



# Quality of Life and Glycemic Control in Saudi Children with Type 1 Diabetes at Different Developmental Age Groups

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## ABSTRACT

**BACKGROUND:** Children with type 1 diabetes (T1D) at different stages of development have age-specific needs, which can influence their perception of quality of life (QoL). In our study, we aimed to emphasize these age-specific needs and assess the perception of QoL in Saudi children with T1D, as well as their parents correlating QoL scores with children's glycemic control.

**METHODS:** This is a cross-sectional study in which children with T1D and their parents from 2 tertiary institutes in Saudi Arabia have answered a standard diabetes-specific QoL questionnaire (PedsQL™ 3.0 diabetes module, translated in Arabic). We also reported glycated hemoglobin (HbA1c) results for these children within a month of completing the questionnaire. The QoL total aggregate and domain scores for self (children) and proxy (parents') reports were compared and correlated with children's HbA1c.

**RESULTS:** A sample was 288 self and proxy reports from 144 children with T1D of 3 age groups: 5 to 7 years (7%), 8 to 12 years (49%), and 13 to 18 years (44%), and their parents. QoL differed significantly between self and proxy reports in the total aggregate and domain scores ( $P$ -values range from .02 to  $<.001$ ). The impact on QoL was significantly higher in female patients ( $P = .043$ ). Insulin pump users had better HbA1c ( $P = .007$ ), and HbA1c level was worse in those who intended to fast at Ramadan ( $P = .005$ ).

**CONCLUSION:** Children with T1D at different developmental age groups perceive QoL differently than their parents. Adjusting management as per age-specific challenges could potentially improve these children's QoL and glycemic control.

**KEYWORDS:** Children, developmental age, glycemic control, HbA1c, parents, QoL, T1D

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## Introduction

Evaluation of health-related quality of life (HRQoL) becomes an essential element of healthcare systems.<sup>1</sup> HRQoL questionnaires have been widely used to measure the overall impact of different health problems on psychosocial life, especially for lifelong diseases. Generic HRQoL instruments, such as the Pediatric QoL generic questionnaire (PedsQL™ 4.0), are designed to apply in a wide range of populations with variable characteristics.<sup>2</sup> Disease-specific HRQoL instruments are increasingly used in children with chronic diseases, such as diabetes, and their families.<sup>3</sup> A number of HRQoL questionnaires were designed for people with diabetes mellitus (DM) to investigate broad and specific conceptualizations of diabetes-specific quality of life (QoL). Longitudinal studies have shown that the psychosocial impact of DM can be used to predict

QoL and morbidity in these patients.<sup>4</sup> Diabetes Modules (PedsQL™ DM 3.0 and 3.2) are the most widely used questionnaires for these purposes in children with T1D.<sup>2,5</sup>

When a child or adolescent is diagnosed with chronic illness, such as diabetes, adaptation to life tend to be a challenge for the whole family. The glycemic control of children with T1D is expected to correlate with the impact of the disease on QoL for the child and family.<sup>6,7</sup> As children are not simply young adults, the impact of T1D on their QoL could be influenced by different developmental age needs (Table 1).<sup>8</sup> Furthermore, the challenges posed by T1D on the child and family, and the children's developmental age challenges, may also vary in different societies with various cultural backgrounds.<sup>9,10</sup> For instance, in our Islamic population, Ramadan fasting is considered mandatory and it is challenging for these



