Assessing maths literacy skills in type 1 diabetic children and their caregivers

Moosa FY, MBBCh, FCPaed(SA), Certificate in Endocrinology and Metabolism (SA) Paeds
Paediatric Senior Specialist and Endocrinologist, Department of Paediatrics, Chris Hani Baragwanath Academic Hospital, University of the Witwatersrand
Segal D, Fellow of the American Academy of Paediatrics (FAAP)
Paediatric Senior Specialist and Endocrinologist, Department of Paediatrics, Charlotte Maxeke Johannesburg Academic Hospital, University of the Witwatersrand
Correspondence to: Dr Fatima Moosa, e-mail: fmoosa3@gmail.com
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Abstract

Background: It is essential that children have adequate numeracy and literacy skills in order to manage their diabetes effectively. The objective was to undertake a pilot study to assess the level of numeracy skills in type 1 diabetic children and their caregivers, and to ascertain if there was a deficit in these skills. This cross-sectional descriptive study comprised 53 children and 37 primary caregivers, who attended the paediatric diabetic clinics at the Chris Hani Baragwanath Academic and Charlotte Maxeke Johannesburg Academic hospitals from March to September 2009.

Method: The participants were interviewed and completed a diabetes mathematical questionnaire. Patient records were accessed.

Results: The mean age of the children was 12.92 ± 2.96 years. The children and the caregivers performed poorly in the applied maths section, and had lower "functional" grades (grades achieved on testing) compared to their actual grades. An inverse relationship was also found between the HbA_{1c} levels and numeracy scores.

Conclusion: Educational programmes need to accommodate patients and caregivers with lower numeracy skills, and should incorporate numeracy training as a core component of diabetes education.

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Introduction

The onset of diabetes heralds a drastic and permanent change in the lifestyle of the affected child, and of the entire family unit. The Diabetes Control and Complications Trial (DCCT), a landmark multi-centre randomised clinical trial, proved that intensive management of diabetes using multiple daily injections can reduce the devastating long-term complications associated with this disease.[1]

The long-term complications of neuropathy, retinopathy, nephropathy and cardiovascular decompensation are commonly highlighted in clinical and academic settings. However, cognitive impairment is a serious, yet less recognised, complication that is not adequately addressed, especially in children, in whom the impact is greatest. Although considerable research has been carried out on the impact that diabetes and neuro-cognition have on each other, the findings are of a contradictory and inconsistent nature.

Diabetes and neurocognitive function

Studies in this field have shown that, compared to their age-matched peers, children with type 1 diabetes perform poorly on intelligence scores, processing speed of timed tasks, executive function, self-monitoring, long-term memory and attention skills.[1-4] These deficits can be recognised from as early as two years following diagnosis, and are progressive.[2] Early onset of disease, before the age of four to five years, was found to be the strongest risk factor for such sequelae, with learning and memory abilities (both visual and verbal) being most affected.[2,3,5] However, similar deficits have been found in patients who have been diagnosed in adolescence and adulthood, and some studies have shown that the duration of disease does not correlate with cognitive function scores.[2,6-9]

Other studies have examined the association between cognitive function and metabolic control, using the glycosylated haemoglobin (HbA_{1c}) level.[1,4,7] The DCCT encompassed an 18-year follow-up, and showed that patients with HbA_{1c} levels of less than 7.4% (considered good control) performed significantly better on tasks relating to motor speed and psychomotor efficiency.[1] Those with levels greater than 8.8% demonstrated slower cognitive functions, increased mental subtraction errors, and loss of inhibition and focus. There were also deficits in attention, processing speed and working memory. McCarthy et al found a similar association.[7]

This disease has a psychological impact too, and it has been shown that children with type 1 diabetes exhibit greater rates of school absenteeism and behavioural and mood disorders, ranging from social withdrawal to overt aggression.[10] This may be due to metabolic instability, fluctuating blood glucose levels, and emotional stressors playing a pivotal, but not exclusive, role. All of these factors impact significantly on the child's overall educational experience, and also affect the child's diabetes management.

To evaluate the degree of cognitive impairment, neurocognitive and neuropsychological tests have been used as the gold standard. Many of these tests are well validated, but some do not have adequately reliable data, and almost all have a high rate of intra-subject variability.[4] Another limitation is that, in order to administer these tests, it is presumed that the participants have some degree of literacy and numeracy.

