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Diabetes outpatient care for adolescents: associations between adolescent experiences, parent experiences and HbA1c

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Diabetes outpatient care for adolescents: associations between adolescent experiences, parent experiences and HbA1c

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Keywords: patient experiences, parent experiences, diabetes, questionnaire, adolescent HbA1c

Word count: 2,507

Abstract

Objective

The aim of the current study was to determine the association between the experiences of adolescents and their parents with paediatric diabetes care at hospital outpatient departments and the association between these experiences and the HbA1c levels of adolescents.

Design

Cross-sectional survey.

Setting

Paediatric diabetes care at hospital outpatient departments in Norway.

Participants

Parents of all outpatients registered in the Norwegian Childhood Diabetes Registry and patients in the same registry aged 12–17 years.

Intervention

1,399 parents participated in a national pilot survey, and 335 patients aged 12–17 years from the 4 largest paediatric outpatient departments in Norway responded in another pilot study. 181 paired parental and patient questionnaires were analysed.

Main outcome measures

The correlations between single items, indicator scores and overall scores were explored, as was that between indicator scores and HbA1c levels.

Results

There was a moderate but significant correlation between the responses of the patients and parents, and a weak but significant negative correlation between the indicator scores of parents

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and the HbA1c levels of the adolescents. There was no significant correlation between HbA1c level and patient indicator scores.

Conclusions

These results highlight the need to obtain information from both parents and adolescents, and indicate that the views of adolescents are not always mirrored by their parents. Most of the parent experience indicators were significantly related to the HbA1c levels of adolescents, implying that interventions to improve parent experiences also might improve clinical outcomes.

Article Summary

Strengths and Limitations

- The study used validated instruments whose survey content and response scales were adapted for the specific patient/parent and age groups included.
- Both parents and adolescents experiences and adherence were explored, and the results can provide guidance concerning the most appropriate care to provide at outpatient clinics.
- The surveys were performed by an independent third party that was not involved in providing health care.
- While the parent survey was nationwide, the adolescent survey was restricted to four clinics and the results should be replicated in larger surveys.
- Another limitation is that our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

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Introduction

Norway has one of the highest incidences of childhood-onset type 1 diabetes in the world, and 0.6% (*n*=28,000) of the total population has type 1 diabetes [1]. Type 1 diabetes usually develops in childhood or early adolescence, and parents therefore play an important role in the day-to-day management of the disease. This responsibility places considerable demands on parents, and family involvement is a crucial component of optimal diabetes management [2].

Adolescents experience challenges to adherence that are intrinsic to their developmental stage and demands for peer normality [3]. Diabetes may become a daily struggle against undesirable blood glucose levels and risk complications, hormonal changes can lead to insulin resistance, and there are several other factors underlying poor glycaemic control in this phase of life [4].

Norwegian children attend follow-up appointments with a paediatrician and a diabetes nurse at their local paediatric outpatient department in hospitals approximately four times yearly. Dieticians and psychologists can also be consulted if requested. Given the importance of the parental role in the health-care decisions and daily follow-up of adolescents, the interactions between the adolescent and parent plus those with the health-care provider are an important component of the outpatient visit.

There is a growing recognition of the importance of assessing the experiences of patients with health care when attempting to provide patient-centred health services. Reviews have found that better patient experiences and satisfaction are associated with higher levels of adherence to recommended prevention and treatment interventions as well as better clinical outcomes [5–7]. An adult population-based survey of patients with type 2 diabetes found that strategies that increased patient satisfaction also contributed to improving the clinical outcomes [8]. Another

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study found that the parent ratings of the quality of outpatient diabetes care were negatively correlated with the mean HbA1c levels of their children. In the same study adolescents aged >13 years who reported a higher quality of care had lower HbA1c levels [9]. However, other studies have not found significant correlations between the satisfaction of young peoples with diabetes care and their HbA1c levels [10–12].

Parents or caregivers are usually asked to respond on behalf of children younger than a certain age. The views of children and adolescents have largely been ignored in large-scale patient-experience surveys, despite evidence that children may be willing to respond from the age of 8 years and that their health-care priorities diverge from those of their parents from the age of 12 years [13–15]. A cross-sectional analysis of national survey data in England showed that including inpatients aged 8–15 years in a patient-experience survey was both feasible and enhanced the information obtained from the responses of parents alone [13].

The results from previous studies show that there are discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20]. A review found that young people aged 16–24 years consistently report worse health-care experiences compared to older adults [18]. Another study found a strong correlation between the quality of diabetes care as perceived by parents and adolescents, but differences in the importance that the two populations placed on different aspects of care [9]. The level of agreement is generally better between parents and their chronically sick children than between parents and their healthy children [21].

Information about potential differences in perceptions could be useful for providers when delivering outpatient care, and when trying to balance the needs and expectations of adolescents and their parents. Also, such findings can provide guidance when measuring and monitoring patient and parent experiences with outpatient care for the purpose of quality improvement. The

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aim of the present study was to determine the association between the experiences of adolescents and parents with paediatric diabetes care at hospital outpatient departments, and the association between these experiences and the HbA1c level of the adolescents. To our knowledge, only two previous studies have simultaneously assessed the associations between parent experiences. adolescent experiences and clinical outcomes for this patient group [9, 12], and none of them were performed in Norway. Based on those previous studies, we hypothesized that there would be a correlation between the perceptions of parents and the adolescents about the quality of outpatient care, but no correlation with the HbA1c level.

Methods

Data

Responses from adolescents were collected in a pilot study that included all patients at the four largest outpatient departments in Norway who were aged 12–17 years, had type 1 diabetes and were registered in the Norwegian Childhood Diabetes Registry (NCDR) (*n*=685). The sample was contacted by post in April 2017. The request included a letter with information about the survey, a printed version of the questionnaire, a prepaid return envelope and also an option to answer electronically. Non-responders were sent up to two postal reminders. The national parent experience survey has been described elsewhere [22, 23] and here we include 181 parents that were matched with the adolescent survey.

All paediatric departments report the results of annual standardized examinations to the NCDR. Background data were transferred from the NCDR to the Norwegian Institute of Public Health

(NIPH) after data collection was completed, but for a few patients data on HbA1c and the number of consultations were not complete at the time of transfer.

Measures

 Two new measures were developed and tested in accordance with the standard methodology of the national user-experience survey programme in Norway [22, 23]: the Parent Experiences of Diabetes Care Questionnaire (PEQ-DC) and the Adolescent Patient Experiences of Diabetes Care Questionnaire (APEQ-DC) [22]. The questionnaires were designed to be applied in surveys of parents of children and adolescents with type 1 diabetes of all ages and of adolescents with type 1 diabetes aged 12–17 years visiting paediatric outpatient departments in Norway, and are included in Additional file 1 and 2.

We asked about experiences at the paediatric outpatient clinic that the child visited for follow-up appointments. Five-point scales with response options that ranged from "not at all" (1) to "a very large extent" (5) were used for most items relating to the experience of care. Smiley faces were used to illustrate the response options in the APEQ-DC. Many items also included a "not applicable / don't know" option. An open-ended question on the last page asked for further comments.

The PEQ-DC and APEQ-DC had similar (but not identical) contents. The results obtained in the development process showed that certain themes or questions were not relevant for both groups. The process highlighted the importance of ensuring that the patient questionnaire was as short as possible while also comprising age-appropriate items. The psychometric testing of the PEQ-DC identified six indicators: consultation, organization, equipment, nurse contact, doctor contact and

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outcome. Five indicators were identified for the APEQ-DC: consultation, information on food/exercise, nurse contact, doctor contact and outcome.

The HbA1c level is a measure of long-term blood glucose levels and reflects the average level over the preceding 4–12 weeks, weighted towards the most-recent 4 weeks. Data were obtained from the NCDR and reported as percentages and in millimoles per mole (mmol/mol).

Statistical analysis

Overall scores for each respondent were calculated by summing the scores for all of the indicators and dividing by their total number. The relationship between the patient and parent experiences at the outpatient clinic was tested by calculating Pearson correlation coefficients for indicator scores and the overall scores. Direct comparisons were possible between the self-reported experiences of the parents and patients for eight questions.

The indicator scores and overall scores were also correlated with the HbA1c level analysed as a continuous variable. Correlations were assessed using Pearson's *r* values.

All statistical analyses were conducted using SPSS version 23.0.

Approval

The study was approved by the Data Protection Authority at Oslo University Hospital. Registration in the NCDR is based on a signed informed consent from the child (older than 12 years) and/or the child's parents. The consent form informs the patient and/or the parents that consent may result in requests to answer questionnaires on patient experiences. Returning the questionnaire constituted consent in the survey.

Patient and public involvement

The survey was about patients and parents experiences with experiences with health care. Patients and parents were included in the development process of the instrument, to secure that the questionnaire included the most important topics for patients and parents.

Results

1,399 (55.4%) parents responded to the questionnaire, while questionnaire responses were received from 335 (53.6%) adolescent patients. The characteristics of the 181 included adolescents and their parents are presented in Table 1. Fifty-four percent of the adolescents were boys, and their mean age was 14.7 years (Table 1). The mean age when diagnosed with type 1 diabetes was 9.4 years, and the mean HbA1c level at the last registration in the NCDR was 8.2% (66.1 mmol/mol). The mean age of the parents was 46.0 years and 78.8% were female (Table 1), while 70.4% had a university or college education.

Table 2 lists the indicator scores and item scores for both adolescents and parents. The adolescent indicators had scores ranging from 57.2 (for information on food/exercise) to 87.3 (for doctor contact), and the overall score was 78.5. The parent indicator scores ranged between 60.6 (for equipment) and 79.9 (for nurse contact), and the overall score was 72.9.

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Table 3 presents the coefficients for the correlations between the indicator scores of the adolescents and parents. All of the correlations were statistically significant except the parent score for doctor contact and the adolescent score for nurse contact. The correlation coefficients ranged from r=0.16 to r=0.44. The strongest correlations were between the adolescent score for the consultation indicator and the parent score for the organization indicator (r=0.44, P<0.001), the overall score indicator (r=0.44, P<0.001), and the outcome indicator (r=0.40, P<0.001). The coefficient for the correlation between the parent and adolescent overall scores was r=0.40 (P<0.001).

Table 4 indicates that all correlations between individual questions with identical wordings in the two surveys were significant. The strongest correlation was for the questions pertaining to meeting the same doctor (r=0.46, P<0.001) and training in how to use equipment (r=0.38, P<0.001).

No significant correlations were found between the adolescent indicators and their HbA1c level (Table 5). Five of the seven parent indicators were significantly correlated with the HbA1c level. The strongest correlation was found between nurse contact and HbA1c level (r=0.22, P<0.01).

Discussion

This study found high average ratings from both adolescents and parents, but with the evaluations from parents being somewhat more critical. The parent experiences did not accurately represent the views of the patient, as demonstrated by weak-to-moderate correlations. Most parent experience indicators were correlated with the HbA1c level, but this was not the case for the adolescent experiences.

