Adherence to insulin pump treatment declines with increasing age in adolescents with type 1 diabetes mellitus

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REGULAR ARTICLE

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Adherence to insulin pump treatment declines with increasing age in adolescents with type 1 diabetes mellitus

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Abstract

Aim: This study assessed the impact of illness perceptions, emotional responses to the disease and its management, and patient characteristics on the adherence to optimal insulin pump management in adolescents with type 1 diabetes mellitus.

Methods: From May to December 2013 and May 2015 to September 2016, we investigated 90 adolescents (50% boys), 12-18 years with type 1 diabetes. We analysed the association of optimal adherence to insulin pump therapy to age, gender, diabetes duration, results of questionnaires relating to fear and problems of self-testing, illness perceptions, emotional distress and family conflicts. Optimal adherence was defined as bolusing insulin on average ≥2.5/3 main meals/d.

Results: Adolescents with suboptimal adherence were on average 1.8 years older (95% Confidence Interval 1.09-2.50 years, $P < .001$) than those with optimal adherence. After adjustment for age, no other patient or parent factors were related to optimal adherence.

Conclusion: Adherence to insulin pump self-management in adolescents with type 1 diabetes declined with increasing age, illustrating the challenges of transition of self-management from parents to the adolescent patient themselves.

KEYWORDS

adherence, adolescent, insulin pump, self-management, type 1 diabetes mellitus

1 | INTRODUCTION

The incidence of type 1 diabetes mellitus in children aged 0-14 years has almost doubled over the last 30 years in the Netherlands, with an estimated prevalence of 145 per 100 000. Type 1 diabetes is now one of the most common chronic diseases in paediatric patients, in the Netherlands.[1] Treatment of type 1 diabetes comprises an intensive, personalised insulin scheme, using either multiple daily subcutaneous injections or continuous subcutaneous insulin infusion (CSII). Optimal management of the disease plays a key role in short-term glycaemic control and in the prevention of long-term adverse sequelae of the disease.[2,3]

In an earlier study in adolescents on CSII, we found that patients who adhered to the recommendation to administer an insulin bolus around every main meal had considerably lower glycated haemoglobin (HbA1c) levels than those who failed to do, with a mean HbA1c difference of 11.6 mmol/mol (95% confidence interval 6.6-16.5).[4] Unfortunately, as is the case in children with other chronic conditions,[5] non-adherence is common in adolescents with type 1 diabetes. Although this is likely to have major deleterious consequences for the long-term outcome of the disease, the literature on factors associated with non-adherence on CSII in type 1 diabetes is surprisingly scant. Earlier studies suggest that the interaction between the

Abbreviations: CSII, continuous subcutaneous insulin infusion; HbA1c, glycated haemoglobin.

adolescent with type 1 diabetes and his or her parents is a key determinant of the adolescent's adherence to insulin therapy. Interaction factors that improve adherence include support, supervision and assistance from parents, working towards supported autonomy for the adolescent patient[6,7]

In other paediatric chronic conditions, illness perceptions and medication beliefs are key drivers of adherence behaviour.[5,8] Apparently, paediatric patients and their parents balance the perceived need of daily medication against the perceived concerns about the burden and side effects of the recommended treatment schedule.[9] Only a few studies have examined the importance of illness perceptions in adherence in children with type 1 diabetes.[9] No studies to date investigated the relationship of illness perceptions and adherence in adolescents with type 1 diabetes on CSII.

The aim of the present study was to evaluate the impact of illness perceptions and patient characteristics on the adherence to optimal CSII management in adolescents with type 1 diabetes.

Key notes

- We investigated the role of illness perceptions, emotional responses to the disease and its management, and patient characteristics to optimal adherence to insulin pump therapy in adolescents with type 1 diabetes.
- Adherence to optimal insulin pump management in adolescents with type 1 diabetes declined with older age.
- In adolescents with type 1 diabetes transition of self-management from parents to the adolescent patient themselves is still a challenge.

2 | METHODS

2.1 | Study sample and study area

For this study, we included patients aged 12-18 years with type 1 diabetes, for at least 1 year, who had been using CSII for at least 3 months. In our study, we defined type 1 diabetes when there was a C-peptide level <0.05 nmol/L and blood glucose level on presentation ≥11.1 mmol/L or fasting plasma glucose ≥7.0 mmol/L. The islet cell auto-antibodies were positive, and there was no evidence of either maturity-onset diabetes of the young or type 2 diabetes.[10]

The patients were invited to participate in this study during two time periods, from May to December 2013 in the Isala Hospital, Zwolle and to include more patients from May 2015 to September 2016 in the Isala Hospital and Deventer hospital, Deventer. These are both general teaching hospitals in the province of Overijssel, providing secondary paediatric care to mixed rural-urban populations.