**Table 1.** Needs and challenges of children with type 1 diabetes at different developmental age groups.<sup>8</sup>

DEVELOPMENTAL AGE	MILESTONES	CHALLENGES/RISKS FROM DIABETES	NEEDS
5-7 years	<ul style="list-style-type: none"> <li>Willing to fit in with what the parents want.</li> <li>Think about crime and punishment in a primitive way.</li> <li>Becomes aware of the boundaries of the body.</li> <li>Starting school can be stressful—adjustment difficulties.</li> <li>Occupied with understanding and exploring the world.</li> <li>Interested to understand how their diabetes work.</li> <li>Awareness of time.</li> </ul>	<ul style="list-style-type: none"> <li>May believe they developed diabetes as a punishment for something wrong.</li> <li>Limitation in the amount in the freedom- parents fear of hypoglycemia.</li> <li>In a family where children of different sexes diabetes may be linked to gender in the child's mind. A child may believe that it would be better to be of the opposite sex.</li> </ul>	<ul style="list-style-type: none"> <li>Plasters very useful to restore and heal.</li> <li>Try to keep track of duration of treatment.</li> <li>Do not tell in advance about injections or testing.</li> </ul>
8-12 years	<ul style="list-style-type: none"> <li>Expand relationship with other adults (teachers etc).</li> <li>Learn how to master impulse control—behave within limits.</li> <li>Latency phase: very receptive to all education including diabetes.</li> <li>Learn to stay within limits set by parents.</li> <li>Social role develops: Can I join in? Will I be accepted?</li> <li>Competition with peers: Who is the best?</li> </ul>	<ul style="list-style-type: none"> <li>10-11 years: start to reflect upon and react to their illness in a new way—Why this happened to me?</li> <li>Wonder about their role in life during this period.</li> <li>First time to realize that diabetes will be for life.</li> </ul>	<ul style="list-style-type: none"> <li>Will benefit from meeting others with diabetes in the same age.</li> <li>Encouragement is important: confirmation that they have done things correctly.</li> <li>Share concerns with child.</li> <li>Make management a natural part of daily life before puberty.</li> </ul>
13-18 years	<ul style="list-style-type: none"> <li>Development of adult identity: Independence and equal understanding—they defend their integrity so strongly.</li> <li>Earlier gaps of stages of development may be revisited.</li> <li>Friends are very important.</li> <li>Interest in their own bodies; shy about exposing their bodies.</li> </ul>	<ul style="list-style-type: none"> <li>Struggling to handle their condition and find it hard to let their parents do it—usually poor control.</li> <li>Fear that their bodies will be inspected in every clinic visit.</li> <li>Concerned about the future: depression, not uncommon to have existential thoughts but also may develop suicidal thoughts.</li> </ul>	<ul style="list-style-type: none"> <li>Give freedom and responsibility to eat outside and experiment with insulin doses.</li> <li>Explain how diabetes and its management affect their body</li> <li>Encourage them to come without their parents or interview them alone with confidentiality.</li> <li>Treat as independent patients but also keep parents informed.</li> <li>Reassure them, crying and showing emotions happens to everybody.</li> <li>Give them independence under supervision.</li> </ul>

patients who eventually face this annually repeated event. The age of beginning to fast is usually during early adolescents and they start to train themselves on this task in late childhood. We hypothesized that the intent to fast can correlate with a change in quality of life and we aimed to test that hypothesis. In most of the situations, the intention to fast will usually result in these patients actually fasting even only for few days during Ramadan. However, there is no clear cut-off age for when children start training in Ramadan fasting in our community and it is culturally accepted that children start fasting too early sometimes, as young as 8 to 9 years. Besides, parents like to encourage their children to fast from an early age to get them acquainted to the concept and children themselves are occasionally eager to start early to copy their older siblings even if for a few days of the month. In this perspective, we must expand our scope of the understanding of children's and parents' perceptions of QoL to approximate variations in children (self) and parents' (proxy) reports. This could potentially inform the setting's educational plans and other strategies to achieve better QoL and diabetes glycemetic control.

The relationship between HRQoL scores and glycemetic control is also interesting to explore in different societies. Literature has shown debating findings of either no significant correlations between the 2 or revealed a negative relationship, that is, achieving better glycemetic control could be at the expense of reasonable QoL especially when tackling the task from parents' versus children's perspectives.<sup>6,11,12</sup>

This study compared the QoL scores reported by Saudi children with T1D with the reports from their parents. It also shows the correlation between glycemetic control and the total aggregate and domain-specific QoL scores reported by parents and children at different developmental age groups.

