

Development and validation of a questionnaire to assess young patients' experiences with diabetes care and transition

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Short title: Diabetes care and service transition

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ABSTRACT

Aim

To describe the development and validation of a questionnaire in a national Norwegian population-based cohort study designed to assess the experiences of young people with type 1 diabetes who had made the transition from paediatric to adult diabetes care.

Methods

The questionnaire was developed by the authors based on literature searches, focus group interviews, discussions with experts and cognitive interviews. We included 776 individuals with type 1 diabetes who were last registered in the Norwegian Childhood Diabetes Registry between 2009–2012 and had been receiving adult health care for at least two years. The data quality was analysed, factor analysis were performed and the internal reliability, test-retest reliability and construct validity were determined.

Results

The response rate was 321 patients (41.4%); 57.6% were female, and the average age at recruitment was 22.9 ± 1.2 years. Seven factors were identified. Satisfactory evidence was provided for the internal consistency, reliability and construct validity of the questionnaire. All scales met the criterion of Cronbach's alpha above 0.4. The test-retest correlations ranged from 0.64–0.92.

Conclusion

The thorough validation of the questionnaire proved satisfactory and indicated that it may be of value for further studies measuring patients' experiences with diabetes care and transition.

Keywords: Adolescent health care, questionnaire, reproducibility of results, transition, type 1 diabetes.

KEY NOTES

- The authors developed a questionnaire to measure the experiences of patients with type 1 diabetes who had made the transition from paediatric to adult health care.

- The questionnaire was tested on 321 patients identified from the Norwegian Childhood Diabetes Registry and validated in a national pilot study.
- The questionnaire's internal consistency, reliability and construct validity were satisfactory, and it was suitable for measuring patient experiences with diabetes care and transition.

INTRODUCTION

Over the last few decades, attention has been directed towards the need for age-adjusted health services for the increasing group of young people with lifelong conditions and special health care needs (1-3). Deterioration of health has been documented for a number of chronic diseases during the transition from adolescence to adulthood--including congenital cardiac malformations, hydrocephalus, rheumatic conditions, chronic digestive diseases, haematological and endocrinological conditions. Young people with type 1 diabetes are primarily at risk of developing increasing levels of haemoglobin A1c (HbA1c) and early signs of complications (4, 5).

In this vulnerable period of life, when the transition takes place, gaps between health services and discontinuity in follow up are reported in several studies (6-8). Initiated by the Norwegian Paediatric Society, our study group was made to examine patients' experiences with the transition process and with health services before and after transfer to adult care. Type 1 diabetes was chosen as a model disease based on its high incidence, the complexity of the disease and the access to national data in the Norwegian Childhood Diabetes Registry (9).

The health care services in Norway are tax financed, based on equal access and full reimbursement of all diabetes treatment including medication, insulin pumps and real-time continuous glucose monitors. All children diagnosed with diabetes attend a diabetes team at one of the 25 paediatric outpatient clinics. Transfer usually takes place at the age of 18 and most of the patients go on to attend a diabetes team at an adult outpatient clinic.

Examining patients' experiences is an important part of health care performance evaluation and is regarded as a core quality measure of national registers (10, 11). Literature searches did not identify any validated questionnaire that focused on young patients' experiences with health care delivery and covered the variety of topics our study intended to explore. Garvey, K. et al's article in 2012 (6) was very informative, regarding the transition experiences of emerging adults with type 1 diabetes, but not directly applicable for our use. Important

contributions were later made to measure the experiences of children as patients. In 2015 Toomey, S. (12) published her article about the new Child Hospital Consumer Assessment of Healthcare and Providers. In 2016 Gore, C. et al (13) presented the first disease-specific patient-reported experience measure concerning children. When our study was initiated in 2013, we decided to develop an age- and condition-specific questionnaire for the purpose of this study. The Norwegian Institute of Public Health runs a programme to systematically measure user experiences with health care (14-17). We have followed this standardised national procedure.

The aim of this paper is to describe the development and validation of the questionnaire in our national population-based cohort study designed to assess the experiences of young people with type 1 diabetes who had made the transition from paediatric health care to adult health care.

