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Use of the national quality registry to monitor health-related quality of life of children with type I diabetes: A pilot study

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Abstract

The management of diabetes is complicated, as treatment affects the everyday life of both children and their families. To enable optimal care for children with type I diabetes, it is important to highlight health-related quality of life (HrQoL) as well as medical outcomes to detect psychological problems that otherwise could be missed. The aim was to study HrQoL in children and adolescents with type I diabetes dependent on gender, age and co-morbidity and to study the consistency between children's self-reporting and parents' proxy reporting. The cross-sectional data were collected using the questionnaire DISABKIDS Chronic Generic Measure and the DISABKIDS diabetes module. Parents in the proxy report perceived their children's HrQoL to be lower than children themselves. Boys reported their HrQoL to be better than girls. Results show that living with an additional disease has an impact on the HrQoL, which is an important factor to consider in the quality registry. Assessing HrQoL on a routine basis may facilitate detection and discussion of HrQoL-related questions in the national quality registry.

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Keywords

Assessment, diabetes, paediatric, statistics

Introduction

Type 1 diabetes is one of the most common chronic diseases in childhood in Sweden and affects the child's everyday life. The management of diabetes is complicated because both child and parents need to adapt their life to their new situation (Nardi et al., 2008). It is important to understand the impact of diabetes and its treatment on the everyday life of children and their families. The greatest outcome benefits may be beyond measures of glycaemic control, and therefore, it is important to measure children's perceived health-related quality of life (HrQoL) (Müller-Godeffroy et al., 2009) and to consider such variables in national quality registries. To enable optimal care for children with diabetes, it is important to include attention not just to medical outcomes but to HrQoL as well and a contingency to detect psychological problems that otherwise could be missed (de Wit et al., 2010). Early identification of children at risk of developing poor HrQoL may increase treatment compliance (Cameron, 2003). The challenge is finding ways to improve HrQoL in children with diabetes and ensure that HrQoL will be maintained throughout childhood and adolescence (Hesketh et al., 2004). The need for research concerning HrQoL in children and adolescents is important when considering the increasing awareness of psychosocial aspects of health (Ravens-Sieberer et al., 2006). Research needs to extend the knowledge about HrQoL in children with chronic conditions, such as type 1 diabetes.

Health-related quality of life

HrQoL is a multidimensional concept that refers to the individual perception of physical, mental, emotional and social functioning and has its focus on the impact that health status has on quality of life (Bullinger et al., 2002; Leidy et al., 1999; Matza et al., 2004) and is unique to each individual (Taylor et al., 2008). To understand the complexity of HrQoL in children with diabetes, it is important to use generic and disease-specific measures. The disease-specific measures focus on day-to-day management and its impact on HrQoL (Müller-Godeffroy et al., 2009) as well as considerations on parent-child behaviours. There is a need for studies that focus on the long-term impact of HrQoL interventions on psychosocial functioning of children with diabetes (Fogel and Weissberg-Benchell, 2010).

To accomplish the development of an overall picture of the health-care system for children with diabetes, available resources to both the child and the family in the health-care infrastructure need to be used (Chaplin et al., 2009). The multidisciplinary diabetes team should assess different kinds of domains concerning quality of life such as psychosocial barriers and promote healthy coping and conduct assessments on a routine basis (Delamater, 2007; de Wit et al., 2008). It is important to encourage the diabetes team to fully develop their program to maximize the support provided to children (and their parents) with diabetes in order to prevent poor HrQoL (Hanberger et al., 2009). An intervention can be helpful to prevent poor HrQoL. For example, clinic-based screening could be integrated into clinical practice (Fogel and Weissberg-Benchell, 2010) if an appropriate HrQoL measure is used, as a starting point to discuss issues concerning HrQoL (Hanberger et al., 2009). The quality registry, SWEDIABKIDS is a national quality registry for children and adolescents with diabetes, and it contains data from all paediatric diabetes clinics in Sweden (43 clinics). The

registry provides an opportunity to follow the results from the child's diabetes treatment over time. In the annual report, results show differences between HbA1c (Samuelsson et al., 2011), but until now, the HrQoL of children with diabetes has not been registered.