Literacy and numeracy

Literacy, by definition, is "the ability to read and write", while numeracy is "the ability to understand and use numbers in daily life".[11] This is particularly pertinent in the life of the diabetic child and his or her family, as they utilise these skills daily. This may include calorie or carbohydrate counting, insulin dose calculations and corrections, number sequencing, pattern recognition, rounding, estimating, fractions, addition, subtraction, multiplication and division. These vital skills assist in the patient's understanding of the disease, and also impact on his or her ability to manage the disease.

Recent studies have shown that poor health literacy is common in patients with chronic diseases, such as diabetes, and in those with impoverished circumstances.[7,11] This may lead to poorer health outcomes. The inability to communicate effectively with the healthcare team, and vice versa, may result in delayed recognition of, or failure to, recognise dangerous blood glucose patterns. It can also lead to poorer judgement in emergency situations and in making daily decisions regarding treatment dosages and adjustments. Appropriate self-management of diabetes involves complex daily behaviours, and the ability to recognise blood glucose patterns and trends. Inadequate diabetes-related numeracy skills have also been found to be significantly associated with poorer glycaemic control in adult populations.[11,12]

Diabetes numeracy testing

A diabetes numeracy test (DNT) has been formulated and validated to assess numerical skills, such as addition, subtraction, multiplication, multi-step mathematics, time, counting and number hierarchy, in adult diabetics across five domains.[13] These include nutrition, exercise, blood glucose monitoring, oral medications and insulin. Huizinga et al identified several potential problem areas, including food label interpretation, carbohydrate calculations, understanding when to refill medications, effecting insulin measurement and insulin adjustment based on blood glucose and carbohydrate intake, and applying medication titration instructions.[13]

To date, no such test has been devised for diabetic children, and neither have similar studies been carried out in children. It was for these reasons that we undertook this study to assess the numeracy skills in our diverse population of paediatric diabetics and their caregivers. Caregivers form an integral part of the diabetes team, and are at the helm of day-to-day management of this disease, especially in younger patients.

Aims

The goals of this study were to determine the level of mathematical skills in those type 1 diabetic children and their primary caregivers attending the paediatric out-patient diabetic clinics at the Chris Hani Baragwanath Academic Hospital (CHBAH) and Charlotte Maxeke Johannesburg Academic Hospital (CMJAH). The aim was to ascertain if there were deficits in the maths literacy skills of our participants (relative to their highest grade achieved), and to establish if there was an association between the level of mathematical skill and degree of metabolic control in our participants (using the average HbA_{1c} value taken over the preceding year).

Method

Participants

A cross-sectional descriptive study was conducted in a group of 53 children with type 1 diabetes, and 37 primary caregivers, attending the paediatric out-patient diabetic clinics at CHBAH and CMJAH from March to September 2009. Inclusion criteria were children with type 1 diabetes diagnosed at least six months prior to being tested, and primary caregivers involved in their day-to-day management. Exclusion criteria included any child with a pre-existing neurological disorder or learning deficit. Blood glucose levels were tested at the time of the interview.

Measures

A face-to-face structured interview and written questionnaire, referred to as the diabetes mathematical questionnaire (DMQ) were used to obtain the data. The questionnaire took approximately 30 minutes to complete. The Tirisano Revised South African National Curriculum Statement (RNCS) for mathematics was used to formulate the mathematical questionnaire, and maths teachers in both private and public sector schools were consulted.

The questionnaire was used to assess the basic level of mathematical skills in each individual tested, and the application of these skills in diabetes management. This took the form of problem-solving exercises, and assisted in determining if these numeracy skills were appropriate for the current grade, or the highest level of education, achieved by each participant.

The questionnaire was subdivided into two sections:

- Section 1 tested basic mathematical skills, such as addition, subtraction, multiplication, division, estimation, matching and sequencing. The questions and their sub-domains were arranged according to grade-appropriate tasks. Grades 1 through 6 were tested.
- Section 2 tested applied mathematical skills, consisting of grade-appropriate numerical tasks designed around diabetes-related scenarios that assessed the application of these basic mathematical skills in day-to-day diabetes management.