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Most previous studies have found discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20], which is in line with our findings. However, one of the very few studies related to diabetes outpatient care found a very strong correlation between patient and parent assessments [9]. There are several possible reasons for explaining the lack of convergence, but we believe the questionnaires used and the measurement approach might be the main reasons. That previous study initially used a general patient-experience questionnaire for adult patients, then adjusted it to an adolescent diabetes version and a parent version [9] but without performing further testing and validation [24]. Although this was not stated explicitly, it appears that the two surveys of how patients and parents perceived the care received were carried out simultaneously. If so, the surveys were not independent, and the parents and adolescents might have completed the questionnaires jointly [24]. This raises questions about the validity of both questionnaires, the measurements made and the estimated correlations.

Unlike the results obtained in previous surveys [13, 16, 19], the current study found that the average indicator scores for adolescents were higher than the average indicator scores for their parents. These previous studies had varying contexts and methodologies, but none of them based their comparisons on questionnaires that were developed and validated specifically for each group. Furthermore, our finding is in accordance with the general patient-satisfaction literature indicating that proxies are more critical than patients [25–30]. The indicator score for adolescents in our study was lowest for information on food/exercise, suggesting that more time should be spent on providing adolescents with such information. These findings are in accordance with previous research highlighting communication and information as an area for improvement [9, 13, 19, 20]. Adolescents gave the highest ratings for the doctor contact indicator, while the parents scored equipment the lowest and nurse contact the highest.

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No significant associations between the adolescent indicators and HbA1c level were found, in line with previous studies [10–12]. However, five of the seven parent indicators were correlated significantly with the adolescent HbA1c levels. Previous studies and reviews have found associations between patient experiences or satisfaction and adherence to recommended prevention and treatment processes and clinical outcomes [5–9]. In this setting it therefore seems that parents have a closer connection to clinical quality than do the adolescents themselves. The implication is that interventions to improve parent experiences also might improve clinical outcomes.

The assumption that adults can answer for children has traditionally gone unchallenged. The views of children and adolescents have largely been ignored in large-scale surveys, and parents or carers are often asked to respond on their behalf. There is a need to develop methods that allow young people to provide feedback on the quality of health care that they themselves consider relevant. The two instruments applied in this study were developed in a rigorous manner. Considering the important role played by parents in diabetes treatment regimes, studies exploring the relationship between experiences and adherence must take into account the perspectives and needs of both parent and adolescent. Understanding differences and similarities between these two groups can provide guidance concerning the most appropriate care to provide at outpatient clinics.

This study was subject to some limitations. While the parent survey was nationwide, the adolescent survey was restricted to four clinics. This raises questions about the generalizability of the findings, and the results should be replicated in larger surveys. Also, our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

Conclusions

All but one of the correlations between the indicator scores of the parents and adolescents were statistically significant, but the agreements between the reported experiences were all only weak or moderate. The results highlight the need to collect information from both parents and adolescents, and confirm that the views of adolescents are not always mirrored by their parents. Most parent experience indicators were significantly related to the adolescent HbA1c level, implying that interventions to improve parent experiences also might improve clinical outcomes. Understanding the correspondence between the viewpoints of parents and adolescents is potentially useful for informing interventions aimed at improving the health care provided at paediatric outpatient departments [22].

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Competing interests

On behalf of both authors, the corresponding author states that there is no competing interests.

Author contributions

T.S. initiated the study. H.H.I. planned the study in consultation with O.A.B. and T.S. H.H.I. performed the statistical analyses with O.A.B. and T.S., and drafted the manuscript. O.A.B. and T.S. participated in the planning process, critically revised the manuscript draft and approved the final version of the manuscript. H.H.I. was the project manager for the two surveys. All authors read and approved the final manuscript.

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Availability of data and material

The data sets generated and/or analysed during this study are not publicly available due to the need to protect personal data.

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Characteristic	%/mean
Adolescents	
Sex, %	
Male (<i>n</i> =98)	54.1
Female (n=83)	45.9
Mean age, years (<i>n</i> =181)	14.7
Mean age when diagnosed with diabetes, years (n=181)	9.4
Mean diabetes duration, years (n=181)	5.4
Mean HbA1c level, % (n=165)	8.2
Number of consultations during previous year (mean: 6.2), %	
1–3 (n=40)	24.4
4–6 (n=48)	29.3
7–9 (n=57)	34.8
10–21 (n=19)	11.6
General condition today, %	
Very poor (n=1)	0.6
Fairly poor (n=3)	1.7
Neither poor nor good (n=31)	17.2
Fairly good (n=89)	49.4
Very good (n=56)	31.1
Norwegian %	0111
Yes (<i>n</i> =169)	93.4
No (<i>n</i> =12)	6.6
Parents	0.0
Sex, %	
Male (<i>n</i> =38)	21.2
Female (<i>n</i> =141)	78.8
Mean age, years (n=179)	46.0
Education, %	10.0
Primary school (<i>n</i> =3)	1.7
Secondary school (<i>n</i> =50)	27.9
University or college (0–4 years) (<i>n</i> =54)	30.2
University of college (>4 years) (<i>n</i> =34)	40.2
Living with the child's other parent, %	70.2
Yes (<i>n</i> =140)	78.7
No (<i>n</i> =38)	21.3
	21.3
Number of consultations during previous year, (mean:4.3), %	17
None (<i>n</i> =3)	1.7
1 (<i>n</i> =7)	4.0
2 (<i>n</i> =21)	11.9
3 (<i>n</i> =58)	32.8
4 or more (<i>n</i> =88)	49.7
ata are % or mean.	

Table 1: Background characteristics of the adolescents (*n*=181) and the parents (*n*=181).

	Mean	SE
Adolescents		
Consultation (7 items)	79.5	14.
Information on food/exercise (2 items)	57.2	25.
Nurse contact (3 items)	85.2	14.
Doctor contact (3 items)	87.3	13.
Outcome (1 item)	83.2	19.
Overall score	78.5	14.
Well received	4.3	0.7
Waiting time	3.8	0.7
Same nurses	4.0	0.9
Nurses knowledgeable	4.5	0.7
Same doctor	4.0	1.1
Doctor knowledgeable	4.4	0.8
Training in how to use equipment	3.8	1.(
Follow-up helped the patient	3.9	0.9
Parents		
Consultation (6 items)	73.7	17.
Organization (5 items)	67.9	14.
Equipment (3 items)	60.6	23.
Nurse contact (4 items)	79.9	14.
Doctor contact (4 items)	79.1	20.
Outcome (5 items)	76.6	18.
Overall score	72.9	14.
Well received	4.4	0.7
Waiting time	3.7	0.8
Same nurses	4.2	0.7
Nurses knowledgeable	4.6	0.6
Same doctor	4.2	0.9
Doctor knowledgeable	4.7	0.6
Training in how to use equipment	4.3	9.0
Follow-up helped the patient	4.3	0.8

All indicators were scored from 0 to 100, where 100 was the best possible experience. Individual items were scored from 1 to 5, where 5 is the best possible experience.

Table 3: Correlations between	adolescent and	l parent ex	perience indicators.

Indicators:				ors: adolescents		
parents	Consultation	Information on food/exercise	Nurse contact	Doctor contact	Outcome	Overall score
Consultation	0.36***	0.29***	0.23**	0.29***	0.26***	0.36***
Organization	0.44***	0.25**	0.27***	0.27***	0.31***	0.37***
Equipment	0.37***	0.23**	0.17*	0.16*	0.18*	0.28***
Nurse contact	0.35***	0.27***	0.29***	0.25**	0.21**	0.34***
Doctor contact	0.20**	0.21**	0.02	0.19*	0.20*	0.21**
Outcome	0.40***	0.27***	0.24**	0.30***	0.32***	0.38***
Overall score	0.44***	0.31***	0.25**	0.30***	0.30***	0.40***
p<0.001, **p<0.01, *p<	0.05.					

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Well received

Waiting time

Same nurses

Same doctor

Data are r values. ****p*<0.001, ***p*<0.01.

Nurses knowledgeable

Doctor knowledgeable

Follow-up helped the child

Training in how to use equipment

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Table 4: Correlations between adolescent and parent experiences for single items. Item

p 0.31***

0.24**

0.22**

0.33***

0.46***

0.23**

0.38***

0.28***

for perturbation on the

Table 5: Correlations of adolescent and parent experiences with HbA1c level.

Table 5: Correlations of adolescent and p		
Indicator/item	HbA1c	
Adolescents		
Consultation	0.05	
Information on food/exercise	0.00	
Nurse contact	0.00	
Doctor contact	-0.04	
Outcome	-0.01	
Overall score	0.00	
Parents		
Consultation	-0.12	
Organization	-0.18*	
Equipment	-0.08	
Nurse contact	-0.22**	
Doctor contact	-0.16*	
Outcome	-0.16*	
Overall score	-0.19*	
Data are <i>r</i> values.		
*p<0.01, *p<0.05.		
p 0.0., p 0.00.		

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Or

4.

1.

Norwegian Institute of Public Health					
Your experiences with the paediatric outpatient clinic					
The questions below concern your experiences with the paediatric outpatient clinic your child attends for diabetes.					
rival and waiting	5. Do you feel that the doctors and nurses				
Are you and your child well received at the outpatient clinic? Not at all To a small extent To some extent To a large extent To a very large extent Not at all Not at all To a small extent To some extent To some extent To a very large extent To a very large extent To a number outpatient clinic?	cooperate well? Not at all To a small extent To some extent To a large extent To a very large extent Not applicable / Don't know 6. Do you feel that the person you have the appointment with is well prepared? Not at all To a small extent To a small extent To a small extent To a very large extent Not at all To a small extent To a large extent Not at all To a very large extent Not applicable / Don't know				
Do you find the waiting room satisfactory?	The nurses				
 To a small extent To some extent To a large extent To a very large extent 	 7. Do you and your child see the same nurses every time you attend the outpatient clinic? Not at all To a small extent To some extent 				
ganisation	To a large extent				
Do you feel that the outpatient clinic is well organised?	 To a very large extent Not applicable / Don't know 				
 Not at all To a small extent To some extent To a large extent To a very large extent Not applicable / Don't know 	 8. Do you and your child get enough time with the nurses? Not at all To a small extent To some extent To a large extent To a very large extent Not applicable / Don't know 				