METHODS

Development and validation of the questionnaire

This study focused on patients with type 1 diabetes who had made the transition from paediatric to adult health care. A combination of methods was used: literature searches, focus group interviews, a questionnaire to assess patient experiences and a comparison of the adult medical records and paediatric data in the Norwegian Childhood Diabetes Registry.

The literature searches were performed to identify the specific challenges of young patients with chronic conditions related to transition and health care quality and consider strategies to develop age- and condition-specific patient experience measures. The searches were done on Medline, PubMed and Cochrane databases, medical journals and selected papers in order to identify research studies and policy statements, and were carried out in English for the period January 1996 to January 2013. 'Adolescence', 'type 1 diabetes', 'qualitative methods', 'surveys', 'transition to adult care' and 'health organisation' were the search terms for Medline at the start of our project. As we applied qualitative methods for the focus groups and quantitative methods for the questionnaire, further searches on PubMed were done in

both research fields to inform the content of interviews and the items and construction of the survey. A multidisciplinary reference group, composed of experts from paediatric and adult diabetes care and representatives from the Norwegian Diabetes Association, was established. Discussions in the expert group were important for the selection of items and design of the questionnaire.

We held three focus groups involving eight young people with type 1 diabetes, four males and four females, between November 2013 and February 2014. The subjects were identified from the Norwegian Childhood Diabetes Registry. They had a minimum of two years' experience with paediatric care and they had been transferred to adult diabetes care two to four years before the study. Their age, gender, HbA1c results and sociodemographic backgrounds showed good variations. In the focus groups, the young participants discussed, in their own words, their experiences and opinions related to diabetes care and transition. A trained mentor facilitated the dialogue, using open-ended and follow-up questions as needed. The interview guide is attached as a supplement (Table S1). The content of each group interview was discussed by the research team, which considered that theoretical saturation had been achieved. The dialogues were transcribed verbatim, and the interviews were analysed by systematic text condensation (18). The analysis made it possible to identify units of meaning across the interviews and classify main themes. After the analysis, four main themes emerged. Three of the themes contributed to and supported the choice of items for measuring patients' experiences with care. These themes were (a) the continuity of care (meeting the same doctor and nurse and the frequency of consultations); (b) the confidence in providers (the skills, communication and availability); and (c) the individualised treatment (adapted to the unique needs of each young person). The fourth theme was about relations to the parents and was included in the items about background, living conditions and support.

A questionnaire with 98 items was developed by the authors. The questionnaire was translated to English for the purpose of this article (Table S2). The items of the questionnaire were divided into five sections. Section one and section three cover identical items about the

patients' experiences and can be answered separately for paediatric health care and adult health care. The questions in the sections explore the experiences of continuity in the contact with doctors and nurses, communication with doctors and nurses and the competence of doctors and nurses, and experiences of treatment adapted to the individual needs, treatment goals and the availability of the diabetes team. The items were answered separately for nurses and doctors to get nuanced information that may reflect differences in organisation and render results more useful for the purposes of local improvement. Section two addresses experiences in the process of transition and transfer. The items about patients' experiences are assessed on a Likert scale with five response options and the opportunity to answer 'not applicable/don't know'. Section four is about the diabetes treatment regimens of the patient. Section five includes items relevant for further assessment of the multifaceted concept of experiences with health care; sociodemographic conditions, coexisting diagnosis, social activity and perceived problems connected to living with diabetes. The items about living with diabetes were answered on a Likert scale with five options. The items concerning background information and facts were answered as 'yes' or 'no' or by choosing one of several defined alternatives.

The validation has included the literature searches, the focus group interviews and the discussions in the expert group which informed the content of the questionnaire. Validation of the content and design of the items was supplemented by individual cognitive interviews performed with 11 persons, and after minor adjustments were made, with another 14 young people in the target group to ensure that the questions were understood as intended, and could be responded to accurately. The validation also included a retest and comprehensive statistical analysis for internal consistency, reliability and validity.

Approval by the Regional Ethics Committee (REC) was applied for in 2013 (2013/822). REC considered it a quality improvement project that did not need their approval. As a consequence, approvals for the study were retrieved from the Data Protection Officer Department at Oslo University Hospital.