## Materials and Methods

This is a cross-sectional study conducted in 2 tertiary hospitals in Saudi Arabia: namely, King Abdulaziz Medical city of the National Guard Hospitals in Riyadh and Jeddah, and King Khalid University Hospital, Riyadh, in 2016 and 2017. All Saudi children aged 5 to 18 years diagnosed with T1D at least 6 months prior to recruitment and were included over 2 months after obtaining ethical approval from the institutional review boards of both centers in the study. We excluded all children diagnosed with any chronic illnesses or autoimmune diseases, patients still in partial remission (honeymoon) phase of the disease, patients with a known diagnosis of learning difficulty or developmental delay, and patients with recent infections requiring hospital admission or an antibiotic course in the last 3 months. We invited all patients who attended the service during the study period with the inclusion criteria. Almost all the approached patients were happy to participate. However, as we were keen to collect data shortly prior to Ramadan, we were satisfied by the reported number that would give enough statistical significance based on prior assessment of appropriate

sample size. In addition, gathering patient's information, we have assessed adherence by the simplest method of parents' report but not with other tools avoiding retrospective bias in our assessment.

A standard HRQoL diabetes specific questionnaire for children with T1D (PedsQL DM™ version 3.0, Arabic translation) was used: their simultaneous glycosylated hemoglobin (HbA1c) results were recorded.<sup>13</sup> The questionnaire included 28 items. Questions were categorized under 5 domains. Each domain assessed an aspect of quality of life. These 5 domains are (1) diabetes symptoms, (2) treatment barriers, (3) treatment adherence, (4) worry, and (5) communication. Scores of the questionnaire were calculated from children and parents' answers, using validated Arabic translated questionnaires. Each question had 5 possible answers (0: no problem, 1: sometimes, 2: occasional, 3: frequently, 4: always there) QoL scores grade from 100 to 0 for each question; where the answers 1 to 4 were transformed into QoL scores as follows: no problem=100, sometimes=75, occasional=50, frequently=25, always there=0). All the question scores were aggregated under 1 domain. The higher the score in each domain, the higher QoL predictor was. These scores were then correlated with the HbA1c results as an indicator of glycemetic control in these children.

Children of 3 age groups: (5-7 years, 8-12 years, and 13-18 years) and one of their parents completed the PedsQL DM™ version 3.0 questionnaires independently, through direct interviews or self-administered questionnaire; except for those less than 7 years of age who were understandably unable to fill in the questionnaire without help from the interviewer or their parents. All of these patients had HbA1c tests done on the same day, or within a month, of completing the PedsQL DM™ questionnaire. Both laboratories in the 2 centers of the study use the same standardized ion exchange high-performance liquid chromatography (HPLC) method for measuring HbA1c.

In our study centers, we hold annual gatherings for patients with diabetes and their parents to discuss the intention of fasting Ramadan a month prior. Adjustments of medication delivery are made accordingly. We collected most of patients and parents' responses to questionnaires in this study by direct interviews during that event. We included all potential ages from 8 years of age since we do not know who would intend to fast that year.

## Statistical analysis

Categorical data were summarized as proportions and continuous data, used as medians (interquartile range), were compared with the Mann-Whitney test. Study-time HbA1c results of each age group were correlated with the aggregate (total) QoL impact scores, using Spearman's correlation coefficient.

A logistic regression analysis was conducted to identify variables associated with a poor QoL score. These factors included

age, gender, duration of diabetes, parents' level of education, insulin pump therapy, and intentions to observe fasting during Ramadan month. All tests, which were 2-sided and  $P$  value  $<0.05$  were considered significant. The SPSS statistical package (version 20) was used to conduct the analysis.