1 2 3 4 5 6 7 8	9.	Do the nurses appear to know a lot about diabetes and diabetes treatment? Not at all To a small extent To some extent To a large extent	14.	Do you feel that the doctor shows care and concern for your child? Not at all To a small extent To some extent To a large extent
9 10 11	10	 To a very large extent Not applicable / Don't know 		 To a very large extent Not applicable / Don't know
12 13	10.	Do you feel that the nurses show care and concern for your child?		pre about what is discussed at pointments
14 15		Not at all		In your opinion, do the topics discussed at
16		To a small extent	15.	the appointments meet your child's needs?
17 19		To some extent		Not at all
18 19		To a large extent		To a small extent
20	-	□ To a very large extent		To some extent
21 22		Not applicable / Don't know		To a large extent
23				To a very large extent
24 25	Th	e doctor		Not applicable / Don't know
26		questions below are about the doctor. If you	40	
27 28 29		more than one doctor, please give us your rall assessment of all the doctors you see.	16.	Is it clear to you and your child what should be followed up before the next appointment?
30 21	11.	Do you and your child see the same doctor		Not at all
31 32		every time you attend the outpatient		To a small extent
33		clinic?		To some extent
34 35		Not at all		To a large extent
36		To a small extent		To a very large extent
37 38		To some extent		Not applicable / Don't know
39		To a large extent	17.	
40		To a very large extent	17.	should be followed up before the next
41 42		Not applicable / Don't know		appointment?
43	12.	Do you and your child get enough time		Not at all
44 45		with the doctor?		To a small extent
46		Not at all		To some extent
47 48		To a small extent		To a large extent
40 49		To some extent		To a very large extent
50		To a large extent		Not applicable / Don't know
51 52		To a very large extent		
53		Not applicable / Don't know	Be	ing a parent/guardian at the clinic
54 55 56	13.	Does the doctor appear to know a lot about diabetes and diabetes treatment?	18.	Are your views as a parent/guardian taken seriously?
57		Not at all		Not at all
58 59		To a small extent		To a small extent
59 60		To some extent		To some extent
		To a large extent		To a large extent
		To a very large extent		To a very large extent
	2	Not applicable മറ്റ്രാല് അർയം only - http://bmjopen	bmj.cor	r[/s]te/Nooapplioable∉sDonthknow

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1	19.	Do you get enough time for conversations	24.	Do you receive satisfactory information
2		without your child being present?		from the outpatient clinic about available devices/equipment?
3		Not at all		
4 5		To a small extent		 Not at all ☐ To a small extent
6		To some extent		
7 8		To a large extent		To some extent
9		To a very large extent		To a large extent
10		Not applicable / Don't know		To a very large extent
11 12	20.	Are you given satisfactory information		Not applicable / Don't know
13		and guidance on how to follow up on your	25.	Do you and your child receive good
14 15		child's diabetes treatment?		training in managing the
16		Not at all		devices/equipment?
17 10		To a small extent		Not at all
18 19		To some extent		To a small extent
20		To a large extent		To some extent
21 22		To a very large extent		To a large extent
23		Not applicable / Don't know		To a very large extent
24 25	21	Do you get the support you need to let		Not applicable / Don't know
25 26	2 1.	your child take more responsibility for his		
27		or her diabetes treatment?	Av	railability
28 29		Not at all	26.	In your opinion, does your child have
30		To a small extent		access to the best possible
31 32		To some extent		devices/equipment?
33		To a large extent		Not at all
34		To a very large extent		To a small extent
35 36		Not applicable / Don't know		To some extent
37				To a large extent
38 39	In	formation and training		To a very large extent
40	22.	Do you receive satisfactory information		Not applicable / Don't know
41 42		about the results of tests and	27.	Does your child have satisfactory access
42 43		examinations?		to a nutritionist?
44		Not at all		Not at all
45 46		To a small extent		To a small extent
47		To some extent		To some extent
48 49		To a large extent		To a large extent
49 50		To a very large extent		To a very large extent
51	23	Do you receive satisfactory information		Not applicable / Don't know
52 53	20.	about the development in your child's	28.	Does your child have satisfactory access
54		health and the risk of complications?		to a psychologist?
55 56		Not at all		Not at all
50 57		To a small extent		── To a small extent
58 50		To some extent		└── To some extent └─
59 60		☐ To a large extent		To a large extent
		To a very large extent		To a very large extent
		Not applicable / Don't know		Not applicable / Don't know
			L .	

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1 2 3 4 5 6 7 8 9 10	29.	Is it easy to get in touch with the outpatient clinic outside of appointments? Not at all To a small extent To some extent To a large extent To a very large extent Not applicable / Don't know	34.	All in all, how dissatisfied or satisfied are you with how the outpatient clinic has followed up on your child and the diabetes treatment? Very dissatisfied Rather dissatisfied Both dissatisfied and satisfied Rather satisfied
 11 12 13 14 15 16 17 18 19 20 21 22 22 	Us	How do you feel about the number of appointments at the outpatient clinic? Too few A sufficient number Too many Not applicable / Don't know	35.	 Very satisfied All in all, how dissatisfied or satisfied are you with how the outpatient clinic has met you as a parent/guardian? Very dissatisfied Rather dissatisfied Both dissatisfied and satisfied Rather satisfied Very satisfied
23 24	31.	Do you feel that your child benefits from attending the outpatient clinic?		
25 26			Ba	ckground questions
20 27		☐ To a small extent		
28 29		To some extent	36.	In the last year, how many times have you been present for all or part of your child's
29 30		☐ To a large extent		appointment?
31		To a very large extent		
32 33		Not applicable / Don't know		1 time
34				2 times
35	32.	Do you, as a parent/guardian, benefit from		3 times
36 37		attending the outpatient clinic?		4 or more times
38		Not at all		
39 40		To a small extent	37.	Are you male or female?
41		To some extent		Male
42		To a large extent		Female
43 44		To a very large extent	20	
45		Not applicable / Don't know	აბ.	What age are you?
46 47				Number of years
48	Ot	her questions	39.	What is your highest level of educational
49 50	33	Does the follow-up at the outpatient clinic		attainment?
51	00.	make you and your child more capable to		Primary school
52		live a good life with diabetes?		Secondary school
53 54		Not at all		Higher education/university (up to 4 years)
55		To a small extent		Higher education/university (4+ years)
56 57		To some extent	40	Do you live with the child's other parent/
57 58		To a large extent	. . .	guardian?
59		☐ To a very large extent		Yes
60		Not applicable / Don't know		
				□ Not applicable ⊥

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questionnaire:	ments about experiences with the outpatient clinic or comments on the
	· ·
	4
	Thank you for taking the time to answer.
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 Norwegian Institute of Public Health

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Your experiences with the children's

The questions below concern your experiences with the outpatient clinic you attend for diabetes. Please tick only one answer for each question.

outpatient clinic

 When you arrive at the outpatient clinic 	4. Do the nurses speak to you in a way that you understand?
 ¹⁷ 1. Are you well received at the outpatient clinic? 	兴 🔲 Not at all
$\frac{19}{20}$ \bigcirc Not at all	😕 🔲 To a small extent
21 \bigcirc To a small extent	😑 🔲 To some extent
$23 \\ 24 \\ \square$ To some extent	🙂 🔲 To a large extent
25 📋 🗌 To a large extent	😛 🔲 To a very large extent
$\stackrel{26}{\bigcirc}$ \square To a very large extent	
28 29	5. Do the nurses appear to know a lot about diabetes and diabetes treatment?
 ³⁰ 2. Do you feel there's a lot of waiting at the outpatient clinic? 	Not at all
32 \sim \sim	To a small extent
$34 \qquad \bigcirc \qquad \square$ Not at all $35 \qquad \bigcirc \qquad \square$ To a small system	😑 🗌 To some extent
	🙂 🔲 To a large extent
	😛 📃 To a very large extent
 39 Control To a large extent 40 Control To a large extent 	O C
41 () To a very large extent 42 43	6. Do you feel safe bringing up things with the nurses that are difficult to discuss?
44 45 The nurses	兴 🔲 Not at all
46 47 3. Do you see the same nurses every time	To a small extent
48 you attend the outpatient clinic?	To some extent
49 50 🔀 🗌 Never	🙂 🔲 To a large extent
51 52 Rarely	😛 🔲 To a very large extent
53 54 Sometimes	Not applicable / Don't know
55 C Often	
57 😛 🗌 Always	
 58	

¹ ₂ The doctor	More about your diabetes check-ups
 The questions below are about your doctor. If you see more than one doctor, please consider all the doctors you see when you are answering the questions. 	 11. Are you given good advice to help you choose the right insulin dose? Not at all
 9 7. Do you see the same doctor every time you 10 attend the outpatient clinic? 	To a small extent
$\begin{array}{c} 11 \\ 12 \end{array} \bigcirc \square \text{ Never} \end{array}$	○ □ To a large extent
13 14 🔀 🗌 Rarely	To a very large extent
15 16 Sometimes	
$\begin{array}{c} 17 \\ 18 \\ 19 \\ \hline \end{array} \bigcirc \Box \text{ Often} \\ Always \\ \hline \end{array}$	12. Do you have a say in what should be followed up before the next appointment?
	; 🗌 Not at all
22	🔀 🗌 To a small extent
 ²³ 8. Do the doctor speak to you in a way that you ²⁴ understand? 	📺 🔲 To some extent
25 26 \bigcirc \bigcirc Not at all	📺 🗌 To a large extent
27 28 \square To a small extent	; 🗌 To a very large extent
29 \bigcirc To some extent	Not applicable / Don't know
30 To a large extent	42. Do the staff who would state outputient aligin
32 $(=)$ To a very large extent	13. Do the staff who work at the outpatient clinic appear to understand what it's like to be
34 35 Not applicable / Don't know	young and have diabetes?
 36 37 9. Do the doctor appear to know a lot about 38 diabetes and diabetes treatment? 	 ◯ Not at all ◯ To a small extent
³⁹ 40 🔀 🗌 Not at all	To some extent
41_{42} \bigcirc \Box To a small extent	😳 🔲 To a large extent
$43 \qquad \bigcirc \qquad \square$ To some extent	⊖ ☐ To a very large extent
44 \bigcirc \square To a large extent	Not applicable / Don't know
46 47 \bigcirc To a very large extent	
 48 49 Not applicable / Don't know 50 	14. Do you get enough time with the doctor or nurse during you appointment?
⁵¹ 10. Do you feel safe bringing up things with the	兴 🗌 Not at all
$_{53}$ doctor that are difficult to discuss?	🙁 🔲 To a small extent
$\begin{array}{c} 54 \\ 55 \\ \hline \end{array} \qquad \boxed{ \ } \qquad \qquad$	😑 🗌 To some extent
56 \bigcirc \square To a small extent 57 \bigcirc \square	🙂 🗌 To a large extent
58 \bigcirc \square To some extent	😛 🔲 To a very large extent
$_{60}$ \bigcirc \square To a large extent	
To a very large extent	