Scoring of both sections was as follows:

- A maximum score of 2 was given if no assistance was required in completing the task, and the answer was correct.
- A score of 1 was given if assistance was required to achieve the correct answer.
- A score of 0 was given if the participant was unable to complete the task, despite receiving assistance.
- In both Section 1 (basic mathematical skills) and Section 2 (applied mathematical skills), a percentage score of 50%, or greater, was set as the minimum competency level for that grade. The difference between the actual grades (current school grade or highest grade achieved) vs. grades achieved on testing ("functional" grade) was also analysed. The tested sections were also stratified according to each core competency skill, such as addition, multiplication, division, subtraction, estimation, sequencing, averaging, data interpretation, fractions and time concepts.

Other pertinent data within the questionnaire included:

- Demographic data (such as age, sex and base hospital)
- Current level of education or highest level or grade achieved
- Diabetes duration
- Average HbA_{1c} level (over the last year)
- Meal plan (specifically enquiring if the patient used carbohydrate counting)
- Insulin regimen
- Presence of existing diabetic complications.

This study was approved by the Human Research and Ethics committee at the University of the Witwatersrand.

Data analysis

Data were captured using Microsoft Excel 2007, and SAS statistical software. Version 9.1 was used to analyse the data. The Student's paired t-test was used to compare the means of variables, such as the percentage scores between basic mathematical skills (Section 1), and applied mathematical skills (Section 2), and actual vs. functional grade levels. Pearson correlation coefficients were calculated to ascertain the relationship between the test scores in each section, and to assess the relationship between the test scores and the participant's metabolic control (HbA_{1c} level). A p-value of < 0.05 was considered to be statistically significant.

Results

The study group comprised 53 children with type 1 diabetes: 32 females (60.38%) and 21 males (39.62%); and 37 primary caregivers: six males (16.22%) and 31 females (83.78%). The reason why there were more children than caregivers was that the samples were not matched, and that children over the age of 18 years were able to give their own consent.

The mean age of the children was 12.92 ± 2.96 years (range 8-19 years) and the mean age of the caregivers was 35.78 ± 6.78 (range 19-47 years). The group comprised children and adults from different racial and ethnic backgrounds, with variable socio-economic status. The majority of patients interviewed were black (81.14% in the children's group, and 81.08% in the caregiver group), with smaller percentages of white and Indian participants.

The majority of caregivers were interviewed at CHBAH (67.57%), and the number of children at each hospital was almost equal (49.06% at CMJAH, and 50.94% at CHBAH). The mean HbA_{1c} level for the diabetic children was 12.84 ± 3.04% (range 7.1-17.5%). A total of five participants were excluded from the study, as three refused to provide consent because of time constraints, and two were too young and were not yet attending school.

The demographic and clinical data of the participants are shown in Table I.

Table I: Demographic and clinical data of the participants

	Children	Caregivers
Total number of participants n (%)	53 (58.89)	37 (41.11)
Female n (%)	32 (60.38)	31 (83.78)
Male n (%)	21 (39.62)	6 (16.22)
Age in years (range)	12.92 ± 2.96 (8-19 years)	35.78 ± 6.78 (19-47 years)
HbA_{1c} level (range)	12.84 ± 3.04 (7.1-17.5)	Not applicable
Mean duration of diabetes (range)	4.73 years (six months to 13 years)	Not applicable
Mean grades (range)	6.89 (3-12)	10.89 (5-12)
Race n (%)		
Black	43 (81.14)	30 (81.08)
White	5 (9.43)	4 (10.81)
Indian	5 (9.43)	3 (8.11)
Base hospital n (%)		
CMJAH	26 (49.06)	12 (32.43)
CHBAH	27 (50.94)	25 (67.57)

Most children were in the age group of 12-15 years (43.40%), and most of the adults fell between the ages of 26-40 years (70.27%), with only six (16.22%) participants having completed some form of tertiary education (Tables II and III). The mean glucose level at the time of testing was 11.9 mmol/l (range 6.5-20.3 mmol/l). A difference was found between race and percentage scores for Section 2 (in the children's group only), with white children performing better (p-value = 0.002, r = 0.41). This could be attributed to previous deficiencies in the schooling system. It suggests that participants from previously disadvantaged backgrounds performed less well than those from relatively more affluent backgrounds. However, this will need to be assessed formally in future studies.