HrQoL of children with diabetes can vary with age and gender. Girls often describe a poorer HrQoL than boys (Chaplin et al., 2009; Graue et al., 2003; Hanberger et al., 2009) and in adolescence HrQoL may decrease (Kalyva et al., 2011; Matziou et al., 2011). Therefore, it is important to follow HrQoL data as early as possible and routinely include these types of measurements in clinical practice (Chaplin et al., 2009). In situations where the child is unable to complete a self-report, the use of parent-completed questionnaire, called proxy reports may be the only option (Upton et al., 2008). Studies have pointed out the potential problems regarding discrepancies between child and parent (proxy) reports (Eiser and Morse, 2001; Matza et al., 2004) as parents tend to underestimate their child's HrQoL (Ingerski et al., 2010; Sattoe et al., 2012). The aims were to study HrQoL of children and adolescents with type 1 diabetes dependent on gender and comorbidity and the consistency between children's self-reporting and parents' proxy reporting.

Methods

Design

This cross-sectional, descriptive pilot study was made in collaboration with the Swedish paediatric diabetes quality registry, SWEDIABKIDS (Samuelsson et al., 2011). The study included self-reports of children and adolescents (age ranged from 1 to 19 years) as well as proxy reports of parents from 11 paediatric outpatient diabetes clinics in different parts of Sweden.

Instrument

The HrQoL instrument DISABKIDS Chronic Generic Measure (DCGM-37) has been developed cross-nationally and includes a chronic generic module as well as a condition-specific module for diabetes. DCGM-37 is recommended for use in a wide variety of studies of children and adolescents with common disorders (Baars et al., 2005). DCGM-37 consists of 37 Likert-type scaled items, which are assigned to six dimensions (Figure 1). Due to previous confusion of mixed positive and negative domains, three domains have been reviewed and the new domain names are used here (Chaplin et al., 2009). For clarification purposes, the old names are written in parentheses. The dimensions are independence, inner strength (emotion), social inclusion, equality (social exclusion), physical ability (limitation) and treatment (Chaplin et al., 2009). Additionally, the subscales are associated with three domains conceptualized by the World Health Organization (WHO): mental, social and physical. Items are rated on the frequency scales of 1–5 and then linearly transformed to a 0–100 scale. A high score on the DCGM-37 is associated with high HrQoL. DCGM-37 is available in both self-report and proxy report form, which includes two age versions (4–7 and 8–18 years). The respondent is asked to think about the past four weeks when answering the questionnaire (Baars et al., 2005; Ravens-Sieberer et al., 2007). The disease-specific module for diabetes (DM-10) assesses degrees of severity, coping strategies and supply requirements of the family. The diabetes module includes 10 items (Ravens-Sieberer et al., 2007). The diabetes module has an impact scale that describes emotional reactions and a treatment scale that refers to planning treatment and carrying equipment (Figure 1) (Baars et al., 2005). Results from pilot testing of the DCGM-37 have indicated satisfactory internal consistency for all dimensions. Construct validity was evaluated with factor analysis as well as convergent and discriminant validities

Figure 1. The structure of the questionnaire DCGM-37 item and DM-10. DCGM-37: DISABKIDS Chronic Generic Measure; DM-10: DISABKIDS diabetes module with 10 items.

were assessed by their relation to other HrQoL instruments (Simeoni et al., 2007; The DISABKIDS Group Europe, 2006).

Data collection

The data were collected from June 2011 to September 2011. All children and their parents that visited the outpatient diabetes clinics during this period were asked to participate in the present study. Those who accepted to participate were asked to provide their email address, and the research group sent an email with a weblink to answer the questionnaire. The construction of the questionnaire enabled only group comparisons, as the answerer could not be traced back to the individuals. A total number of 563 parents accepted to participate and received the questionnaire (proxy report) and 404 completed the questionnaires, producing a response rate of 71.7%. The self-reports were completed by 217 out of 404 children who accepted to participate, which produced a response rate of 53.7%.