1 2 3	15. How do you feel about the number of appointments you have at the outpatient clinic	19. Do you receive good training in managing the devices/equipment?
4 5	each year?	兴 🔲 Not at all
6 7	A sufficient amount	🔀 🔲 To a small extent
8	Too many	😑 🗌 To some extent
9 10	Not applicable / Don't know	🙂 🔲 To a large extent
11 12		😛 🔲 To a very large extent
13 14	Food and exercise	Not applicable / Don't know
15 16 17	16. Are you given good information and guidance about food?	Appointment with others
18 19 20	Not at all	20. Can you get an appointment with a nutritionist if you need one? (A nutritionist
21 22	To a small extent	gives advice about food and diet)
23 24	To some extent	Yes
25	○ ☐ To a large extent	No
26 27	 (⊖) ∐ To a very large extent 	Not applicable/Don't know
28 29 30	17. Are you given good information and guidance about exercise?	21. Can you get an appointment with a psychologist if you need one?
31 32	兴 🗌 Not at all	Yes
33 34	🔀 🔲 To a small extent	No
35 36	😑 🔲 To some extent	Not applicable/Don't know
37 38	🙂 🗌 To a large extent	Pringing parents/guardians with you
39 40	😛 🔲 To a very large extent	Bringing parents/guardians with you
41 42	Not applicable / Don't know	22. How often do your parents/guardians attend the outpatient clinic with you?
43 44	Devices/equipment	Never
45 46	Devices/equipment	Rarely
47 48	18. Are you involved in deciding which	Sometimes
49 50	devices/equipment you should use?	
51 52	(六) ∐ Not at all	Always
53	C To a small extent	23. If your parents/guardians attend the
54 55	To some extent	appointment with you, who does the doctor or nurse mostly speak to?
56 57	C To a large extent	Mostly to me
58 59	To a very large extent Not applicable / Don't know	Mostly to my parents/guardians
60		About the same to each of us
		Parents/guardians do not come with me

24. If needed, can you get an appointment with	26. Who completed this questionnaire?
your doctor or nurse without your parents/	
² quardians being present?	Me on my own
4 Yes	Me and my parents/guardians together
	My parents/guardians on their own
6 No 7	
8 Not applicable/Don't know	
9	27. All in all, how are you feeling today?
10	
11	🤆 🖂 Very bad
12 Other questions	
13	; 🗌 Fairly bad
	😑 🗌 Both and
¹⁴ 25. All in all, has attending the outpatient clinic	
helped you with your diabetes?	😳 🗌 Rather good
17	
18 🔅 🗌 Not at all	😛 🗌 Very good
19	
$_{20}$ \bigcirc To a small extent	28. Do you alternate between living with each of
$\stackrel{21}{\longrightarrow}$ To some extent	
	your parents/guardians?
$\overset{23}{\bigcirc}$ \Box To a large extent	Yes
24	
²⁵ 🔁 To a very large extent	No
26	Not applicable
27	
28	
$_{30}^{29}$ Any additional comments about the outpatier	at clinic or how you found completing the
	re ennie of now you found completing the
31 questionnaire: 32	
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48 49 50 51 52 53	
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Thank you for taking the time to answer.

1 2 3 4	Reporting	cheo	cklist for cross sectional study.							
 5 Based on the STROBE cross sectional guidelines. 7 										
8 9	Instructions to authors									
10 11 12	Complete this checkl	Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.								
13	Your article may not	currentl	y address all the items on the checklist. Please modify your text to include the missing information	. If you are						
14 15 certain that an item does not apply, please write "n/a" and provide a short explanation.										
16 17 18	Upload your complet	ted checl	klist as an extra file when you submit to a journal.							
19 20	In your methods sect	ion, say	that you used the STROBE cross sectional reporting guidelines, and cite them as:							
21 22 23 24 25			er M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observation Statement: guidelines for reporting observational studies.	onal Studies Page						
26 27			Reporting Item	Number						
28 29 30 31	Title and abstract			2						
32 33	Title	<u>#1a</u>	Indicate the study's design with a commonly used term in the title or the abstract	2						
34 35 36	Abstract	<u>#1b</u>	Provide in the abstract an informative and balanced summary of what was done and what was found	2,3						
37 38 39	Introduction									
40 41 42	Background / rationale	<u>#2</u>	Explain the scientific background and rationale for the investigation being reported	4-6						
43 44 45	Objectives	<u>#3</u>	State specific objectives, including any prespecified hypotheses	2,7						
46 47 48	Methods									
49 50	Study design	<u>#4</u>	Present key elements of study design early in the paper	2, 7						
51 52 53 54	Setting	<u>#5</u>	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7-9						
55 56 57 58	Eligibility criteria	<u>#6a</u>	Give the eligibility criteria, and the sources and methods of selection of participants.	2,8						
58 59 60			For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml							

1 2 3		<u>#7</u>	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	8,9
4 5 6 7	Data sources / measurement	<u>#8</u>	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one	8,9
8 9 10	Bias	<u>#9</u>	group. Give information separately for for exposed and unexposed groups if applicable. Describe any efforts to address potential sources of bias	4,13
11 12 13	Study size	<u>#10</u>	Explain how the study size was arrived at	7,8
14 15 16	Quantitative variables	<u>#11</u>	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	8-10
17 18 19	Statistical methods	<u>#12a</u>	Describe all statistical methods, including those used to control for confounding	8-10
20 21 22	Statistical methods	<u>#12b</u>	Describe any methods used to examine subgroups and interactions	8-10
23 24 25	Statistical methods	<u>#12c</u>	Explain how missing data were addressed	n/a
26 27	Statistical methods	<u>#12d</u>	If applicable, describe analytical methods taking account of sampling strategy	n/a
28 29 30	Statistical methods	<u>#12e</u>	Describe any sensitivity analyses	n/a
31 32	Results			
33 34 35	Participants	<u>#13a</u>	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and	n/a
36 37 38			analysed. Give information separately for for exposed and unexposed groups if applicable.	
39 40	Participants	<u>#13b</u>	Give reasons for non-participation at each stage	n/a
41 42	Participants	<u>#13c</u>	Consider use of a flow diagram	n/a
43 44 45 46 47	Descriptive data	<u>#14a</u>	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	10,20
48 49 50	Descriptive data	<u>#14b</u>	Indicate number of participants with missing data for each variable of interest	n/a
51 52 53 54	Outcome data	<u>#15</u>	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
54 55 56 57 58 59 60	Main results	<u>#16a</u> F	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included for peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	n/a

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1 2	Main results	<u>#16b</u>	Report category boundaries when continuous variables were categorized	n/a
- 3 4 5 6	Main results	<u>#16c</u>	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
7 8 9 10	Other analyses	<u>#17</u>	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
10 11 12	Discussion			
13 14	Key results	<u>#18</u>	Summarise key results with reference to study objectives	11, 13-14
15 16 17 18	Limitations	<u>#19</u>	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13
19 20 21 22	Interpretation	<u>#20</u>	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12,13
23 24 25	Generalisability	<u>#21</u>	Discuss the generalisability (external validity) of the study results	13
26	Other			
27 28 29	Information			
29 30 31	Funding	<u>#22</u>	Give the source of funding and the role of the funders for the present study and, if applicable,	14
32			for the original study on which the present article is based	
33 34 ⁷	The STROBE checklis	st is dist	ributed under the terms of the Creative Commons Attribution License CC-BY. This checklist was	completed
35 36	on 07. June 2019 using	g <u>https:/</u> /	/www.goodreports.org/, a tool made by the EQUATOR Network in collaboration with Penelope.a	<u>ui</u>
37 38 39 40 41 42				
43 44				
45 46				
47 48				
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59 60		F	or peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	

BMJ Open

Associations between adolescent experiences, parent experiences and HbA1c: results following two surveys based on The Norwegian Childhood Diabetes Registry (NCDR)

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Secondary Subject Heading:	Paediatrics, Diabetes and endocrinology, Patient-centred medicine
Keywords:	patient experiences, parent experiences, diabetes, questionnaire, HbA1c



Associations between adolescent experiences, parent experiences and HbA1c: results following two surveys based on The Norwegian Childhood Diabetes Registry (NCDR)

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Abstract

Objective

The aim of the current study was to determine the association between the experiences of adolescents and their parents with paediatric diabetes care at hospital outpatient departments and the association between these experiences and the HbA1c levels of adolescents.

Design

Cross-sectional survey.

Setting

Paediatric diabetes care at hospital outpatient departments in Norway.

Participants

Parents of all outpatients registered in the Norwegian Childhood Diabetes Registry and patients in the same registry aged 12–17 years.

Intervention

1,399 parents participated in a national pilot survey, and 335 patients aged 12–17 years from the four largest paediatric outpatient departments in Norway responded in another pilot study. 181 paired parental and patient questionnaires were analysed.

Main outcome measures

The correlations between single items, indicator scores and overall scores were explored, as was that between indicator scores and HbA1c levels.

Results

There was a moderate but significant correlation between the responses of the patients and parents. For 40 of the 42 associations the correlations were significant, ranging from 0.16 to 0.42.

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A weak but significant negative correlation was found between the indicator scores of parents and the HbA1c levels of the adolescents. The strongest correlations were between HbA1c level and nurse contact and organization, both with a correlation coefficient of 0.21 (P<0.01). There was no significant correlation between HbA1c level and patient indicator scores.

Conclusions

These results highlight the need to obtain information from both parents and adolescents, and indicate that the views of adolescents are not always mirrored by their parents. Three of the seven parent experience indicators were significantly related to the HbA1c levels of adolescents, but replication in future research with larger sample sizes is warranted.

Article Summary

Strengths and Limitations

- The study used validated instruments whose survey content and response scales were adapted for the specific patient/parent and age groups included.
- Both parents and adolescents experiences were explored, and the results can provide guidance concerning the most appropriate care to provide at outpatient clinics.
- The surveys were performed by an independent third party that was not involved in providing health care.
- While the parent survey was nationwide, the adolescent survey was restricted to four clinics and the results should be replicated in larger surveys.
- Another limitation is that our study was based on responses being received from both parents and adolescents, which may have introduced selection bias.

Introduction

Norway has one of the highest incidences of childhood-onset type 1 diabetes in the world, and 0.6% (*n*=28,000) of the total population has type 1 diabetes [1]. Type 1 diabetes usually develops in childhood or early adolescence, and parents therefore play an important role in the day-to-day management of the disease. This responsibility places considerable demands on parents, and family involvement is a crucial component of optimal diabetes management [2].

Adolescents experience challenges to adherence that are intrinsic to their developmental stage and demands for peer normality [3]. Diabetes may become a daily struggle against undesirable blood glucose levels and risk complications, hormonal changes can lead to insulin resistance, and there are several other factors underlying poor glycaemic control in this phase of life [4].

Norwegian children attend follow-up appointments with a paediatrician and a diabetes nurse at their local paediatric outpatient department in hospitals approximately four times yearly. Dieticians and psychologists can also be consulted if requested. Given the importance of the parental role in the health-care decisions and daily follow-up of adolescents, the interactions between the adolescent and parent plus those with the health-care provider are an important component of the outpatient visit.