Table II: Stratification of participants' ages

Children		Caregivers	
Age groups (years)	n (%)	Age groups (years)	n (%)
	18 (33.96)	19-25	3 (8.11)
12-15	23 (43.40)	26-40	26 (70.27)
16-19	12 (22.64)	> 40	8 (21.62)

Table III: Number of completed years of schooling (caregiver group)

Number of completed school years	Number (%)
< 7 years	4 (10.81)
7-11 years	10 (27.02)
12 years	17 (45.95)
> 12 years	6 (16.22)

Mathematical variables

Comparison of the mean percentage scores for Section 1 and Section 2

The children's mean percentage scores for the basic mathematical skills (Section 1) and the applied mathematical skills (Section 2) were 69.3% (SD ± 18.62) and 56.63% (SD ± 27.82) respectively, and the mean percentage scores of the caregivers for the same sections were 73,30% (SD ± 15.92) and 60.71% (SD ± 23.61) respectively.

The analyses revealed that there were significant differences in the mean percentage scores for the basic skills and the applied skills in both the children (p-value < 0.001, t = 5.57) and caregivers (p-value < 0.0001, t = 5.21). Participants scored poorly in the applied mathematical questions (Figure 1). They performed better when their basic maths skills were tested, but were unable to apply these skills to diabetes-related scenarios.

Good correlation was found between the percentage scores for basic mathematical skills (Section 1) and applied mathematical skills (Section 2) respectively, implying that the questions in the applied skills section were at the same level as the questions in the basic skills section. This was found in both the children (p-value < 0.0001, r = 0.82) and caregiver (p-value < 0.0001, r = 0.81) groups (Figures 2 and 3).

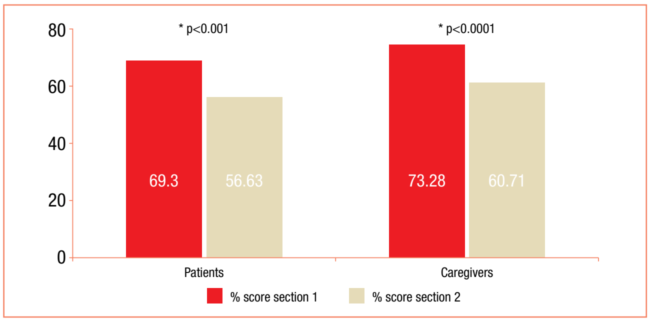

Figure 1: Comparison between the mean percentage scores for basic mathematical skills (Section 1) and applied mathematical skills (Section 2) for both children and caregivers

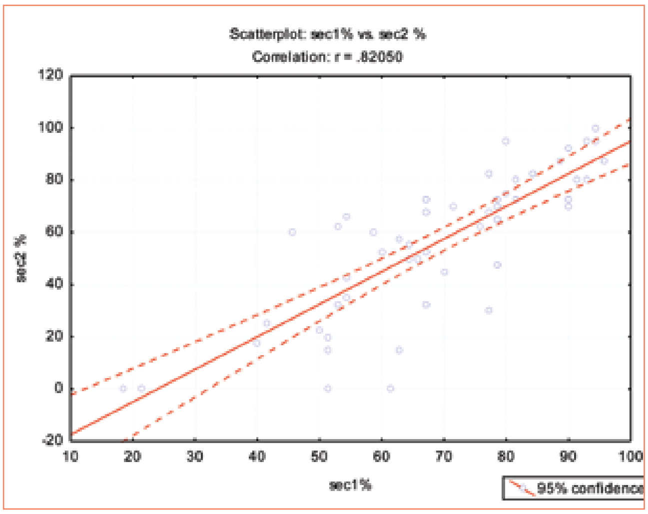

Figure 2: Scatterplot showing the correlation between scores for Section 1 and Section 2 (children's group)

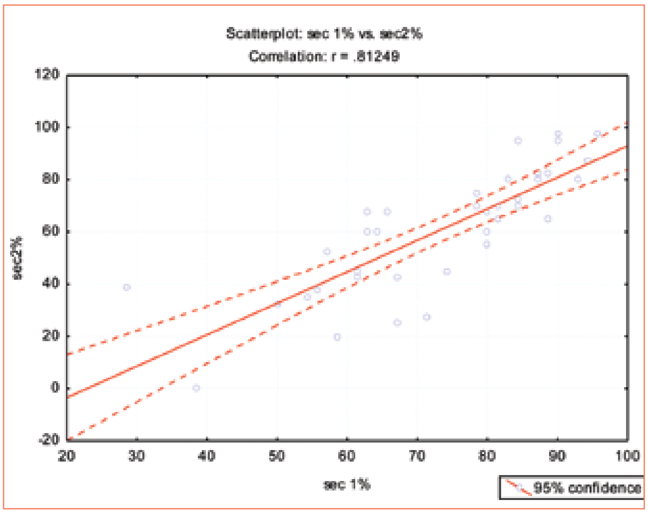

Figure 3: Scatterplot showing the correlation between scores for Section 1 and Section 2 (caregiver group)