The exclusion criteria were mental retardation, insufficient knowledge of the Dutch language to understand the requirements of the study and any other serious conditions that were likely to interfere with the end points of the study. Further details, including meal patterns, of the study have been published previously.[4]

2.2 | Study procedures and data collection

Two weeks before a scheduled follow-up visit, information about the study was sent by mail to eligible patients and their parents. This information explained the aim of the study and the requirement to fill in a number of questionnaires when they decided to participate the study. One week later, they were contacted by telephone and the patient was asked if he or she agreed to participate in the study. After obtaining written-informed consent during the outpatient clinic visit, we downloaded data from the previous 2 months on self-monitored blood glucose levels, insulin boluses, and the timing of each of these, from the patient's insulin pump and blood glucose meter. We thus captured data on adherence to self-monitored blood glucose and insulin boluses over the time period of 2 months before the clinic visit. From these data, we calculated the number of insulin boluses around the three main meals. We defined optimal adherence to CSII therapy as performing on average at least two and a half out of three boluses around the main meals. Lack of a breakfast bolus was defined as absence of a bolus between 5 and 10:30 AM on weekdays and between 5 AM and noon during weekend or holidays; for lunch between noon and 3pm and for dinner between 5 and 8 PM.[4]

2.3 | Questionnaires

The adolescent patients and their parents were both asked to complete the following questionnaires during the outpatient visit.

A fear of self-testing questionnaire, validated nine-item self-report instrument quantifying the fear of self-monitored blood glucose. Each item was scored as almost never (zero points), sometimes (one point) or often (two points) and almost always (three points) with a maximum total score of 27. A score ≥ six indicates needle fear.[11]

Blood glucose monitoring communication questionnaire was used the nine items of the caregiver version and the nine items from the youth part of this validated questionnaire to evaluate affective responses to self-monitored blood glucose in the patient and their caregiver. Each item was scored as almost never (one point), sometimes (two points), or almost always (three points) resulting in a total score 9–27 points. Higher scores reflect the experience of a more negative affect.[12]

We used the validated problem area in diabetes questionnaire adapted for use in adolescents and parents. This is a 61-item questionnaire problem area in diabetes questionnaire—teen, in which each item is scored on a six-point Likert scale (one = not a problem and six = serious problem). The higher the total item score, the more the adolescent is experiencing emotional distress related to type 1 diabetes management.[13]

Parents completed a similar questionnaire, the 26-item problem area in diabetes questionnaire—parent, which assessed their perceived emotional burden associated with caring for a child with type 1 diabetes.

To assess illness perceptions, we used the validated illness perception questionnaire, which contains eight questions scored on a ten-point Likert scale, zero means no effect at all and ten means that it severely affects their life, with a total score from 0 to 80.[14] Questions relate to cognitive illness perceptions related to identity, cause, timeline, consequences, cure control, emotional perceptions and overall illness comprehensibility. Because assessing the impact of illness perceptions on adherence was the main aim of this study, we used both the total score and the score of each question separately in analyses.

The diabetes family conflict scale, a validated questionnaire measuring negative emotions around blood glucose monitoring, quality of life and perceived parental burden from diabetes management was used. There are caregiver and adolescent versions, each with 19 items in two domains disagreement and responsibility. The level of family conflict related to diabetes-specific tasks is rated on a three-point Likert scale (one = almost never argue, two = sometimes argue, and three = almost always argue), yielding a scale range of 19-57 (19 = no conflict to 57 = high level of conflict).[15]