There is a growing recognition of the importance of assessing the experiences of patients with health care when attempting to provide patient-centred health services. Reviews have found that better patient experiences and satisfaction are associated with higher levels of adherence to recommended prevention and treatment interventions as well as better clinical outcomes [5–7]. An adult population-based survey of patients with type 2 diabetes found that strategies that increased patient satisfaction also contributed to improving the clinical outcomes [8]. Another

study found that the parent ratings of the quality of outpatient diabetes care were negatively correlated with the mean HbA1c levels of their children. In the same study adolescents aged >13 years who reported a higher quality of care had lower HbA1c levels [9]. However, other studies have not found significant correlations between the satisfaction of young peoples with diabetes care and their HbA1c levels [10–12].

Parents or caregivers are usually asked to respond on behalf of children younger than a certain age. The views of children and adolescents have largely been ignored in large-scale patient-experience surveys, despite evidence that children may be willing to respond from the age of 8 years and that their health-care priorities diverge from those of their parents from the age of 12 years [13–15]. A cross-sectional analysis of national survey data in England showed that including inpatients aged 8–15 years in a patient-experience survey was both feasible and enhanced the information obtained from the responses of parents alone [13].

The results from previous studies show that there are discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20]. A review found that young people aged 16–24 years consistently report worse health-care experiences compared to older adults [18]. Another study found a strong correlation between the quality of diabetes care as perceived by parents and adolescents, but differences in the importance that the two populations placed on different aspects of care [9]. The level of agreement is generally better between parents and their chronically sick children than between parents and their healthy children [21].

Information about potential differences in perceptions could be useful for providers when delivering outpatient care, and when trying to balance the needs and expectations of adolescents and their parents. Also, such findings can provide guidance when measuring and monitoring patient and parent experiences with outpatient care for the purpose of quality improvement. The

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aim of the present study was to determine the association between the experiences of adolescents and parents with paediatric diabetes care at hospital outpatient departments, and the association between these experiences and the HbA1c level of the adolescents. To our knowledge, only two previous studies have simultaneously assessed the associations between parent experiences. adolescent experiences and clinical outcomes for this patient group [9, 12], and none of them were performed in Norway. Based on those previous studies, we hypothesized that there would be a correlation between the perceptions of parents and the adolescents about the quality of outpatient care, but no correlation with the HbA1c level.

Methods

Data

Responses from adolescents were collected in a pilot study that included all patients at the four largest outpatient departments in Norway who were aged 12–17 years, had type 1 diabetes and were registered in the Norwegian Childhood Diabetes Registry (NCDR) (n=685). The purpose of the pilot study was to determine the data quality, validity and internal consistency reliability of the newly developed instrument. A report published in 2018 documents the development of the instrument and the data collection method [22]. The sample was contacted by post in April 2017. The request included a letter with information about the survey, a printed version of the questionnaire, a prepaid return envelope and also an option to answer electronically. Nonresponders were sent up to two postal reminders. The national parent experience survey has been described elsewhere [23, 24] and here we include 181 parents that were matched with the

adolescent survey. Unique patient identification numbers were used to match parent responses with that of their children.

All paediatric departments report the results of annual standardized examinations to the NCDR. Background data were transferred from the NCDR to the Norwegian Institute of Public Health (NIPH) after data collection was completed, but for a few patients data on HbA1c and the number of consultations were not complete at the time of transfer.

Measures

Two new measures were developed and tested in accordance with the standard methodology of the national user-experience survey programme in Norway [23, 24]: the Parent Experiences of Diabetes Care Questionnaire (PEQ-DC) and the Adolescent Patient Experiences of Diabetes Care Questionnaire (APEQ-DC) [23]. The questionnaires were designed to be applied in surveys of parents of children and adolescents with type 1 diabetes of all ages and of adolescents with type 1 diabetes aged 12–17 years visiting paediatric outpatient departments in Norway, and are included in Additional file 1 and 2.

We asked about experiences at the paediatric outpatient clinic that the child visited for follow-up appointments. Five-point scales with response options that ranged from "not at all" (1) to "a very large extent" (5) were used for most items relating to the experience of care. Smiley faces were used to illustrate the response options in the APEQ-DC. Many items also included a "not applicable / don't know" option. An open-ended question on the last page asked for further comments.

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The PEQ-DC and APEQ-DC had similar (but not identical) contents. The results obtained in the development process showed that certain themes or questions were not relevant for both groups. The process highlighted the importance of ensuring that the patient questionnaire was as short as possible while also comprising age-appropriate items. The psychometric testing of the PEQ-DC identified six indicators: consultation, organization, equipment, nurse contact, doctor contact and outcome. Five indicators were identified for the APEQ-DC: consultation, information on food/exercise, nurse contact, doctor contact and outcome.

The HbA1c level is a measure of long-term blood glucose levels and reflects the average level over the preceding 4–12 weeks, weighted towards the most-recent 4 weeks. Data were obtained from the NCDR and reported as percentages and in millimoles per mole (mmol/mol).

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Statistical analysis

Overall scores for each respondent were calculated by summing the scores for all of the indicators and dividing by their total number.

The Mann-Whitney U test was used to test the differences in scores between patients that reached the recommended < 7.5% treatment goal, and patients that did not reach the recommended treatment goal. Corresponding analyses were conducted for the parents, based on the HbA1c value of their children. The Mann-Whitney U test was also used to compare the self-reported experiences of the parents and patients for eight single items.

The relationship between the patient and parent experiences at the outpatient clinic was tested by calculating Spearman's rank correlation coefficients for indicator scores, the overall scores and

single items. Multivariate linear regression analyses were used to further assess the associations between the patient and parent experiences, controlling for age, gender and HbA1c level.

The indicator scores and overall scores were also correlated with the HbA1c level analysed as a continuous variable. Correlations were assessed using Spearman's rank correlation. Multivariate linear regression analyses were used to assess the associations, controlling for age and gender.

All statistical analyses were conducted using SPSS version 23.0.

Approval

Both surveys were approved by the Data Protection Authority at Oslo University Hospital. Registration in the NCDR is based on a signed informed consent from the child (older than 12 years) and/or the child's parents. The consent form informs the patient and/or the parents that consent may result in requests to answer questionnaires on patient and parent experiences of diabetes care. Returning the questionnaire constituted consent in the survey.

Patient and public involvement

The survey was about patients and parents experiences with experiences with health care. Patients and parents were included in the development process of the instrument, to secure that the questionnaire included the most important topics for patients and parents.

Results

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1,399 (55.4%) parents responded to the questionnaire, while questionnaire responses were received from 335 (53.6%) adolescent patients. We were able to match 181 parents with the adolescent survey, and the overall coverage rate in this study was 26.4%. The characteristics of the 181 included adolescents and their parents are presented in Table 1. Fifty-four percent of the adolescents were boys, and their mean age was 14.7 years (Table 1). The mean age when diagnosed with type 1 diabetes was 9.4 years, and the mean HbA1c level at the last registration in the NCDR was 8.2% (66.1 mmol/mol). The mean age of the parents was 46.0 years and 78.8% were female (Table 1), while 70.4% had a university or college education.

Table 2 lists the indicator scores and item scores for both adolescents and parents. The adolescent indicators had scores ranging from 57.2 (for information on food/exercise) to 87.3 (for doctor contact), and the overall score was 78.5. The parent indicator scores ranged between 60.6 (for equipment) and 79.9 (for nurse contact), and the overall score was 72.9. Analyses showed that for four of the single items the adolescent scores were significantly higher than the parent scores (results not shown). Table 2 also shows the indicator scores and item scores for patients who achieved the recommended < 7.5% treatment goal and patients who did not achieve the < 7.5% treatment goal. Corresponding results are shown for parents, based on the HbA1c values of their children. No significant differences in scores were found for patients who achieved the < 7.5% treatment goal and patients who did not achieve the < 7.5% treatment goal and patients who did not achieve the < 7.5% treatment goal and patients who did not achieve the < 7.5% treatment goal and patients who achieved the < 7.5% treatment goal and patients who did not achieve the < 7.5% treatment goal and patients who did not achieve the treatment goal. Parents of children who reached the treatment goal had significantly higher scores on one of the single items (nurses knowledgeable).

Table 3 presents the coefficients for the correlations between the indicator scores of the adolescents and parents. All of the correlations were statistically significant except the adolescent score for nurse contact and the parent score for doctor contact, and the adolescent score for doctor

contact and the parent score for equipment. The significant correlation coefficients ranged from 0.16 to 0.42. The strongest correlations were between the adolescent score for the consultation indicator and the parent score for the outcome indicator (rho=0.42, P<0.001) and the overall score indicator (rho=0.41, P<0.001) respectively. The correlation coefficient between the adolescent score for the overall score indicator and the parent score for the overall score indicator and the parent score for the overall score indicator and the parent score for the overall score indicator and the parent score for the overall score indicator and the parent score for the overall score indicator was also 0.41 (P<0.001). The coefficient for the correlation between the parent and adolescent overall scores was 0.41 (P<0.001).

Table 4 indicates that all correlations between individual questions with identical wordings in the two surveys were significant. The strongest correlation was for the questions pertaining to meeting the same doctor (rho=0.50, P<0.001) and if the patient and parent were well received (rho=0.32, P<0.001).

No significant correlations were found between the adolescent indicators and their HbA1c level (Table 5). Three of the seven parent indicators were significantly correlated with the HbA1c level. The strongest correlation was found between HbA1c level and nurse contact and organization, both with a correlation coefficient of 0.21 (P<0.01).

We also tested if the difference in overall mean scores for the parent and the adolescent had an influence on the HbA1c level, but the results did not support this association (results not shown here).

Discussion

This study found high average ratings from both adolescents and parents, but with the evaluations from parents being somewhat more critical. The parent experiences did not accurately represent

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the views of the patient, as demonstrated by weak-to-moderate correlations. Three of seven parent experience indicators were correlated with the HbA1c level, but this was not the case for the adolescent experiences.

Most previous studies have found discrepancies between assessments of health-care services by children and their parents or caregivers [13, 16–20], which is in line with our findings. However, one of the very few studies related to diabetes outpatient care found a very strong correlation between patient and parent assessments [9]. There are several possible reasons for explaining the lack of convergence, but we believe the questionnaires used and the measurement approach might be the main reasons. That previous study initially used a general patient-experience questionnaire for adult patients, then adjusted it to an adolescent diabetes version and a parent version [9] but without performing further testing and validation [25]. Although this was not stated explicitly, it appears that the two surveys of how patients and parents perceived the care received were carried out simultaneously. If so, the surveys were not independent, and the parents and adolescents might have completed the questionnaires jointly [25]. This raises questions about the validity of both questionnaires, the measurements made and the estimated correlations.