Statistical analysis

In accordance with the DISABKIDS manual (The DISABKIDS Group Europe, 2006), the data were derived from a summation and transformation of the scores from each domain (0–100). Statistical calculations were conducted using IBM SPSS Statistics 19.0 (Statistical Package for the Social Sciences). Descriptive statistics (frequencies, percentages, means and standard deviations) were used to characterize demographic variables. Since data were not normally distributed, nonparametric tests were used. Mann–Whitney *U* test was performed to test the differences between child and proxy reports and gender. The values of *p* < .05 were considered statistically significant.

A logistic regression analysis between DISABKIDS general HrQoL score and age, gender and other disease was performed. The DISABKIDS transformed score of HrQoL was dichotomized (from 0 to 74 and 75 to 100 percentile) (The DISABKIDS Group Europe, 2006) as the dependent variable and compared with age (0–11 and 12–19 years), gender (boy or girl) and other disease (yes or no).

Table 1. Clinical characteristics of the studied population.

DCGM-37 + DM-10	Self-report n (%)	Proxy report n (%)
Gender		
Boys	98 (45)	214 (53)
Girls	119 (55)	190 (47)
Age groups (years)		
0–6	–	43 (11)
7–12	48 (22)	161 (40)
13–15	70 (32)	102 (25)
16–19	95 (44)	94 (23)
Missing	4 (2)	4 (1)
Total	217	404
Co-morbidity		
Asthma/allergy	10 (5)	22 (5)
Thyroid disease	5 (2)	12 (3)
Coeliac disease	15 (7)	37 (9)
Neuropsychiatric disorders		4 (1)
Other*	5 (2)	9 (2)
Total	35 (16)	84 (20)

DCGM-37: DISABKIDS Chronic Generic Measure; DM-10: DISABKIDS diabetes module.

*Example of other diseases: epilepsy, kidney disease, skin disease and heart failure.

Ethical considerations

The ethical principles of respect for autonomy, non-maleficence, beneficence and justice were considered as stated in The Declaration of Helsinki (The Swedish Research Council, 1999). Verbal and written information about the study was given to each family and child. The participants gave their informed consent to take part in the study after verbal and written information. Based on the nature of the study as a quality improvement project, approval was not sought from the ethics committee. According to Swedish law of research ethics, a formal ethical permission was not deemed necessary.

Results

Clinical characteristics of the participants are presented in Table 1. The self-report consists of 45% boys and 55% girls and the proxy report of parents consists of 53% boys and 47% girls. The data were divided into four age groups and the youngest age group (newborn–six years) is only represented in the proxy report. The most frequent additional disease was coeliac disease with a frequency of 7% in the children's self-report and 9% in the proxy report.

Differences were established in all dimensions of DISABKIDS when comparing self- and proxy reports with the exception of *physical ability* and *diabetes treatment* (Table 2). The mean general HrQoL score in the self-report is 74 and in the proxy report 70, which means that parents estimate children's HrQoL lower than the children themselves.

Gender differences

When comparing the self-report scores of girls and boys, the mean general HrQoL score was 78 for boys and 71 for girls (Table 3). Boys had higher mean score than girls in all domains, but there

Table 2. Comparison between self and proxy-reports.

DCGM-37 + DM-10	Self-report			Proxy report			p Value
	n	Mean	SD (±)	n	Mean	SD (±)	
Independence	217	76	16	401	72	14	<.001
Physical ability	213	68	17	397	67	15	.220
Inner strength	211	70	20	395	66	19	.002
Equality	204	78	14	392	73	15	<.001
Social inclusion	208	82	15	390	76	16	<.001
Treatment	198	70	23	380	64	21	<.001
General HrQoL score	207	74	15	392	70	14	<.001
Impact	203	61	21	389	58	18	.02
Diabetes treatment	199	52	27	382	56	21	.212

DCGM-37: DISABKIDS Chronic Generic Measure; DM-10: DISABKIDS diabetes module; HrQoL: health-related quality of life.

were no differences in the domains of *social inclusion* and *impact*. In the proxy report, the mean of general HrQoL score was 70 for boys and 69 for girls. No differences were seen in any of the dimensions when comparing gender in the proxy report. There were only significant differences in two of the nine dimensions, when girls were compared between self- and proxy reports (*equality* and *diabetes treatment*). Differences between boys in self- and proxy reports occurred in eight of nine dimensions; the dimension *physical ability* was the only one not significantly different.

