HI-ATT teams ($F(1, 288) = 5.38$, $p = .021$).

Table 5
Differences in healthcare use and clinical outcomes

LO-ATT teams		HI-ATT teams		Effect size [†]	<i>p</i> -value*	
<i>No. of scheduled consultations (mean; SD)</i>						
T1	n = 130	8.56 (± 5.58)	n = 185	7.85 (± 6.47)	.11	.309
T2	n = 130	6.31 (± 5.11)	n = 185	6.91 (± 7.69)	-.08	.437
T3	n = 128	5.97 (± 4.24)	n = 177	7.38 (± 4.49)	-.31	.006
T4 [‡]	n = 124	4.55 (± 3.29)	n = 172	5.01 (± 4.70)	-.10	.353
<i>No-show at first appointment in adult care (N; %)</i>						
	n = 119	17 (14.3%)	n = 174	19 (10.9%)	NA	.389
<i>No. of missed consultations (mean; SD)</i>						
T1	n = 129	.33 (± .90)	n = 185	.38 (± .95)	-.05	.637
T2	n = 129	.33 (± .75)	n = 185	.35 (± .81)	-.02	.889
T3	n = 126	.71 (± 1.49)	n = 177	.67 (± 1.42)	.03	.778
T4	n = 122	.48 (± .84)	n = 172	.45 (± .94)	.03	.794
<i>No. of hospital admissions (mean; SD)</i>						
T1	n = 130	.21 (± .46)	n = 188	.22 (± .64)	-.02	.810
T2	n = 130	.16 (± .50)	n = 189	.19 (± .67)	-.04	.676
T3	n = 128	.20 (± .77)	n = 176	.25 (± .87)	-.06	.570
T4	n = 124	.22 (± .69)	n = 170	.11 (± .48)	.16	.144
<i>No. of emergency department visits (mean; SD)</i>						
T1	n = 130	.18 (± .40)	n = 187	.18 (± .42)	.00	.992
T2	n = 130	.10 (± .39)	n = 187	.16 (± .49)	-.12	.267
T3	n = 128	.21 (± .57)	n = 176	.25 (± .71)	-.06	.609
T4	n = 124	.27 (± .71)	n = 169	.19 (± .65)	.11	.340
<i>HbA1c (mean NGSP, IFCC; SD)</i>						
[†] Cohen's <i>d</i> (based on largest SD)						
* Independent Samples T-test or Pearson Chi-Square Test (<i>p</i> < .05)						
[‡] Transition phase: T1: second year before transfer; T2: year before transfer; T3: year after transfer; T4: second year after transfer.						

	LO-ATT teams		HI-ATT teams		Effect size [†]	<i>p</i> -value*
T1	n = 121	8.6% (71; ±14.10)	n = 171	8.7% (72; ±16.49)	- .04	.750
T2	n = 120	8.6% (71; ±13.69)	n = 179	8.6% (71; ±15.88)	- .02	.893
T3	n = 95	8.6% (70; ±13.42)	n = 153	8.6% (71; ±15.83)	- .05	.667
T4	n = 91	8.6% (71; ±13.57)	n = 141	8.6% (70; ±15.34)	.10	.436
† Cohen's <i>d</i> (based on largest SD)						
* Independent Samples T-test or Pearson Chi-Square Test (<i>p</i> < .05)						
‡ Transition phase: T1: second year before transfer; T2: year before transfer; T3: year after transfer; T4: second year after transfer.						

< INSERT Table 5 >

3.4 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 ± 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 [13], only 10.6% of our study participants met targeted HbA1c scores of ≤ 53 mmol/mol (for children, adolescents and young adults until the age of 25 years); 14.6% had very high scores (≥ 86 mmol/mol). HbA1c measurements were carried out more often in pediatric than in adult care (5.64 ± 2.44 versus 4.40 ± 2.10 , $p = .000$; $n = 261$). Moreover, those with higher HbA1c scores more often had consultations in pediatric care than in adult care ($r = .187$, $p = .001$).

4 Discussion

4.1 Comparisons with existing literature

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. [31]. 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 [18, 19]. 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 [7, 25, 32]. 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. [31] 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 [33]. 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 [33]. 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 [34].

From a clinical perspective, adolescents and young adults generally have the worst HbA1c scores among T1DM patients [7]. 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) [35], which is even better than the 10.6% proportion 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 [36], research suggests that transition interventions may be effective in maintaining glycemic control after transfer to adult care [10, 23]. 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 and self-management, and consequently diabetes control [10]. Strengthening young adults' confidence in self-management is the third key feature of transitional care associated with improved outcomes, mentioned by Colver et al. [31]. 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 [7, 25]. Therefore, in our 'Better Transition in Diabetes' innovation program, Dutch versions of the Ready Steady Go instruments [37] have been implemented to help young adults gaining 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. Designating a transition coordinator may help ensure continuity of care and support [7, 25], 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 [38, 39].

4.2 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 [19]. We therefore performed a retrospective, controlled pre-post design over a four-year period (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 [10]. Finally, the suboptimal response rate to the questionnaire (38.4%) might be a limitation of this study, although this is comparable with that in other post-transition diabetes studies [40].

5 Conclusions

The attention and effort being paid to transition in Dutch diabetes care for young adults (in particular in the HI-ATT teams) do not seem enough to enhance their experiences and outcomes, except for preparation for transfer. However, investments in transitional care should not only focus on preparing the young adults for and organizing a smooth transfer. The period afterwards – when confidentiality needs to be rebuilt – is at least as important. Additional consultations in the years after transfer will likely ensure continuity of care and promote young adults' confidence in managing their diabetes. Another aspect to be considered is the continuing role of parents in light of the shifting responsibilities between parents and young adults. Almost none of the diabetes teams participating in our study paid special attention to parental involvement. Finally, more consistent use of interventions could perhaps make a difference in transition experiences and outcomes. Future evaluation research of transitional care should consider the actual implementation and adaptation of interventions used.

Abbreviations

HbA1c glycosylated hemoglobin

HI-ATT more attention for transitional care

ISPAD International Society of Pediatric and Adolescent Diabetes

LO-ATT less attention for transitional care

T1DM type 1 diabetes mellitus

Declarations

Ethics approval and consent to participate

The Ethics Review Board of Erasmus MC approved the original study protocol as well as the updated addendum (MEC-2014-246). 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 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.

Consent for publication

Not applicable.

Availability of data and material

All data generated or analyzed during this study are included in this published article.

Competing interests

The authors declare that there are no conflicts of interest.

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Authors' contributions

Study conception and design: MP, JS, AvS; Data collection: MP, JS, MB; Analysis and interpretation of data: MP, JS, MB, RB, AvS; First drafting of the manuscript: MP, JS; Critical revision for important intellectual content: MP, JS, MB, RB, AvS; final approval of the version to be published: MP, JS, MB, RB, AvS. All authors participated sufficiently in the work to take public responsibility for appropriate portions of the content; and agree to be accountable for all aspects of the work.

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