Unlike the results obtained in previous surveys [13, 16, 19], the current study found that the average indicator scores for adolescents were higher than the average indicator scores for their parents. These previous studies had varying contexts and methodologies, but none of them based their comparisons on questionnaires that were developed and validated specifically for each group. Furthermore, our finding is in accordance with the general patient-satisfaction literature indicating that proxies are more critical than patients [26–31]. The indicator score for adolescents in our study was lowest for information on food/exercise, suggesting that more time should be spent on providing adolescents with such information. These findings are in accordance with

previous research highlighting communication and information as an area for improvement [9, 13, 19, 20]. Adolescents gave the highest ratings for the doctor contact indicator, while the parents scored equipment the lowest and nurse contact the highest.

No significant associations between the adolescent indicators and HbA1c level were found, in line with previous studies [10–12]. However, three of the seven parent indicators were correlated significantly with the adolescent HbA1c levels. The results from the current study also showed that parents of children who reached the recommended < 7.5% treatment goal reported better experiences related to the nurses' knowledge. Previous studies and reviews have found associations between patient experiences or satisfaction and adherence to recommended prevention and treatment processes and clinical outcomes [5–9]. In this setting it therefore seems that parents have a closer connection to clinical quality than do the adolescents themselves. The implication is that interventions to improve parent experiences also might improve clinical outcomes but more research conducted with larger sample sizes is needed to conclude upon this observed association.

The assumption that adults can answer for children has traditionally gone unchallenged. The views of children and adolescents have largely been ignored in large-scale surveys, and parents or carers are often asked to respond on their behalf. There is a need to develop methods that allow young people to provide feedback on the quality of health care that they themselves consider relevant. The two instruments applied in this study were developed in a rigorous manner. Considering the important role played by parents in diabetes treatment regimes, studies exploring the relationship between experiences and adherence must take into account the perspectives and needs of both parent and adolescent. Understanding differences and similarities between these

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two groups can provide guidance concerning the most appropriate care to provide at outpatient clinics.

This study was subject to some limitations. Data on non-respondents were not available, and we were not able to compare the characteristics of the current sample with the characteristics of those who did not respond to the survey. However, results from the national parent survey was published in a recent article and showed similar background characteristics for the current sample and the total national sample of 1399 respondents. While the parent survey was nationwide, the adolescent survey was restricted to four clinics. Only 181 paired parental and patient responses were analyses, an overall coverage rate of 26.4%. This raises questions about the generalizability of the findings, and the results should be replicated in larger surveys. Also, our study was based on responses being received from both parents and adolescents, which may have introduced CL.CZ selection bias.

Conclusions

All but one of the correlations between the indicator scores of the parents and adolescents were statistically significant, but the agreements between the reported experiences were all only weak or moderate. The results highlight the need to collect information from both parents and adolescents, and confirm that the views of adolescents are not always mirrored by their parents. Three of seven parent experience indicators were significantly related to the adolescent HbA1c level. However, more research is needed to further explore the associations between parent experiences and the HbA1c level. Understanding the correspondence between the viewpoints of parents and adolescents is potentially useful for informing interventions aimed at improving the health care provided at paediatric outpatient departments [23].

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Competing interests

On behalf of both authors, the corresponding author states that there is no competing interests.

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Author contributions

T.S. initiated the study. H.H.I. planned the study in consultation with O.B. and T.S. H.H.I. performed the statistical analyses with O.B. and T.S., and drafted the manuscript. O.B. and T.S. participated in the planning process, critically revised the manuscript draft and approved the final version of the manuscript. H.H.I. was the project manager for the two surveys. All authors read and approved the final manuscript.

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Availability of data and material

The data sets generated and/or analysed during this study are not publicly available due to the need to protect personal data.

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Characteristic	%/mean
dolescents	
Sex, %	
Male (<i>n</i> =98)	54.1
Female (<i>n</i> =83)	45.9
Mean age, years (n=181)	14.7
Mean age when diagnosed with diabetes, years (n=181)	9.4
Mean diabetes duration, years (n=181)	5.4
Mean HbA1c level, % (n=165)	8.2
Number of consultations during previous year (mean: 6.2), %)
1–3 (n=40)	24.4
4–6 (n=48)	29.3
7–9 (n=57)	34.8
10–21 (n=19)	11.6
General condition today, %	
Very poor (n=1)	0.6
Fairly poor (n=3)	1.7
Neither poor nor good (n=31)	17.2
Fairly good (n=89)	49.4
Very good (n=56)	31.1
Norwegian %	
Yes (<i>n</i> =169)	93.4
No (n=12)	6.6
Parents	
Sex, %	
Male (<i>n</i> =38)	21.2
Female (<i>n</i> =141)	78.8
Mean age, years (n=179)	46.0
Education, %	
Primary school (n=3)	1.7
Secondary school (<i>n</i> =50)	27.9
University or college (0–4 years) (n=54)	30.2
University or college (>4 years) $(n=72)$	40.2
iving with the child's other parent, %	
Yes (<i>n</i> =140)	78.7
No (<i>n</i> =38)	21.3
Number of consultations during previous year, (mean:4.3), %	
None (<i>n</i> =3)	1.7
1 (<i>n</i> =7)	4.0
2 (n=21)	11.9
3 (<i>n</i> =58)	32.8
3 (1-30)	

Table 1: Background characteristics of the adolescents (*n*=181) and the parents (*n*=181).

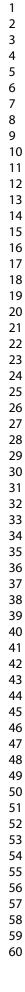


Table 2: Indicator scores and single item scores of adolescents and parents in the total sample and for adolescents and parents where the patients have achieved/not achieved the treatment goal.

		All respondents (n=181)		Patients with HbA1c < 7.5% (n=48)		ts with > 7.5% 117)		
	Mean	SD	Mean	SD	Mean	SD		
Adolescents								
Consultation (7 items)	79.5	14.4	78.5	16.4	79.5	14.1	0.	
Information on food/exercise (2 items)	57.2	25.7	58.0	26.1	56.0	25.0	0.	
Nurse contact (3 items)	85.2	14.7	84.7	14.8	85.0	15.1	0.	
Doctor contact (3 items)	87.3	13.7	88.6	13.2	86.6	14.3	0.	
Outcome (1 item)	83.2	19.4	81.8	21.1	83.2	18.9	0.	
Overall score	78.5	14.1	78.4	15.3	78.1	13.8	0.	
Well received	4.4	0.7	4.4	0.7	4.3	0.7	0.	
Waiting time	3.7	0.8	3.8	0.6	3.7	0.9	0.	
Same nurses	4.2	0.7	4.4	0.7	4.2	0.7	0.	
Nurses knowledgeable	4.6	0.6	4.5	0.7	4.6	0.6	0.	
Same doctor	4.2	0.9	4.1	1.1	4.2	0.9	0.	
Doctor knowledgeable	4.7	0.6	4.7	0.6	4.6	0.6	0.	
Training in how to use equipment	4.3	0.8	4.2	0.8	4.3	0.9	0.	
Follow-up helped the patient	4.3	0.8	4.3	0.8	4.3	0.8	0.	
Parents								
Consultation (6 items)	73.7	17.5	75.1	17.1	71.5	17.7	0.	
Organization (5 items)	67.9	14.2	70.5	12.5	65.9	15.1	0.	
Equipment (3 items)	60.6	23.6	65.0	23.3	57.1	23.2	0.	
Nurse contact (4 items)	79.9	14.8	82.8	13.2	78.0	15.1	0.	
Doctor contact (4 items)	79.1	20.0	81.1	17.7	77.0	21.2	0.	
Outcome (5 items)	76.6	18.3	78.0	15.4	74.4	19.5	0.	
Overall score	72.9	14.2	75.2	13.2	70.7	14.4	0.	
Well received	4.3	0.7	4.4	0.5	4.2	0.7	0.	
Waiting time	3.8	0.7	3.8	0.6	3.7	0.8	0.	
Same nurses	4.0	0.9	4.1	1.0	3.9	0.9	0.	
Nurses knowledgeable	4.5	0.7	4.7	0.6	4.4	0.7	0.	
Same doctor	4.0	1.1 🧹	4.0	1.1	3.9	1.1	0.	
Doctor knowledgeable	4.4	0.8	4.5	0.8	4.3	0.8	0.	
Training in how to use equipment	3.8	1.0	3.9	0.9	3.6	1.0	0.	
Follow-up helped the patient	3.9	0.9	3.8	0.9	3.9	1.0	0.	

All indicators were scored from 0 to 100, where 100 was the best possible experience. Individual items were scored from 1 to 5, where 5 is the best possible experience. Differences in scores were tested by Mann-Whitney *U* test.

Table 3: Associations between adolescent and	parent experience indicators measured	by correlations ^a and regressions ^b .
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				Indicators: adolescents								
Indicators: parents	Consult	tation	Informati food/exe		Nurse c	ontact	Doctor c	ontact	Outco	ome	Overall	score
	Correlation	Beta	Correlation	Beta	Correlation	Beta	Correlation	Beta	Correlation	Beta	Correlation	Beta
Consultation	0.34***	0.34***	0.30***	0.26**	0.20**	0.20*	0.26**	0.26**	0.27***	0.24**	0.34***	0.33***
Organization	0.39***	0.44***	0.24**	0.25**	0.24**	0.25**	0.22**	0.24**	0.28***	0.30***	0.33***	0.37***
Equipment	0.33***	0.40***	0.23**	0.24**	0.16*	0.17*	0.13	0.15	0.17*	0.20*	0.26**	0.29***
Nurse contact	0.34***	0.36***	0.24**	0.27***	0.24**	0.27***	0.22*	0.23**	0.20**	0.20*	0.31***	0.34***
Doctor contact	0.22**	0.21**	0.27***	0.23**	0.00	0.02	0.23**	0.18*	0.23**	0.19*	0.23**	0.22**
Outcome	0.42***	0.40***	0.30***	0.26**	0.24**	0.20*	0.32***	0.27***	0.33***	0.31***	0.41***	0.36***
Overall score	0.41***	0.46***	0.32***	0.32***	0.22**	0.23**	0.28***	0.28***	0.29***	0.30***	0.38***	0.41***

^aSpearman's rank correlation coefficients;^bStandardized regression coefficients adjusted for patient age, gender and HbA1c level.

***p<0.001, **p<0.01, *p<0.05.

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Table 4: Associations between adolescent and parent experiences for single items measured by correlations^a and regressions^b.

Item		Correlation	Beta
Well rece	ived	0.32***	0.28***
Waiting ti	me	0.22**	0.21**
Same nu	ses	0.25**	0.22**
Nurses kr	nowledgeable	0.26***	0.29***
Same do	ctor	0.50***	0.46***
Doctor kn	owledgeable	0.29***	0.22**
Training i	n how to use equipment	0.24**	0.41***
Follow-up	helped the child	0.30***	0.27**

Data are "Spearman's rank correlation coefficients and bstandardized regression coefficients adjusted for patient age, gender and HbA1c level. to beet teries only

***p*<0.001, ***p*<0.01.

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Table 5: Associations between adolescent and parent experiences and HbA1c level measured by correlations^a and regressions^b.