Co-morbidity

The comparisons between those children with additional disease (co-morbidity) and those who had type 1 diabetes only are shown in Table 4. The general HrQoL mean score for children’s self-reports with additional disease were 69, and for the children with type 1 diabetes only, the mean score was 75. The general HrQoL mean score in the proxy report was 64 for the group with additional disease and 71 for those with type 1 diabetes only. The group with co-morbidity had a lower mean score in all HrQoL domains compared to the group with type 1 diabetes only and statistically significant differences in all domains in the children’s self-reports, with the exception of *independence*, *physical ability*, *treatment* and *diabetes treatment*. The differences were significant in all domains in the proxy reports apart from the *independence* domain. The logistic regression analysis showed that according to children’s reports another disease has no linkage to HrQoL, but being a boy or a girl is decisive. Pursuant to parents reports, having another disease is the prejudiced factor of a poorer HrQoL (Table 5).

Discussion

The results of this study indicate that the proxy reports of parents estimating their children’s HrQoL was lower than the self-report from the children themselves and that there are differences with respect to gender in the domains of DISABKIDS. This knowledge on children’s HrQoL and differences are important aspects to consider for children having diabetes as well as for children with other chronic conditions. As a complement to medical variables, these results could be of importance for clinicians when meeting children with type 1 diabetes. Assessing HrQoL is very

Table 3. Comparison between gender in the separate reports. In the third column, self- and proxy reports, the comparison is between girls/girls and boys/boys.

	Self-report				Proxy-report				Self- and proxy report			
	Girls		Boys		Girls		Boys		Girls/girls		Boys/boys	
	<i>n</i>	Mean/SD	<i>n</i>	Mean/SD	<i>n</i>	Mean/SD	<i>n</i>	Mean/SD	<i>p</i> Value	<i>p</i> Value	<i>p</i> Value	<i>p</i> Value
DCGM-37 + DM-10												
Independence	119	74 ± 17	98	79 ± 15	187	72 ± 14	214	72 ± 14	.605	.163	<.001	<.001
Physical ability	118	67 ± 17	95	70 ± 17	186	67 ± 16	211	68 ± 14	.683	.768	.114	.114
Inner strength	117	65 ± 22	94	76 ± 17	184	65 ± 20	211	67 ± 17	.596	.587	<.001	<.001
Equality	115	79 ± 16	93	86 ± 13	180	75 ± 17	210	78 ± 14	.167	.021	.001	.001
Social inclusion	113	77 ± 16	91	79 ± 13	182	73 ± 15	210	73 ± 16	.812	.10	.002	.002
Treatment	109	64 ± 24	89	77 ± 20	176	64 ± 23	204	64 ± 20	.649	.834	<.001	<.001
General HrQoL score	114	71 ± 15	93	78 ± 13	182	69 ± 15	210	70 ± 14	.893	.363	<.001	<.001
Impact	111	59 ± 21	92	65 ± 20	180	59 ± 17	209	57 ± 18	.148	.932	.001	.001
Diabetes treatment	108	45 ± 27	91	61 ± 25	177	55 ± 22	205	56 ± 21	.773	.001	.028	.028

DCGM-37: DISABKIDS Chronic Generic Measure; DM-10: DISABKIDS diabetes module; HrQoL: health-related quality of life

Table 4. Comparison between co-morbidity, yes = additional disease and no = only diabetes type 1, self- and proxy report.