2.4 | Statistical analysis

We analysed the association of optimal adherence to CSII self-management (as defined above) as the dependent variable, and age, gender, diabetes duration, and the results of the fear of self-testing questionnaire, blood glucose monitoring communication questionnaire, illness perception questionnaire, problem area in diabetes questionnaire—teen and the diabetes family conflict scale as independent variables. Univariate analyses were carried out using Fisher's exact test for categorical variables and the Student's *t* test for continuous variables. We also analysed the relationship of patient factors (blood glucose monitoring communication questionnaire, illness perception questionnaire, diabetes family conflict scale disagreement, diabetes family conflict scale responsibility, fear of self-testing questionnaire, and problem area in diabetes questionnaire) and parent factors (blood glucose monitoring communication questionnaire, diabetes family conflict scale disagreement, diabetes family conflict scale responsibility, and problem area in diabetes questionnaire) to optimal CSII management, after adjustment for patient age, in two separate multivariate logistic regression models. All independent variables were numeric. Multiple imputations (fully conditional specification method) were used for missing data on independent variables (five data sets were constructed assuming missing completely at random, since we could not find any systematic missingness). A description of the variables used in the imputation prediction model is given in Appendix S1. Non-linearity was assessed by Stata's Linktest. Overall goodness of fit was tested by Hosmer and Lemeshow's goodness of fit test. Because all independent variables were numeric, no interactions were explored. Statistical analyses were carried out using IBM SPSS Statistics for Windows, Version 23.0 (IBM Corp.), Stata/SE 15.1 (StataCorp) and OpenEpi, version 3.01.

2.5 | Ethical considerations

Written-informed consent was obtained from patients and caregivers. The study was approved by the Medical Ethics Committee of Isala Hospital, Zwolle, the Netherlands (number 41428-075-12).

3 | RESULTS

3.1 | Patient characteristics

Out of 138 invited adolescents with type 1 diabetes, 90 consented to participation (65%), half of which were boys. The mean age of the participants was 14.4 (SD 1.8), and their mean diabetes duration of 6.5 years. There were no statistically significant differences between patients who did and did not participate in the study, except that included patients had lower HbA1c values than non-included adolescents (95% CI for difference 0.5-11.1 mmol/mol, Table 1).

A comparison of demographic, clinical and questionnaire variables between the 59 patients with optimal management and the 31 with suboptimal management is presented in Table 2. Increasing age was the independent variable most strongly related to suboptimal management. In addition, there were associations of suboptimal management to scores on illness perception questionnaire, diabetes family conflict scale, fear of self-testing questionnaire and problem area in diabetes questionnaire—teen subscales (Table 2). Although the adolescents' blood glucose monitoring communication scores did not show a significant association to suboptimal management, higher diabetes family conflict scale responsibility scores, reflecting more involvement from the parent in the diabetes management of the adolescent, were associated with a higher likelihood of optimal diabetes management. In addition, we found a significant difference in fear of self-testing questionnaire scores between the two groups, suggesting that fear of self-testing plays a role in suboptimal diabetes management, despite the fact that the overall fear of self-testing questionnaire scores were considerably lower than the questionnaire score threshold for needle fear greater than or equal to six.

TABLE 1 Patient characteristics of participating patients and those who declined participation

	Participants (n = 90)	Non-participants (n = 48)	*P* value
Male gender	45 (50%)	21 (63%)	.18*
Age (years)	14.4 (SD 1.8)	14.2 (SD 1.7)	.58**
Diabetes duration (years)	6.5 (SD 3.7)	7.1 (SD 3.4)	.42**
HbA1c (mmol/mol)	65.3 (SD 12.7)	71.1 (SD 14.2)	.03**
Coeliac disease	7 (7.8%)	1 (3.0%)	.34*
Thyroid disease	9 (10%)	1 (3.0%)	.21*
Microalbuminuria	1 (1.1%)	0	1.00*
Retinopathy	0	0	-

*Chi squared test.
**Student's *t* test.

TABLE 2 Optimal management vs suboptimal management in relation to the results of the questionnaires[a]