Comparison of the means of the actual and functional grades

A significant correlation was also found between the means of the actual and functional grades of the children (p-value = 0.014, r = 0.345), with the means of the functional grades being less than their actual grades. A similar, but weaker correlation, was found in the caregiver group (Figure 4).

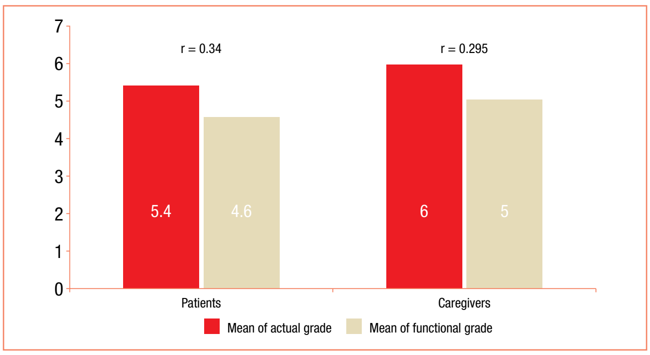

Figure 4: Comparison of the means of actual vs. functional grade levels

A positive correlation was found between actual grade and percentage scores for both basic mathematical skills (Section 1), r = 0.26 and r = 0.38, and applied mathematical skills (Section 2), r = 0.37 and r = 0.46, for the children and caregivers respectively. An even stronger correlation was found between the percentage scores for both sections and the functional grade (p-value < 0.0001, r = 0.50, and p-value < 0.0001, r = 0.86, for Section 1; p-value < 0.001, r = 0.50, and r = 0.73 for Section 2, in the children and caregivers respectively), implying that the functional grade was a better indicator of the participants' actual mathematical skills. When comparing actual to functional grades, a significant correlation was found in the children's group only (p-value = 0.001, r = 0.45), not in the caregiver group (p-value = 0.777, r = 0.48).

Actual maths deficits

Table IV highlights the actual deficits in maths skills. Both the patients and caregivers performed equally poorly in the tasks of rounding off digits, the use of formulae, and data interpretation. The numbers in bold print signify those sections with a pass rate of less than, or equal to, 50%.

Table IV: Actual mathematical skills deficits in patients and caregivers

Questions	Patients (% passed)	Caregivers (% passed)
Division	66.1	78.4
Addition	56.7	51.4
Fractions	86.9	93.3
Multiplication	58.5	66.2
Rounding	**50**	**44.6**
Time	71.7	75
Sequencing	71.7	82.4
Grouping data	60.4	64.9
Formulae	**43.4**	**18.9**
Tables/data	**39.4**	**32.1**
Averages	69.8	56.8

Medical variables

Relationship between metabolic control (HbA_{1c} level) and actual test scores

A negative correlation (p-value = 0.029, r = -0.32) was found between HbA_{1c} levels and the scores for the applied mathematical skills of the children (Figure 5), implying that those who scored poorly in this section had higher HbA_{1c} levels, indicative of poorer metabolic control. In spite of this study not being powered specifically to define this correlation, the finding of a weak correlation suggests that further studies, with more patients, are needed in order to better define this relationship.

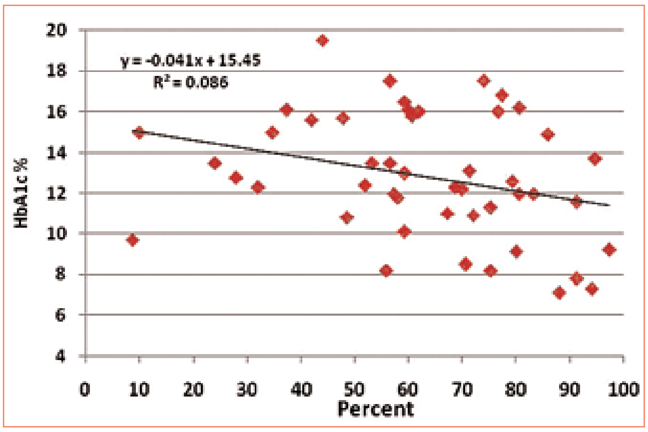

Figure 5: Scatterplot delineating the relationship between HbA_{1c} levels and scores for applied mathematical skills (Section 2) for the children

Discussion

Diabetes is a chronic disease that leads to long-term complications, including neurocognitive impairment. Much has been hypothesised about the aetiological and pathophysiological mechanisms behind this. Hypoglycaemia and hyperglycaemia are the two most important factors.