Data collection

The inclusion criteria were the diagnosis of type 1 diabetes since childhood, registration in the Norwegian Childhood Diabetes Registry at least two years before being transferred to adult services and receiving adult diabetes care for two to four years before inclusion in the study. The sample population was 796 patients with their last annual registration in the Norwegian Childhood Registry in 2009–2012, and 776 were eligible to take part in the study. The questionnaire was sent by post in February 2015 to the patients' addresses in the Norwegian Childhood Registry, and two postal reminders were sent. All recipients were given the option of completing the paper questionnaire or answering an electronic version, and one in three recipients took advantage of this alternative. A total of 321 patients (41.4%) returned a completed form. All the data were recorded in a database using SPSS Statistics for Windows, version 23.0 (IBM Corporation, New York, USA).

Data from the questionnaire were coupled with background data from the National Childhood Diabetes Registry. This registry has 100% coverage on hospital level and 97% coverage on patient level (9). The data were also coupled with data from the medical records in adult care that were collected for the 321 participants, all of whom had given written consent. All the completed forms were included in the validation analysis in this national pilot study. We sent a second copy of the questionnaire to 50 of the patients who responded, to perform a test-retest analysis. These were sent five to nine weeks after their initial responses were received, and 32 (64%) were completed.

Statistical analysis

The properties of the questionnaire were examined on both item and scale levels. The items were checked for missing data and ceiling effects, which were the percentage of respondents who provided the most positive responses in each category (19).

An exploratory factor analysis was performed using principle component analysis to search for underlying constructs and simplify data by analysing factors and items related to the scale scores. Based on the Kaiser criterion, we extracted all factors with eigenvalues that were

higher than one and applied an oblique rotation (promax method with an assumption of correlated scales). Factor loadings of 0.4 or higher were considered satisfactory (20).

Based on theoretical considerations of usefulness, three scale scores were constructed for experiences with paediatric diabetes care, and three corresponding scales were constructed for adult diabetes care. This made it possible to compare and assess scores for health personnel and individualised treatment.

Internal consistency of the subscales was examined using Cronbach's alpha. Alpha values of 0.70 or higher were considered satisfactory, and values of 0.90 or higher were considered excellent (21). The item-total correlation showed the degree of association between each item and the total score of the other items in the scale. An item-total correlation was considered adequate if it was above 0.4.

The test-retest reliability was assessed using the intra-class correlation coefficient for agreement between the continuous measures. The test-retest procedure was carried out an average of seven weeks after the first questionnaires were completed. Acceptable agreement scores were higher than 0.70 for the intra-class correlation coefficient (20).

The construct validity, which assesses the degree to which the scale measures the construct that it was designed for, was explored by Spearman's rank correlation. This was used to carry out comparisons between the scale scores, as well as comparisons with additional items not included in the scale. Correlations from 0.2 to 0.4 were considered weak, and correlations of 0.4 or higher were considered adequate (20). SPSS Statistics for Windows, version 23.0 (IBM Corporation, New York, USA), was used for all the statistical analyses and statistical significance was assumed for $p < 0.05$.

RESULTS

Responder characteristics

Characteristics of responders are presented in Table 1. A table comparing responders and non-responders is added as supplemental material (Table S3). A total of 321 patients with a mean age of 22.9 ± 1.2 years out of 776 patients (41.4%) participated in the study. The mean

age at transfer was 18.0 ± 1.2 years. The majority (57.6%) were females, and males accounted for a lower proportion of responders than non-responders (42.4% versus 64.0%, $p < 0.01$). No significant differences were found between responders and non-responders with regards to age, duration of diabetes, insulin modality and blood glucose measurements.

However, the HbA1c levels were lower among responders.

At recruitment, the mean period since diabetes diagnosis in the responders was 13.0 ± 3.8 years, and 45.4% of them used an insulin pump. The mean HbA1c level of the responders was 8.8% (73 mmol/mol) at the last registration in the Norwegian Childhood Diabetes Registry before the transfer, and the mean HbA1c level was 9.1% (76 mmol/mol) for the non-responders, which is a significant difference ($p < 0.01$). Education, main activity and living arrangements were also included in the responders' characteristics in Table 1.

Data quality and validation

Descriptive statistics

Descriptive statistics for the items and factor scales are presented in Table 2.