## Results

Data were collected from a total of 288 self and proxy reports completed by 144 children with T1D and their parents. Applying the exclusion criteria and collecting data purposely only a month prior to Ramadan, the response rate was 90% ( $n=144/160$ ) in our study. We analyzed their responses in 5 domains of PedsQL™ DM questionnaire categorizing them into 3 different developmental age groups (5 to 7 years,  $n=11$ ), (8 to 12 years,  $n=72$ ), and (13 to 18 years,  $n=61$ ). The average duration of diagnosis with T1D in our patients was 5 years  $\pm 3.2$  and the mean HbA1c was 10.4%. Recruited children are all school attendees and most of their caregivers were their mothers ( $n=85$ , 60%) (Table 2). The majority of parents included in the study were either at a secondary level of education or a university level ( $n=101$ , 66.4%). Most of participating families in the study ( $n=118$ , 82.5%) were of a moderate socio-economic status. The majority of patients were on multi-dose injections of insulin ( $n=117$ , 81.7%).

A significant difference was noted between self and proxy QoL reports in total aggregate scores ( $P<.001$ ). The discrepancy was specifically noted in 3 domains: treatment barriers ( $P<.001$ ), treatment adherence ( $P<.02$ ), and worry ( $P<.001$ ) (Table 3). With further analysis, the difference between patients and parents' perceptions of QoL were examined in different developmental age groups. A significant difference was found in the total aggregate scores, as well as the 3 above domains in all age groups, except for the total aggregate QoL score in the 5 to 7 years age group, in which no difference was noted between self and proxy reports (Table 3).

We compared QoL scores in self and proxy reports with children's HbA1c level in each group. In proxy reports, the total aggregate score significantly correlated with children's HbA1c in the 5 to 7 year-age-group ( $P=.04$ ), which was mainly contributed by the "treatment adherence" domain ( $P=.05$ ). However, no significant correlations were observed between HbA1c and QoL scores in individual domains of the questionnaire for the proxy reports of all age groups. Similarly, there were no correlations between the total aggregate scores of QoL in self-reports with children's HbA1c results in all age groups. In regards to domain scores for self-reports, treatment barriers were significantly correlated with HbA1c results in the younger age group ( $P=.019$ ). In adolescents, a significant correlation was found between HbA1c results and QoL scores in the communication domain ( $P=.042$ ) (Table 4). In addition, there was no significant correlation in the self- and proxy reports in the middle-age group (8 to 12 years).

Patients on insulin pumps in our study group showed better glycemic control compared to those using insulin injections ( $P$ -value = .007). Female gender was associated with worse QoL ( $P$ -value = .043), but no other potential risk factors of poor QoL have been identified by regression analysis. Patients who intended to fast during Ramadan were observed to have poorer glycemic control ( $P$ -value = .005). However, neither using an insulin pump nor intention to observe fasting during Ramadan showed significant correlations with the total aggregate scores of QoL in our study group.

## Discussion

The relationship between QoL and glycemic control in patients with T1D and their parents is a bidirectional relationship. On the one hand, glycosylated hemoglobin (HbA1c) is influenced by multiple factors, including QoL, which is affected by routine challenges faced by patients and their parents during management.<sup>7</sup> On the other hand, glycemic control could also affect QoL and decision-making in the management process. Parents seemed to vary in their perception of QoL of their children with T1D in different age groups in our cohort. The variations can be attributed from an aspect to different developmental age needs in these children.<sup>14</sup> We noted no significant variations in the aggregate scores of QoL of different age groups in self-reports. As in some previous reports, our study showed that insulin pump users produced better HbA1c compared to injection users, although this did not necessarily mean that pump patients should entertain better QoL.<sup>9</sup> It has been suggested that economic status has a substantial impact on QoL as well as therapy adherence.<sup>15</sup> Overall, self and proxy reports in different QoL domains showed variable age-specific correlations with glycemic control.