Indicator/item	HbA	HbA1c	
	Correlation	Beta	
Adolescents			
Consultation	0.01	0.07	
Information on food/exercise	-0.01	0.02	
Nurse contact	-0.02	0.03	
Doctor contact	-0.05	-0.03	
Outcome	-0.03	0.00	
Overall score	-0.05	0.02	
Parents			
Consultation	-0.12	-0.11	
Organization	-0.21**	-0.14	
Equipment	-0.15	-0.07	
Nurse contact	-0.21**	-0.19*	
Doctor contact	-0.13	-0.18*	
Outcome	-0.15	-0.15	
Overall score	-0.20**	-0.17*	

Data are -Spearman's rank correlation coefficients and ^bstandardized regression coefficients adjusted for patient age and gender. "p<0.01, "p<0.05.

4 5

6 7 Norwegian Institute of Public Health

Your experiences with the paediatric outpatient clinic

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8 9 The questions below concern your experiences with the 10 \bot paediatric outpatient clinic your child attends for diabetes. 11 12 5. Do you feel that the doctors and nurses Arrival and waiting 13 cooperate well? 14 Are you and your child well received at the 1. 15 Not at all outpatient clinic? 16 To a small extent 17 Not at all 18 To some extent To a small extent 19 To a large extent 20 To some extent 21 To a very large extent To a large extent 22 Not applicable / Don't know 23 To a very large extent 24 Do you feel that the person you have the 6. 25 2. Do you feel there's a lot of waiting at the appointment with is well prepared? 26 outpatient clinic? 27 Not at all Not at all 28 To a small extent 29 To a small extent 30 To some extent To some extent 31 To a large extent 32 To a large extent To a very large extent 33 To a very large extent 34 Not applicable / Don't know 35 3. Do you find the waiting room satisfactory? 36 The nurses 37 Not at all 38 To a small extent Do you and your child see the same 7. 39 nurses every time you attend the 40 To some extent 41 outpatient clinic? To a large extent 42 Not at all To a very large extent 43 To a small extent 44 45 To some extent 46 Organisation To a large extent 47 48 To a very large extent 4. Do you feel that the outpatient clinic is well 49 Not applicable / Don't know organised? 50 51 Not at all 8. Do you and your child get enough time 52 To a small extent with the nurses? 53 54 To some extent Not at all 55 To a large extent To a small extent 56 To a very large extent 57 To some extent 58 Not applicable / Don't know To a large extent 59 To a very large extent 60 Not applicable / Don't know \bot

9.	Do the nurses appear to know a lot about diabetes and diabetes treatment?	14.	Do you feel that the doctor shows care and concern for your child?
	 Not at all To a small extent 		Not at allTo a small extent
	To some extent		To some extent
	To a large extent		To a large extent
	To a very large extent		To a very large extent
	Not applicable / Don't know		Not applicable / Don't know
10.	Do you feel that the nurses show care and concern for your child?		ore about what is discussed at pointments
	Not at all	15	In your opinion, do the topics discussed at
	To a small extent	10.	the appointments meet your child's needs?
	To some extent		Not at all
I	☐ To a large extent		To a small extent
<u> </u>	☐ To a very large extent		To some extent
	Not applicable / Don't know		To a large extent
			To a very large extent
Th	e doctor		Not applicable / Don't know
The	questions below are about the doctor. If you		
	more than one doctor, please give us your all assessment of all the doctors you see.	16.	Is it clear to you and your child what should be followed up before the next appointment?
11.	Do you and your child see the same doctor		Not at all
	every time you attend the outpatient		To a small extent
	clinic?	6	To some extent
	Not at all		To a large extent
	To a small extent		To a very large extent
	To some extent		Not applicable / Don't know
	To a large extent		
	To a very large extent	17.	Do you and your child have a say in what should be followed up before the next
	Not applicable / Don't know		appointment?
12.	Do you and your child get enough time		Not at all
	with the doctor?		To a small extent
	Not at all		To some extent
	To a small extent		To a large extent
	To some extent		To a very large extent
	To a large extent		Not applicable / Don't know
	To a very large extent		
	Not applicable / Don't know	Be	ing a parent/guardian at the clinic
13.	Does the doctor appear to know a lot about diabetes and diabetes treatment?	18.	Are your views as a parent/guardian taken seriously?
	Not at all		Not at all
	To a small extent		To a small extent
	To some extent		To some extent
	To a large extent		To a large extent
	To a very large extent		To a very large extent
2	Not applicable ເວັດຊາຍສາຊັ່ງ ແລະ ເປັນ Not applicable ເວັດຊາຍສາຊັ່ງ ເພື່ອງ ເພື	bmj.cor	

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	19.	Do you get enough time for conversations	24.	Do you receive satisfactory information
1 ว		without your child being present?		from the outpatient clinic about available
2 3		Not at all		devices/equipment?
4		To a small extent		Not at all
5 6		To some extent		To a small extent
7		To a large extent		To some extent
8		To a very large extent		To a large extent
9 10		Not applicable / Don't know		To a very large extent
11				Not applicable / Don't know
12	20.	Are you given satisfactory information		
13 14		and guidance on how to follow up on your child's diabetes treatment?	25.	Do you and your child receive good
15		_		training in managing the
16		Not at all		devices/equipment?
17		To a small extent		Not at all
18 19		To some extent		To a small extent
20		To a large extent		To some extent
21		To a very large extent		☐ To a large extent
22 23		Not applicable / Don't know		To a very large extent
24				Not applicable / Don't know
25	21.	Do you get the support you need to let		
26 27		your child take more responsibility for his or her diabetes treatment?	Av	ailability
28		_		
29		Not at all	26.	In your opinion, does your child have access to the best possible
30 31		To a small extent		devices/equipment?
32		To some extent		Not at all
33		To a large extent		
34 35		To a very large extent		To a small extent
36		Not applicable / Don't know		To some extent
37				To a large extent
38 39	In	formation and training		To a very large extent
40	22	Do you receive satisfactory information		Not applicable / Don't know
41	22.	about the results of tests and	27.	Does your child have satisfactory access
42 43		examinations?		to a nutritionist?
43 44		Not at all		Not at all
45		To a small extent		To a small extent
46 47		To some extent		└─ To some extent
47 48				To a large extent
49		To a large extent		To a very large extent
50 51		To a very large extent		Not applicable / Don't know
52	23.	Do you receive satisfactory information		
53		about the development in your child's	28.	Does your child have satisfactory access
54		health and the risk of complications?		to a psychologist?
55 56		Not at all		Not at all
57		To a small extent		To a small extent
58		To some extent		☐ To some extent ⊥
59 60		To a large extent		To a large extent
		To a very large extent		To a very large extent
		Not applicable / Don't know		Not applicable / Don't know
			I.	

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1 2 3 4 5 6 7 8 9 10	29.	Is it easy to get in touch with the outpatient clinic outside of appointments? Not at all To a small extent To some extent To a large extent To a very large extent Not applicable / Don't know	34.	All in all, how dissatisfied or satisfied are you with how the outpatient clinic has followed up on your child and the diabetes treatment? Very dissatisfied Rather dissatisfied Both dissatisfied and satisfied Rather satisfied
11	20			Very satisfied
12 13	30.	How do you feel about the number of appointments at the outpatient clinic?	35.	All in all, how dissatisfied or satisfied are
14		Too few		you with how the outpatient clinic has met
15 16		A sufficient number		you as a parent/guardian?
17		☐ Too many		Very dissatisfied
18 19		Not applicable / Don't know		Rather dissatisfied
20				Both dissatisfied and satisfied
21	Us	sefulness		Rather satisfied
22 23	31.	Do you feel that your child benefits from		Very satisfied
24	•	attending the outpatient clinic?		
25 26		□ Not at all	Ba	ckground questions
27		□ To a small extent	26	In the last year, how many times have you
28 29		To some extent	30.	In the last year, how many times have you been present for all or part of your child's
30		To a large extent		appointment?
31		□ To a very large extent		
32 33		Not applicable / Don't know		□ 1 time
34				2 times
35 36	32.	Do you, as a parent/guardian, benefit from		3 times
37		attending the outpatient clinic?		4 or more times
38		Not at all		
39 40		To a small extent	37.	Are you male or female?
41		To some extent		Male
42 43		To a large extent		Female
44		To a very large extent	38	What age are you?
45		Not applicable / Don't know	50.	Number of years
46 47				
48	Ot	her questions	39.	What is your highest level of educational
49 50	33.	Does the follow-up at the outpatient clinic		attainment?
51		make you and your child more capable to		Primary school
52 53		live a good life with diabetes?		Secondary school
53 54		Not at all		Higher education/university (up to 4 years)
55		To a small extent		Higher education/university (4+ years)
56 57		To some extent	40	Do you live with the child's other parent/
58		To a large extent		guardian?
59 60		To a very large extent		Yes
60		Not applicable / Don't know		
				□ Not applicable ⊥

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Your experiences with the children's outpatient clinic

The questions below concern your experiences with the outpatient clinic you attend for diabetes. Please tick only one answer for each question.

 When you arrive at the outpatient clinic 	4. Do the nurses speak to you in a way that you understand?
 17 1. Are you well received at the outpatient clinic? 	兴 🔲 Not at all
19_{20} \bigcirc Not at all	🔀 🔲 To a small extent
$21 \\ 22 \\ \square$ To a small extent	😑 🔲 To some extent
$\begin{array}{c} 23 \\ 24 \end{array} \square \text{ To some extent} \end{array}$	🙂 🔲 To a large extent
25 📋 🗌 To a large extent	😛 🔲 To a very large extent
 26 27 28 29 30 <	5. Do the nurses appear to know a lot about diabetes and diabetes treatment?
³¹ outpatient clinic?	🕥 🤅 🗌 Not at all
33 \bigcirc \square Not at all	🔀 🔲 To a small extent
34 \bigcirc \square Not at all 35 \bigcirc \square To a small extent	😑 🗌 To some extent
37 (\Box) To some extent	🙂 🔲 To a large extent
$\frac{38}{39} \qquad \boxed{} \text{ To a large extent}$	😛 📃 To a very large extent
40	
41 () To a very large extent 42 43	6. Do you feel safe bringing up things with the nurses that are difficult to discuss?
44 45 The nurses	兴 🔲 Not at all
46 47 3. Do you see the same nurses every time	🔀 🔲 To a small extent
48 you attend the outpatient clinic? 49	😑 🔲 To some extent
50 💛 🗌 Never	🙂 🔲 To a large extent
$\begin{array}{c} 51 \\ 52 \end{array} \square Rarely \end{array}$	😛 🔲 To a very large extent
$53 \\ 54 $ \square Sometimes	Not applicable / Don't know
55 🕐 🗍 Often 56	
$\begin{array}{ccc} 57 & \bigoplus & \square \\ 58 & & \blacksquare \end{array} \begin{array}{c} Always \\ \hline & & \blacksquare \end{array}$	
59 Not applicable / Don't know 60	