	Optimal management (n = 59)	Suboptimal management (n = 31)	95% CI of difference	*P* value
Male gender	31 (52.5%)	14 (45.2%)		.66
Age (years)	13.8 (1.6)	15.6 (1.7)	1.09 to 2.50	<.001
Diabetes duration (years)	6.0 (3.6)	7.5 (3.7)	−0.05 to 3.10	.06
BGMC (score from 0–27)[b]	11.1 (2.5)	11.9 (3.8)	−0.59 to 2.10	.27
IPQ consequences (score from 0-10)[b]	5.5 (2.0)	5.4 (2.1)	−1.00 to 0.80	.83
IPQ timeline (score from 0-10)[b]	8.6 (1.8)	8.7 (2.0)	−0.68 to 0.93	.77
IPQ personal control (score from 0-10)[b]	7.3 (1.9)	6.6 (2.2)	−1.61 to 0.10	.09
IPQ treatment control (score from 0-10)[b]	7.6 (1.9)	7.4 (1.6)	−1.02 to 0.53	.54
IPQ identity (score from 0-10)[b]	3.7 (2.4)	4.2 (2.0)	−0.47 to 1.52	.30
IPQ concerns (score from 0-10)[b]	3.6 (2.5)	4.8 (2.3)	0.17 to 2.29	.02
IPQ comprehensibility (score from 0-10)[b]	8.8 (1.3)	8.2 (1.7)	−1.25 to 0.03	.06
IPQ emotions (score from 0-10)[b]	4.7 (2.8)	5.3 (2.6)	−0.55 to 1.78	.30
IPQ total (score from 0-10)[b]	31.1 (9.8)	34.6 (9.3)	−0.78 to 7.6	.11
Total DFCS disagreement child (score from 9-57)[b]	24.6 (5.7)	26.6 (5.0)	−0.42 to 4.37	.11
Total DFCS responsibility child (score from 9-57)[b]	34.4 (8.2)	31.0 (7.0)	−6.83 to 0.15	.06
Total FST (score from 0–27)[b]	0.7 (1.2)	1.6 (2.3)	0.14 to 1.59	.02
Total PAID-T (score from 26–156)[b]	50.7 (20.6)	60.0 (22.3)	−0.11 to 18.56	.05
Total BGMC parents (score from 0–27)	11.1 (2.4)	11.3 (2.4)	−0.85 to 1.26	.70
Total DFCS disagreement parent (score from 9-57)	23.9 (5.2)	25.6 (4.7)	−0.41 to 3.92	.11
Total DFCS responsibility parent (score from 9-57)	36.2 (7.7)	32.7 (6.8)	−6.76 to − 0.33	.03
Total PAID-P (score from 26–156)	58.2 (18.5)	61.7 (21.7)	−5.00 to 12.08	.42

Abbreviations: BGMC: blood glucose monitoring communication questionnaire; DFCS: diabetes family conflict scale; FST: fear of self-testing questionnaire; IPQ: the brief illness perception questionnaire; PAID-P: the problem area in diabetes questionnaire parents; PAID-T: the problem area in diabetes questionnaire teen.

[a]According to Rubin's rule pooled mean (standard deviation) or percentages.

[b]Questionnaire filled in by the adolescent.

Higher emotional distress experienced by the adolescent patient was almost significantly related to suboptimal management (*P* = .05, Table 2).

Because the patient's age was the strongest determinant of adherence to optimal diabetes management, we analysed the influence of patient and parent factors on adherence to optimal diabetes management after adjustment for patient age in two separate multiple logistic regression models patient factors and parent factors as listed in (Table 2). The results of these analyses are presented in Table 3.

After adjustment for patient age, none of the other patient or parent factors were significantly associated with adherence to optimal diabetes management (Table 3).

4 | DISCUSSION

This study showed a significant and inverse association between patient age and optimal CSII management in adolescents with type 1 diabetes. In univariate analyses, suboptimal diabetes management was also related to fear of self-testing questionnaire scores, suggesting that fear of self-testing plays a role in suboptimal diabetes management, and with illness perception questionnaire, diabetes family conflict scale and problem area in diabetes questionnaire—teen subscores, suggesting an impact of illness perceptions and problems and conflicts in diabetes management between the adolescent patients and their caregivers on adherence to optimal self-management. After adjustment for patient age, however, these patient and parent factors were no longer significantly related to optimal diabetes management. This suggested that in our population the transition of diabetes management from their parents to the adolescents was suboptimal.

During adolescence, the responsibility for managing a chronic disease, such as diabetes, should gradually shift from the parents to the adolescents themselves. The responsibility of the parents diminishes with the ageing of the adolescent[16-18] and its related development in deductive thinking and independence. Although it is becoming increasingly clear that this development continues well beyond the age of 20 years, the largest part of self-management transfer takes place when the patient is between the ages of 13 and 16.[19] Our research indirectly confirmed the results of previous studies that adherence diminished when the diabetes management shifts from the parents to the adolescent, and the metabolic regulation

TABLE 3 Results of logistic regression analyses examining relationship of patient and parent factors to optimal continuous subcutaneous insulin infusion management, after adjustment for patient age