Several factors in patients' demographics may affect control of diabetes, as different ages may have different needs (Table 1). It has been reported that as children grow, the burden of diabetes decreases.<sup>16</sup> Younger patients with T1D were found to report anxiety and depression more frequently than older children.<sup>17</sup> However, in our study, we noted no significant differences in QoL aggregate scores, based on age in self-reports. A study comparing QoL between younger and older adolescents found that less parental control and increased self-care autonomy seen in older adolescents can positively affect their QoL scores.<sup>14,18</sup> In line with this previous report, we noticed that children from 8 to 12 years, with more parental control, reported worse QoL scores in the diabetes symptoms domain. Children who intended to fast during Ramadan in our group were noted to have poorer glycemic control ( $P$ -value = .005). It was not clear whether that could be related to fear of an impending challenge or due to other age-related challenges as part of adolescent behavior. However, this would require greater adjustments to their diabetes control to realize better QoL when fasting.<sup>19</sup> Moreover, children with T1D who intended to

**Table 2.** Patients and parents' demographics.

	NUMBER	%
Age (years)		
5-7	11	7.1%
8-12	72	48.4%
13-18	61	44.5%
Gender		
Male	66	45.8%
Female	78	54.2%
Socioeconomic status		
Poor	19	13.2%
Middle	118	81.9%
Good	7	4.9%
Accompanying parent		
Mother	85	60.0%
Father	32	21.9%
Both parents	27	17.4%
Parent's level of education		
Illiterate	6	4.2%
Primary	37	25.7%
Secondary	52	36.1%
University	49	34%
Current insulin regimen		
Conventional*	15	9.8%
MDI**	117	81.7%
Pump	12	8.5%
Adherence to treatment		
Poor	43	29.2%
Average	55	40.3%
Good	46	30.5%
Intention to fast during Ramadan		
No	73	53.5%
Yes	71	46.5%
Total	144	100%

\*Conventional—twice or 3 times injections per day; \*\*MDI—Multidose injections.

observe Ramadan fasting should be psychosocially supported to override this upcoming challenge. Although we have not assessed QoL scores during Ramadan in this study, our findings suggest that observing fasting for the first time can be

associated with poorer QoL scores as a significant challenge in their lives. More focused study that is targeted on this particular time period is needed.

In our study, females had worse QoL scores compared to males. This was reported in other studies, as the etiology is unclear.<sup>16,20,21</sup> Gender differences during puberty might play a role, since female patients usually require more insulin in this period due to hormonal changes.<sup>22,23</sup> Female patients with type 1 diabetes tend to worry more and are generally less satisfied than males.<sup>10,24</sup> Recent studies showed that depression has higher prevalence in adolescent girls vs. boys in the Saudi population, which can be a confounding factor.<sup>25</sup>

Inconsistency between child and parental reports of QoL has different reasons.<sup>9,26</sup> In general, parents have varying perceptions and may not share these concerns with children in different developmental age groups.<sup>8</sup> Moreover, Hanberger et al.<sup>27</sup> attributed the discrepancy in QoL in self and proxy reports to the burden diabetes poses on parents. In a recent report, there were significant negative weak correlations between parental stress and PedsQL scores that is, the higher the parental stress, the lower the quality of life of the diabetic child in self and proxy reports.<sup>12</sup> In our population, we noticed disagreement between child and parent reports in the domains of treatment barriers, adherence, and worry. This was consistently with previous reports on QoL in children with T1D.<sup>28</sup> No difference was found in total aggregate scores of QoL in patients' reports in all age groups, whereas from parents' perspectives, children in the younger age group were more concerned than other groups. This could be due to the fact that parents worry more about younger children regarding the burden of injections and regular blood glucose monitoring, as well as long-term consequences of the disease, and unreported hypoglycemic episodes.<sup>29-31</sup> Further, a discrepancy was noted in the younger age group (5 to 7 years), in which children reported more difficulties in treatment barriers, although parents did not. Children's perception in the domain of treatment barriers and, to some extent in the communication domain, correlated with their glycemic control in the younger age group; this indicated a significant concern about injections and blood glucose monitoring, as well as difficulty in expressing themselves to the caretaker.