¹ ₂ The doctor	More about your diabetes check-ups
 The questions below are about your doctor. If you see more than one doctor, please consider all the doctors you see when you are answering the questions. 	 11. Are you given good advice to help you choose the right insulin dose? Not at all
 9 7. Do you see the same doctor every time you 10 attend the outpatient clinic? 	To a small extent
$\begin{array}{c} 11 \\ 12 \end{array} \bigcirc \square \text{ Never} \end{array}$	○ □ To a large extent
$^{13}_{14}$ \bigcirc Rarely	To a very large extent
15 16 Sometimes	
$\begin{array}{c} 17 \\ 18 \\ 19 \\ \hline \end{array} \bigcirc \Box \text{ Often} \\ Always \\ \hline \end{array}$	12. Do you have a say in what should be followed up before the next appointment?
	; 🗌 Not at all
22	🔀 🗌 To a small extent
 ²³ 8. Do the doctor speak to you in a way that you ²⁴ understand? 	📺 🔲 To some extent
25 26 \bigcirc \bigcirc Not at all	📺 🗌 To a large extent
27 28 \square To a small extent	; 🗌 To a very large extent
29 \bigcirc To some extent	Not applicable / Don't know
30 To a large extent	42. Do the staff who would state outputient aligin
32 $(=)$ To a very large extent	13. Do the staff who work at the outpatient clinic appear to understand what it's like to be
34 35 Not applicable / Don't know	young and have diabetes?
 36 37 9. Do the doctor appear to know a lot about 38 diabetes and diabetes treatment? 	 ◯ Not at all ◯ To a small extent
$\overset{39}{40}$ \overleftrightarrow Not at all	To some extent
$\begin{array}{c} 41 \\ 42 \end{array} \qquad \boxed{} To a small extent$	∵ □ To a large extent
$43 \qquad \bigcirc \qquad \square$ To some extent	⊖ ☐ To a very large extent
44 45 \bigcirc To a large extent	Not applicable / Don't know
46 47 $\overleftrightarrow{\bigcirc}$ To a very large extent	
 48 49 Not applicable / Don't know 50 	14. Do you get enough time with the doctor or nurse during you appointment?
⁵¹ 10. Do you feel safe bringing up things with the	兴 🗌 Not at all
$_{53}$ doctor that are difficult to discuss?	🙁 🔲 To a small extent
$\begin{array}{c} 54 \\ 55 \\ \hline \end{array} \qquad \boxed{ \ } \ \ \ } \ \ \ \ \ \ \ \ \ \ \ \ \ $	😑 🗌 To some extent
56 \bigcirc \square To a small extent 57 \bigcirc	🙂 🔲 To a large extent
58 \bigcirc \square To some extent	😛 🔲 To a very large extent
$_{60}$ \bigcirc \square To a large extent	
To a very large extent	

1 2 3	15. How do you feel about the number of appointments you have at the outpatient clinic	19. Do you receive good training in managing the devices/equipment?
4 5	each year?	🔀 🗌 Not at all
6 7	A sufficient amount	🔀 🔲 To a small extent
8	Too many	😑 🗌 To some extent
9 10	Not applicable / Don't know	🙂 🔲 To a large extent
11 12		😛 🔲 To a very large extent
13 14	Food and exercise	Not applicable / Don't know
15 16 17	16. Are you given good information and guidance about food?	Appointment with others
18 19 20	Not at all	20. Can you get an appointment with a nutritionist if you need one? (A nutritionist
21 22	To a small extent	gives advice about food and diet)
23	To some extent	Yes
24 25	○ ☐ To a large extent	No
26 27	😇 🗌 To a very large extent	Not applicable/Don't know
28 29 30	17. Are you given good information and guidance about exercise?	21. Can you get an appointment with a psychologist if you need one?
31 32	😕 🗌 Not at all	Yes
33 34	😕 🔲 To a small extent	No
35 36	To some extent	Not applicable/Don't know
37 38	🙂 🔲 To a large extent	
39 40	😛 🔲 To a very large extent	Bringing parents/guardians with you
41 42	Not applicable / Don't know	22. How often do your parents/guardians attend the outpatient clinic with you?
43 44		Never
45 46	Devices/equipment	Rarely
47 48	18. Are you involved in deciding which	Sometimes
49 50	devices/equipment you should use?	Often
51	 ◯ Not at all ◯ — 	Always
52 53	Contraction To a small extent	23. If your parents/guardians attend the
54 55	To some extent	appointment with you, who does the doctor or
56 57	◯ To a large extent	nurse mostly speak to?
58 59	😇 🔲 To a very large extent	Mostly to my parents/guardians
60	Not applicable / Don't know	About the same to each of us
		Parents/guardians do not come with me

 24. If needed, can you get an appointment with your doctor or nurse without your parents/ guardians being present? Yes No Not applicable/Don't know 	 26. Who completed this questionnaire? Me on my own Me and my parents/guardians together My parents/guardians on their own 27. All in all, how are you feeling today? Very bad
Other questions Other questions Other questions Helped you with your diabetes? Image: Not at all Image: Not at all	 Fairly bad Both and Rather good Very good 28. Do you alternate between living with each of your parents/guardians? Yes No Not applicable
 Any additional comments about the outpatient questionnaire: 33 34 	t clinic or how you found completing the
35	<u> </u>
41 42 43 44 45 46	
47	
52 53 54 55 56 57	
58 59 60	

Thank you for taking the time to answer.

1 2 3 4	Reporting	cheo	cklist for cross sectional study.			
5 6 7	Based on the STROP	BE cross	sectional guidelines.			
8 9	Instructions to	autho	ors			
10 11 12	Complete this check	list by er	ntering the page numbers from your manuscript where readers will find each of the items listed belo	ow.		
13 Your article may not currently address all the items on the checklist. Please modify your text to include the missing inform						
14 15 16	apply, please write "n/a" and provide a short explanation.					
17 18	Upload your comple	ted checl	klist as an extra file when you submit to a journal.			
19 20	In your methods sect	tion, say	that you used the STROBE cross sectional reporting guidelines, and cite them as:			
21 22	von Elm E, Altman I	DG, Egg	er M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observatio	onal Studies		
23	in Epidemiology (ST	TROBE)	Statement: guidelines for reporting observational studies.			
24 25		,				
26				Page		
27 28			Reporting Item	Number		
29 30 31	Title and abstract					
32 33	Title	<u>#1a</u>	Indicate the study's design with a commonly used term in the title or the abstract	2		
34 35 36	Abstract	<u>#1b</u>	Provide in the abstract an informative and balanced summary of what was done and what was found	2,3		
30 37						
38 39	Introduction					
40 41 42	Background /	<u>#2</u>	Explain the scientific background and rationale for the investigation being reported	4-6		
42 43	rationale					
44 45	Objectives	<u>#3</u>	State specific objectives, including any prespecified hypotheses	2,7		
46 47 48	Methods					
49 50	Study design	<u>#4</u>	Present key elements of study design early in the paper	2, 7		
51 52 53 54	Setting	<u>#5</u>	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7-9		
55 56 57 58	Eligibility criteria	<u>#6a</u>	Give the eligibility criteria, and the sources and methods of selection of participants.	2,8		
59 60			For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml			

1		<u>#7</u>	Clearly define all outcomes, exposures, predictors, potential confounders, and effect	8,9
2 3			modifiers. Give diagnostic criteria, if applicable	
4				
5 6	Data sources /	<u>#8</u>	For each variable of interest give sources of data and details of methods of assessment	8,9
7	measurement		(measurement). Describe comparability of assessment methods if there is more than one	
8			group. Give information separately for for exposed and unexposed groups if applicable.	
9 10 11	Bias	<u>#9</u>	Describe any efforts to address potential sources of bias	4,13
12 13 14	Study size	<u>#10</u>	Explain how the study size was arrived at	7,8
15	Quantitative	<u>#11</u>	Explain how quantitative variables were handled in the analyses. If applicable, describe	8-10
16 17	variables		which groupings were chosen, and why	
18 19 20	Statistical methods	<u>#12a</u>	Describe all statistical methods, including those used to control for confounding	8-10
21 22	Statistical methods	<u>#12b</u>	Describe any methods used to examine subgroups and interactions	8-10
23 24 25	Statistical methods	<u>#12c</u>	Explain how missing data were addressed	n/a
26 27	Statistical methods	<u>#12d</u>	If applicable, describe analytical methods taking account of sampling strategy	n/a
28 29 30	Statistical methods	<u>#12e</u>	Describe any sensitivity analyses	n/a
	Results			
31	1000000			
32		11.2		,
32 33 34	Participants	<u>#13a</u>	Report numbers of individuals at each stage of study—eg numbers potentially eligible,	n/a
32 33 34 35		<u>#13a</u>	examined for eligibility, confirmed eligible, included in the study, completing follow-up, and	n/a
32 33 34		<u>#13a</u>		n/a
32 33 34 35 36 37 38 39		<u>#13a</u> <u>#13b</u>	examined for eligibility, confirmed eligible, included in the study, completing follow-up, and	n/a n/a
32 33 34 35 36 37 38 39 40 41	Participants		examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	
32 33 34 35 36 37 38 39 40	Participants Participants Participants	<u>#13b</u> <u>#13c</u>	examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable. Give reasons for non-participation at each stage Consider use of a flow diagram	n/a n/a
32 33 34 35 36 37 38 39 40 41 42 43 44	Participants Participants	<u>#13b</u>	examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable. Give reasons for non-participation at each stage Consider use of a flow diagram Give characteristics of study participants (eg demographic, clinical, social) and information	n/a
32 33 34 35 36 37 38 39 40 41 42 43	Participants Participants Participants	<u>#13b</u> <u>#13c</u>	examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable. Give reasons for non-participation at each stage Consider use of a flow diagram Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and	n/a n/a
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1 2	Main results	<u>#16b</u>	Report category boundaries when continuous variables were categorized	n/a
- 3 4 5 6	Main results	<u>#16c</u>	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
7 8 9	Other analyses	<u>#17</u>	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
10 11 12	Discussion			
13 14	Key results	<u>#18</u>	Summarise key results with reference to study objectives	11, 13-14
15 16 17 18	Limitations	<u>#19</u>	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13
19 20 21 22	Interpretation	<u>#20</u>	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12,13
23 24 25	Generalisability	<u>#21</u>	Discuss the generalisability (external validity) of the study results	13
25 26	Other			
27 28 29	Information			
30	Funding	<u>#22</u>	Give the source of funding and the role of the funders for the present study and, if applicable,	14
31 32			for the original study on which the present article is based	
33 34	The STROBE checkli	st is dist	ributed under the terms of the Creative Commons Attribution License CC-BY. This checklist was	s completed
35 36	on 07. June 2019 usin	g <u>https:/</u> /	www.goodreports.org/, a tool made by the EQUATOR Network in collaboration with Penelope.e	ai
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