Some researchers have suggested that early-onset disease is a surrogate for the impact of hypoglycaemia on the developing brain, claiming that younger children are at greater risk of developing serious hypoglycaemia-related events, such as seizures.[1,2] In part, this is due to their unpredictable eating and activity patterns, and their inability to communicate and recognise hypoglycaemic symptoms. It has also been shown that the hippocampus is the area that is most vulnerable to the effects of prolonged severe hypoglycaemia.[2,4,14]

Repeated and prolonged episodes of hypoglycaemia have been implicated as the main cause of significant cognitive impairment, both in the acute and chronic phases. Acute episodes have been shown to impact negatively on immediate memory (visual and verbal), as well as delayed and working memory. Visual-motor integration and spatial skills, including global cognitive function, are also impaired.[4,9,15] In the long term, severe hypoglycaemic events cause impaired verbal and full-scale intelligence quotient scores, with deficits in attention, psychomotor efficiency, vigilance, memory and language skills.

However, in recent years it has been argued that hypoglycaemia is not the only "villain", and that its effects on overall cognition are not as detrimental as previously thought.[3] Chronic hyperglycaemia may well have been the major culprit all along, and increasing evidence has come to the fore supporting this. Chronic hyperglycaemia has been shown to disrupt myelin formation and neurotransmitter regulation in the developing brain, as well as cause damage on a microvascular level, causing end-organ damage.[4,14] This manifests as cognitive dysfunction (mainly slowed responses), and diminished memory and learning capacity.

More recent studies have also shown that severely fluctuating blood glucose levels have a significant impact on the developing brain, and have been proven to be even more neurotoxic than sustained hyperglyacaemia.[4,16]

Understanding the reasons behind poor control is pivotal in improving diabetes management. In most instances, it is assumed that patients and caregivers understand everything about a comprehensive diabetes educational programme, although this may not always hold true.

As mentioned, numeracy is "the ability to understand and use numbers in daily life".[11,12] On a daily basis, diabetic patients need to complete a range of numeracy-related tasks.

For example, basic mathematical skills, such as addition, subtraction, fractions, multiplication, division, sequencing and averaging, are needed for:

- Counting calories
- Adjusting insulin doses
- Determining food portions and food exchanges
- Understanding blood glucose measurements, and the concepts of "hyperglycaemia" (blood glucose levels > 7 mmol/l) and "hypoglycaemia" (blood glucose levels < 3 mmol/l)
- Blood glucose pattern recognition and problem solving.

The concept of time is also essential, as it has an impact on when blood glucose monitoring is performed and when insulin is administered, especially in relation to meal times. The interpretation of data, in the form of tables and graphs, and the application of quantitative information assist patients in understanding nutritional labels and applying this information when planning their own meals.

Number hierarchy allows diabetic patients to understand trends in their blood glucose readings, and the application of formulae is needed when determining insulin sensitivity and correction doses. Diabetic patients also need to understand the concept of averages, as this facilitates their understanding of the relevance of HbA_{1c} levels, and their role as a marker of glycaemic control.

If these basic maths skills are not mastered at an early age, this will have a negative impact on diabetes management, and it may be the reason behind patients developing poor metabolic control and complications. This creates a vicious cycle, in which poor numeracy leads to higher blood sugar, which in turn impairs judgement, memory and concentration, leading to errors in diabetes care, with resultant maintenance or exacerbation of hyperglycaemia and extreme glycaemic variability.[3,4,14]

Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services, needed to make appropriate health decisions. This includes a constellation of skills, such as the ability to perform basic reading and numerical tasks required to function in the healthcare environment". Poor health literacy is the inability to achieve this. It has been proven that poor health literacy is common among adult patients with diabetes, and that such patients have greater difficulty understanding their disease, and have worse glycaemic control and clinical outcomes.[11] However, few studies have confirmed these findings in the paediatric diabetic population.