DCGM-37 + DM-10	Self-report				p Value	Proxy report				p Value
	n = yes	Mean/SD	n = no	Mean/SD		n = yes	Mean/SD	n = no	Mean/SD	
Independence	35	71 ± 18	179	77 ± 16	.073	83	69 ± 15	318	73 ± 14	.065
Physical ability	35	65 ± 16	175	69 ± 17	.153	82	61 ± 16	315	69 ± 15	<.001
Inner strength	35	63 ± 21	173	72 ± 20	.021	83	59 ± 18	312	68 ± 18	<.001
Equality	35	77 ± 16	170	84 ± 15	.015	81	70 ± 16	309	78 ± 15	<.001
Social inclusion	34	73 ± 13	167	79 ± 15	.008	82	68 ± 18	310	74 ± 15	.009
Treatment	32	63 ± 26	163	71 ± 22	.104	76	55 ± 23	304	66 ± 20	<.001
General HrQoL score	35	69 ± 15	169	75 ± 14	.016	82	64 ± 15	310	71 ± 14	<.001
Impact	35	54 ± 20	165	63 ± 21	.013	82	53 ± 18	307	59 ± 17	.003
Diabetes treatment	33	46 ± 26	163	54 ± 27	.147	82	46 ± 18	300	58 ± 22	<.001

HrQoL: health-related quality of life; DCGM-37: DISABKIDS Chronic Generic Measure; DM-10: DISABKIDS diabetes module.

Table 5. Logistic regression with general HrQoL score of DISABKIDS questionnaire as dependent variable (0–74/75–100 percentile), compared with age (0–11/12–19 years), other disease (yes/no) and gender (boy/girl).

Independent variable	Self-report <i>n</i> = 195				Proxy report <i>n</i> = 384			
	<i>p</i>	AOR	95% CI Lower	Upper	<i>p</i>	AOR	95% CI Lower	Upper
Age	.167	.601	.292	1.237	.875	1.035	.673	1.591
Gender	.003	2.488	1.376	4.499	.135	.721	.469	1.107
Other disease	.091	1.984	.897	4.387	.001	2.666	1.465	4.851

AOR: adjusted odds ratio; CI: confidence interval; HrQoL: health-related quality of life.

complex and observed differences between self- and proxy reports are explicit. It is important to look beyond the mean scores on HrQoL measures because there are variations between domains (Grootenhuys et al., 2007). The results indicated that boys had higher scores than girls, and the comparison with proxy reports also differ with regard to gender. Disagreement between children's self-reporting and parents' proxy reporting could be a consequence of their individual beliefs about health and well-being. Parents tend to estimate their children's HrQoL to be lower than children themselves. These results are similar to other studies (Morrow et al., 2012; Sattoe et al., 2012; Weissberg-Benchell et al., 2009) and illustrate the difficulty in assessing HrQoL in children from the parent's perspective. The differences between child and proxy report could be indicative of a lack of parental knowledge concerning children's beliefs and experiences, or a perceptual difference in perspective between child and the parent. Parents may vary in awareness and tolerance of their child's health status (Upton et al., 2008), which could explain the differences. Parents often lack first-hand information regarding school experiences or their children's social interactions with friends (Ravens-Sieberer et al., 2006). The difference between how parents estimate girls' HrQoL differs only in the scoring of three domains (social inclusion, equality and diabetes treatment). However, the difference to boys is substantial. Parents tend to report that boys have lower HrQoL than boys reporting themselves. One explanation for the fact that children with type 1 diabetes tend to estimate their HrQoL as higher compared with the reports by their parents could be that children with a chronic condition receive help and support from friends and school personnel (Barlow and Ellard, 2006). The perspectives from both self- and proxy reports are needed to provide a more complete picture of how a chronic condition and its treatment impacts on the lives of children. Assessment of HrQoL in children and adolescents must consider development and changes over time, as the child's age and cognitive development, as well as the condition itself, are factors that affect the outcomes of HrQoL (Petsios et al., 2011). The quality registry can offer a structure to follow the assessment of HrQoL over time as a complement to medical variables, such as HbA1c. This study reveals the opportunity a quality registry can offer, when measuring the HrQoL of children with diabetes and pay attention to those who have an additional disease that has an impact on the HrQoL.