Missing values ranged from 0.0% to 0.9%, while the number of participants who indicated that they did not know the answer to a question or that a question was not applicable, ranged from 1.2% to 13.4%. Mean scores for single items were generally skewed towards a positive rating (Table 2). The mean scores for the items about patient experiences in paediatric care were 4.1 to 4.6 on a scale of one to five, while the mean scores in adult health care ranged from 3.7 to 4.6. The question addressing if information was received about follow up was the only item that had a mean score of less than 3 (2.9).

The ceiling effect, with regards to contact with the doctors and nurses who provided paediatric diabetes care, was above 50% for all eight items (Table 2) and above 50% for three of the eight equivalent items about adult health care, namely the comprehensibility of information given by doctors or nurses and the competence of nurses.

Factor analysis

Separate analyses were performed for the patients' experiences with paediatric diabetes care, adult care and their transition between the two services. Factors directly related to experiences with health care personnel were constructed based on theoretical considerations of comparability and expediency. A total of seven factors were identified (Table 2). There were three factors that related to experiences in paediatric health care--doctors, nurses and individualised treatment--and three equivalent factors in relation to adult care. The items related to the nurses and the doctors were broken down into who the patient saw, whether the health personnel was competent, whether the consultation was long enough and whether the patient understood what was being discussed. Individualised treatment covered identified goals, individualised services and the availability of support. Factor loadings for experiences with paediatric care ranged from 0.45 to 0.87 and from 0.60 to 0.93 for adult care. There was also a seventh factor related to the transition process, and this produced factor loadings from 0.53 to 0.90.

Negative items were reverse-coded. Scales were transformed to scores ranging from 0 to 100, with a higher score representing a better experience for items and factor scales. The mean factor scores ranged from 63.7 to 87.0. The scale score for experiences with a paediatrician had the highest mean score (87.0), and the scale score for being prepared for the transition had the lowest mean score (63.7). There were greater differences between paediatric and adult care scores for some categories than others. The highest differences were for the experiences with paediatric (87.0) and adult doctors (75.4)--with smaller differences for experiences with paediatric and adult care nurses (86.5 versus 82.2, respectively) and the factor about individualised paediatric or adult care treatment (77.2 versus 72.5, respectively).

Internal consistency

Cronbach's alpha was applied to assess the internal consistency of the score scales. All seven scales satisfied the criterion of 0.70 or higher, ranging from 0.76 to 0.85 (Table 2). The

total correlation coefficient met 0.40 for all items, ranging from 0.40 to 0.74. The correlation coefficient was above 0.50 for 23 of the 26 items.

Test-retest reliability

Test-retest reliability was assessed using intra-class correlation coefficients (Table 2), and the results ranged from 0.64 to 0.85, with six of the seven factors scoring 0.70 or higher. The only exception was for the individual care provided by adult health services, which scored 0.64.

Construct validity

Table 3 shows the construct validity. The Spearman's correlations between the scale scores related to experiences with health care were all 0.40 or higher and were considered adequate (0.59 to 0.69 in paediatric care and 0.58 to 0.63 in adult care). The correlations between the scale score on being prepared for the transition (Table 3) and the scale scores on paediatric care ranged from 0.34 to 0.45. All correlations were significantly positive ($p = 0.01$).

Spearman's rank correlations were also performed for background data and single items that were not part of the factor scales. These included the mean levels of HbA1c in paediatric care, based on the last four annual registrations in the Norwegian Childhood Diabetes Registry, and the mean levels of HbA1c in adult care, based on the medical records after transfer. They also included overall satisfaction, age at transfer, current age, diabetes duration and age at diagnosis (Table 3). The mean paediatric levels of HbA1c showed a weak inverse correlation with the factor about contact with paediatric doctors and individualised treatment in paediatric care (-0.21 and -0.23 , respectively, $p < 0.01$). The mean adult levels of HbA1c did not correlate with the scales about doctors, nurses or individualised treatment in adult care. The correlations between overall satisfaction and the scale scores on contact with the doctors, contact with the nurses and individualised treatment were considered adequate, as they ranged from 0.49 to 0.65 for paediatric care (p

< 0.01) and from 0.61 to 0.74 for adult care ($p < 0.01$). The patient's current age, age at transfer, age at diagnosis and diabetes duration did not correlate with any of the factor scales.