In our study, it was found that both the patients and the caregivers fared more poorly in basic mathematical tasks (Section 1) than would have been expected for their grade level at school, suggesting a deficit in basic maths education. Both groups performed even more poorly when asked to apply their basic maths skills to diabetes-related scenarios (Section 2). The finding of a positive correlation between the percentage scores for Section 1 and Section 2 in both groups implies that the questions in the applied skills section were at the same level as the questions in the basic skills section.

Specifically, both groups did poorly in those tasks related to estimation, the interpretation of data from tables, and the application of formulae, skills that are needed on a daily basis in order to manage diabetes effectively.

There was also a significant correlation between the actual grades (school grades) of the children, their "functional" grades (the grade equivalent obtained on testing), and the percentage scores in both sections. Lower functional scores indicated that they performed below their expected grade level when tested. A similar correlation was found in the caregiver group, but specifically in the applied maths section. This finding could also imply that overall maths skills were poor in both groups. The "functional" grade was also a more reliable indicator of the participants' actual maths skill level.

In spite of this study not being powered specifically to define this relationship, the negative correlation found between HbA_{1c} levels and the applied mathematical scores suggests that poor numeracy skills have a negative impact on diabetes care, and that further studies, with more patients, are needed in order to better define this relationship.

As mentioned, many external factors may also contribute to poor numeracy skills in patients, such as disadvantaged socio-economic circumstances, poor schooling or educational history, family dynamics, food security issues, cultural beliefs, and emotional stressors. These additional contributors need to be addressed too, so as to minimise their negative impact on diabetes management.

Conclusion

There have been significant gains in the understanding of diabetes, its management and complications, and specifically its effects on cognitive function. Diabetes impacts on cognition, while adequate management of diabetes mellitus is dependent on the patient's understanding and utilisation of basic literacy and numeracy skills. It has been proven that lack of these skills has a negative impact on diabetes management and metabolic control.[17,18]

Educational programmes need to be developed to accommodate patients and caregivers with inadequate numeracy skills. Such programmes need to incorporate numeracy training as a core component of diabetes education, and need to be tailored to each person's individual needs. Schools need to be involved as well, so as to target the problem at grass-roots level. This will address the need for diabetes education, and also ensure that the required basic literacy and numeracy skills are attained by learners at all levels.

By devising such programmes, we hope that patients will become empowered to manage their diabetes more effectively, and that long-term complications will also be avoided. However, future research is needed to determine the exact impact of such numeracy-focused interventions, specifically on diabetes outcome and metabolic control. A second study is currently in progress at our centre, assessing the effect of a numeracy-based intervention on diabetes management and glycaemic control.

Limitations

The following limitations in our study need to be acknowledged:

- The study questionnaire was not piloted or tested on normal children, as the RNCS for mathematics was taken as the "gold standard", and questions were based on their grade-specific learning outcomes. As a result, there was no control group.
- Even though all of the children underwent blood glucose testing (haemostix) prior to attempting the questionnaire, no adjustment was made for the confounding variable of patients' blood glucose levels at the time of testing

(specifically the degree of hyperglycaemia). However, none of the patients were hypoglycaemic at the time of testing.

- The test was designed to measure participants' existing numeracy skills (as related to diabetes), but may reflect differences in diabetes knowledge or prior diabetes education, and differences in provider management and communication.
- Questions were formulated up to Grade 6 level, as the minimum required numeric competency skills needed for diabetes management are incorporated in the learning outcomes of this level. Making the questionnaire more comprehensive, and including individual questions for subsequent grades, would have lengthened the questionnaire.
- Each section of questions should have been equally weighted with respect to the number of questions, so as to facilitate more equal distribution of questions that would impact on the final grading and score.
- The language in which the tests were conducted was not always in the child's or caregiver's vernacular, but assistance was available, and language issues were taken into consideration. If translation was required, the participants were not penalised. Everyday, real-world scenarios were used during testing.

Declaration

We, the authors, declare that the submitted work is an original paper. There are no third-party sources.

We are the original authors, and ethics approval has been obtained from the Human Research and Ethics Committee at the University of the Witwatersrand (Ethics approval no: M090315).

There are no conflicts of interest to declare.

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