The results of this study, which show that there are differences between girls and boys, are confirmed by other studies (Chaplin et al., 2009; Hanberger et al., 2009; Kalyva et al., 2011). When comparing the results with that of WHO: a collaborative cross-national study, health behaviour in school-aged children (HBSC, healthy children), girls in the Swedish survey reported their general health to be poorer than boys. The level of self-rated health also decreased with age (Statens

Folkhälsoinstitut, 2011), which could be another possible explanation for the differences. It is plausible that the HrQoL of children with chronic conditions, which necessitate treatments such as injections and dietary restrictions, is affected (Chaplin et al., 2009). When comparing HrQoL in children with chronic conditions, patients with diabetes report better HrQoL than children with rheumatologic conditions, obesity or asthma (Varni et al., 2007), and compared to the group of children with an additional disease, there was significance within five of nine domains in the self-report. The proxy report also showed significant differences in all domains, except *independence*, which indicated that living with a chronic condition affects the child's life (Ziaian et al., 2006). The domain *diabetes treatment* did not show any difference when comparing self-reports, but there was difference in the proxy reports. One explanation could be that this domain only asks about treatment effects concerning the diabetes and not about living with an additional condition. Parents tend to believe that an additional disease affects the child more than the children do themselves. However, results in this study show that living with more than diabetes has an impact on children's HrQoL, which also is of great importance to follow in the quality registry.

All current research is related to understanding children's point of view based on proxy reports from parents or caregivers perspectives and not that from the child. Future research needs to simplify the use of HrQoL measurements on a regular basis for use in clinical practice to the youngest children.

Methodological considerations

The strength of the present study was the ability to use a validated questionnaire, which had specific questions for diabetes. DISABKIDS questionnaire was applied to a wide age range of children as well as adolescents. One of the limitations of the present study was the impossibility to make a drop out analysis, because of the method used. The response rate was higher for the parents' reports compared with the children's self-reports, which could be explained by the way the questionnaire was dispatched. Type one error due to self-selection can be discussed. Personal characteristics in the evaluation of HrQoL is critical. The participants might be more amenable to health and quality of life issues, which could have affected their reports about HrQoL. Furthermore, the cross-sectional data enabled only comparisons on a group level as the answers from the questionnaire were unidentifiable, which also limited the possibilities to use medical variables such as HbA1c. When comparing the co-morbidities, the authors are aware of differences in treatment and severity between diseases, which also is a limitation in this study. To enable the youngest children's perspective (aged four to seven years), the DISABKIDS Smiley Questionnaire children could have been used instead of depending on the proxy reports, which was not possible in the present study. If Smiley Questionnaires are ought to be used, the methodology has to proceed to develop the use in clinical practice, because of the differences from ordinary questionnaires.

Clinical implications and conclusions

Following HrQoL of children with type 1 diabetes may lead to improvements in the care of their diabetes and consequently children's health. However, these measurement needs to be used on a regular basis as HrQoL tends to vary between gender and during the years to adulthood. The focus on health-care infrastructure needs to be on health, well-being and quality of life as well as medical variables. Using measures like DISABKIDS in quality registry could be an effective method in early identification of children and adolescents at risk of developing poor HrQoL. The contribution

of increased knowledge about HrQoL lies in facilitating goals shared by children and the health-care providers (Marshall et al., 2006). To assess HrQoL on a routine basis may facilitate detection and discussion of further HrQoL-related questions. Monitoring of HrQoL has to be a part of the routine praxis within the multidisciplinary diabetes team and should be all team members' responsibility. Sharing HrQoL information with the patient could be a starting point in further tailoring diabetes care for the child living with diabetes (de Wit et al., 2007). If the results of the questionnaire are showed to the child and parents during their visit, it could broaden the understanding of health-related issues. More research is needed about the clinical use of DISABKIDS and if it is possible to use the questionnaire as a starting point to discuss the child's experience of health and quality of life.

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