	Patient factors Adjusted odds ratio (95% CI)	Parent factors Adjusted odds ratio (95% CI)
BGMC (score from 0–27)	(1.03 (0.83 to 1.27) P = .79	0.97 (0.73 to 1.29) P = .83
IPQ total	1.01 (0.94 to 1.10) P = .75	No data
Total DFCS disagreement (score from 9-57)	0.94 (0.85 to 1.04) P = .23	0.95 (0.85 to 1.06) P = .35
Total DFCS responsibility (score from 9-57)	1.00 (0.92 to 1.08) P = .71	0.98 (0.88 to 1.09) P = .67
Total FST (score from 0–27)	0.85 (0.58 to 1.23) P = .37	No data
Total PAID (score from 26–156)	0.98 (0.95 to 1.02) P = .35	0.97 (0.94 to 1.01) P =.15)
Nagelkerke R^2	.34	.40
Linktest quadratic prediction	P = .95	P = .67
Hosmer-Lemeshow goodness of fit test	P = .66	P = .76

Abbreviations: BGMC, blood glucose monitoring communication questionnaire; DFCS, diabetes family conflict scale; FST, fear of self-testing questionnaire; IPQ, the brief illness perception questionnaire; PAID, the problem area in diabetes questionnaire.

deteriorates when this transition is not accompanied by improving self-efficacy of the adolescent.[16] Involvement of the parent, also in later stages of adolescence, seems to support adherence to diabetes management and to the development of self-efficacy (belief or confidence in the ability to carry out tasks involved in diabetes management).[17,18,20,21]

The involvement of the parents during adolescence can have a positive effect on adherence to therapy and on the development of adequate self-management in the adolescent patient. Conversely, parental psychological control with pressure on and coercion of the adolescent is associated with poorer adherence.[7,21] The few studies assessed adherence to blood glucose measurements and showed that parental support led to more daily measurements.[22,23] With increasing age, the adolescent's illness perceptions about type 1 diabetes gradually change to recognise the disease as incurable and chronic, with potentially serious long-term complications.[24] Although this suggested that the development of increasing control over the disease as the adolescent becomes older, our and other studies showed a worsening of adherence during the period of puberty.[20,21] In addition to the decrease in parental involvement in disease self-management, this may also be influenced by the ideas of their peers.[25]

Despite its potential impact on diabetes management, literature about needle anxiety in adolescents is scarce,[26] having been mainly described in young children with type 1 diabetes.[27] The univariate relation of fear of self-testing to suboptimal diabetes management in our study confirms the findings of an earlier study.[28] The overall low total score on the fear of self-testing questionnaire suggests that fear of self-testing is rare in adolescents, however.[26]

New technological possibilities, such as intermittent or continuous glucose monitoring, may help to reduce fear of self-testing and its potentially deleterious effect on adherence to optimal type 1 diabetes self-management.[29]

To our knowledge, this was the first study examining the impact of patient and parent factors on long-term adherence to optimal disease management in adolescents with type 1 diabetes on insulin pump therapy.

Our study was unique in using objectively measured adherence with downloaded data from the insulin pump and glucose meter which were used as a dependent variable instead of self-reported adherence which is notoriously unreliable.[30] We acknowledged the following limitations. Some data were lost due to technical problems in downloading from the devices in 13 patients (14%). Post hoc analyses, however, showed that this had no impact on our main study outcomes (data not shown). Secondly, well-adherent patients were likely to be overrepresented in the study population because HbA1c levels were slightly lower in participating than in non-participating patients (Table 1). Thirdly, although the fear of injection and self-testing questionnaires have not been validated in paediatric patients, they have been shown to help in identifying children with fear of self-injection and self-testing.[11] In the absence of a uniformly accepted gold standard of optimal CSII management, we used the definition that our centre uses in clinical care, which may limit generalisability of our results to centres using other definitions of optimal CSII management. Finally, the relatively small sample size of our study population limited its power to examine determinants of adherence in more detail or in subgroup analyses. Further studies with larger sample sizes on determinants of adherence to insulin pump therapy are therefore needed.

5 | CONCLUSION

Adherence to optimal diabetes management in adolescents with type 1 diabetes on CSII was significantly associated with the patient's age, illustrating the challenges of transition of self-management from parents to the adolescent patient themselves. The results suggest that adolescents with type 1 diabetes need self-management support from their parents and the medical team, and shared responsibility of disease management, throughout adolescence, to acquire the autonomy to manage the disease successfully themselves. Parents' involvement in the adolescent's self-management of type 1 diabetes should only cease after the adolescent's self-efficacy in managing the disease has been established to the satisfaction of the adolescent patient, the parents, and the medical team. This underscores the need for the development of a valid and succinct instrument to assess diabetes management self-efficacy.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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