DISCUSSION

Patients' experiences are valuable when assessing the quality of health care. Few studies have addressed this aspect in relation to adolescents with diabetes making the transition to adult care. This is the first study in this area in Norway, a high-incidence country for childhood-onset diabetes. The questionnaire for our population-based nationwide study was developed to gather patients' experiences with the transition to adult care and with diabetes care before and after the transfer. A standardised process was followed when we developed the questionnaire, and our thorough analysis showed that the questionnaire demonstrated satisfactory results for internal consistency, reliability and validity.

The levels of missing data per item were low, indicating that the questions were acceptable to the respondents. The levels of responses stating that the questions did not apply were somewhat higher for adult care, reflecting organisational differences. The levels of missing data and not applicable data did not exceed 14% for any item, which was considered acceptable.

A total of seven factors were identified. The test-retest reliability showed high agreement between the scale scores. Internal consistency was satisfactory, and the item-total correlation showed an adequate degree of association between each item and the total score. The Spearman's rank correlation test proved there was a good correlation between the scales measuring experiences with paediatric diabetes care and being prepared for the transition and the scales measuring experiences with adult health care. Overall, the analyses showed that the factors that were identified were useful, both in this study and for comparing data.

The response rate was 41.4%, but the acceptable level in patient experience studies has not been made clear (22). However, surveys of adolescents and young adults have tended to

provide comparable response rates (7, 23, 24). A potential limitation to our study was that the questionnaire had to be sent by post to the addresses last registered in the Norwegian Childhood Diabetes Registry. We did not have means of contacting the patients by telephone or e-mail, which might have increased the response rate (6). All recipients were given the opportunity to answer electronically, but only one in three patients who responded chose this alternative. Personal contact might have produced a higher response rate but with increased potential for social desirability bias, as respondents may find it difficult to be as honest in their responses (22, 25).

The responders did not differ from the national data on the main activity for their age and were equally distributed between health regions. Responders and non-responders did not differ significantly in age, diabetes duration, insulin modality or blood glucose measurements. Non-responders were more likely to be male and have higher HbA1c levels, as reported by similar studies (6), and this may have influenced the results. Recall bias was another potential limitation, as responders answered questions about their paediatric care and transition two to four years after the transfer.

The responses to items about health personnel were generally skewed in a positive direction. It was found that the criteria related to ceiling effects varied between studies (19, 26) and noted that high ceiling effects on items about relationships between medical staff and their patients have been found in other studies and may indicate problems with measuring change over time (11, 27). However, significant differences were found when the respondents answered identical questions about paediatric and adult health care, and this indicated that the items and the scales for the answers provided sufficient opportunities for distinct responses. Our study also used a 5-point scale, which has been found to perform better than a 10-point scale in this area of research (28).

The patient–practitioner relationship is an important factor that affects satisfaction in adult health care (10), and the same responses have been found when parents provide feedback on paediatric care (16, 29). It was hypothesised that there would be a correlation between overall satisfaction and the scales that measured experiences with health personnel and

individualised treatment in paediatric as well as adult care and between overall satisfaction with paediatric care and how prepared they were for the transition. The correlations proved to be moderate to strong.

HbA1c levels vary with age during adolescence (4, 5), and it was hypothesised that the positive scale scores for health care experiences would correlate with HbA1c levels. A statistically significant, but weak, inverse correlation was found between HbA1c levels and experiences with doctors and individualised treatment in paediatric care. However, there was no correlation between HbA1c levels and the scales for adult care. Few studies have examined the correlations between health outcomes and the organisation of health services. A Cochrane review on the transition of care for adolescents found that there were no studies of interventions that targeted how care was organised. More research is needed to assess the effect of how health care is organised on health outcomes and patient experiences with care before and after transitions (30).

CONCLUSION

This national pilot questionnaire study highlighted important aspects of paediatric and adult care for type 1 diabetes and the transition from one service to another. Our study showed good evidence for internal consistency, reliability and validity for our questionnaire, indicating that it may be of value for further nationwide population-based studies and the evaluation of measures of quality improvement in longitudinal studies.

ABBREVIATIONS

HbA1c: Haemoglobin A1c

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

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