In a previous multicenter study, adolescents with suboptimal glycemic control and high QoL reported good frequency of glucose monitoring, fewer depressive symptoms and less negative affect.<sup>6</sup> However, in a more recent Turkish study, there was no correlations between HRQoL and metabolic control in children with T1D.<sup>11</sup> Although, there was no correlation between HRQoL and A1c in children's self-reports in that study, the improving HRQoL scores in parents' proxy-reports were associated with good glycemic control in these children.<sup>11</sup> In our study, a lower score of QoL in the communication domain correlated with poor HbA1c in the adolescent group, suggestive of difficulties in communicating their challenges

**Table 3.** Median QoL scores for patients and parents.

	PATIENTS' (SELF) REPORT QOL* SCORE (RANGE)	PARENTS' (PROXY) REPORT QOL SCORE (RANGE)	P-VALUE (OVERALL)	P-VALUE (5-7YEARS)	P-VALUE (8-12YEARS)	P-VALUE (13-18YEARS)
Diabetes symptoms	675 (575-775)	625 (550-775)	.220	NS**	NS	NS
Treatment barriers	275 (200-325)	200 (150-275)	<.001	.014	.007	.0001
Treatment adherence	525 (450-600)	500 (400-600)	.020	.001	.0001	.0001
Worry	200 (100-250)	125 (75-175)	<.001	.019	.001	.0001
Communication	225 (150-300)	225 (150-300)	.518	NS	NS	NS
Total	365 (320-420)	330 (295-385)	<.001	.11	.0001	.0001

\*QoL—Quality of life, \*\*NS —Not significant.

**Table 4.** Comparison of HbA1c with child's QoL scores in each age group.

QOL* DOMAINS		5-7YEARS	8-12YEARS	13-18YEARS
Diabetes symptoms	Correlation coefficient	.054	0.191	0.062
	P-value	.504	.100	.613
Treatment barriers	Correlation coefficient	**	−0.159	−0.165
	P-value	.019	.172	.174
Treatment adherence	Correlation coefficient	−.004	−0.028	0.001
	P-value	.962	.811	.991
Worry	Correlation coefficient	−0.092	−0.103	−0.096
	P-value	.254	.380	.432
Communication	Correlation coefficient	−0.156	−0.012	**
	P-value	.053	.921	.042
Total aggregate	Correlation coefficient	−0.120	−0.080	−0.145
	P-value	.135	.495	.235

\*QoL —Quality of life, \*\*Correlation is significant at the 0.05 level (2-tailed).

with parents and treatment teams. These correlations emphasize the importance of parallel behavioral therapy programs in adolescents, with intensive diabetes management to achieve better QoL and glycemic goals.<sup>32,33</sup>

## Conclusion

Children with T1D have age-specific needs, therefore, face variable challenges and might perceive QoL differently from their parents. Pump therapy could result in better glycemic control, but not necessarily better QoL in these patients. Female patients have poorer QoL, so require more attention in this perspective of management. Addressing age-related needs must be part of a routine education and management goals for children with T1D to achieve better QoL and glycemic control.

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## Authors' Contribution

AB—Conceived the idea, study design, data analysis, drafting and editing manuscript.

BA—Data collection, drafting and editing manuscript.

SM, HO, AB, NZ, —Data collection, drafting, editing and approving final manuscript.

MB—Data analysis, drafting and editing manuscript.

AA, MD, IA—Drafting, editing and approving final manuscript.

## Ethics

The Institutional Review Board (IRB) of King Abdullah International Medical Research Center (KAIMRC) granted an approval of this study (IRB approval number: SP17/157/R). Informed consent, as well as assent for children aged 10 to 18 years, for participation in the study and publication of medical details and responses to questionnaires was also obtained from the parents of these patients.

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