CHAPTER 1: INTRODUCTION

1.1 Background

Diabetes Mellitus is a syndrome of disordered metabolism that manifests with elevated blood glucose levels. The onset of diabetes heralds a drastic and permanent change in the lifestyle of the affected child, as well as the entire family unit. Type 1 diabetes is a complex disease requiring insulin administration in conjunction with a structured meal plan that should take into consideration social, economic, cultural and logistical factors, so as to achieve optimal disease control (1).

1.2 Classification of diabetes

Diabetes mellitus is either due to an absolute deficiency of insulin or diminished biological effectiveness of insulin, or both. Diabetes is usually classified into type 1 and type 2, previously termed ‘insulin dependent’ and ‘non-insulin dependent’ diabetes respectively (1,2).

Type 1 diabetes occurs as a result of destruction of the pancreatic islet cells (specifically the β cells). This is due to an autoimmune process in more than 95% of cases, with less than 5% being due to idiopathic causes (1,2). These patients are prone to developing keto-acidosis and require insulin replacement therapy. Type 1 diabetes occurs at any age but commonly arises in children and young adults, with a peak incidence before school age and again at puberty (a bimodal pattern) (1,2).

Type 2 diabetes is a heterogeneous disorder encompassing a spectrum of defects, but is most commonly associated with insulin resistance in the presence of impaired compensatory insulin secretion. It is more prevalent in the adult population, but with the increasing incidence of obesity, type 2 diabetes is now prevalent in the paediatric population as well (1,2).

1.3 Complications of diabetes

The Diabetes Control and Complications Trial (DCCT), a landmark multi-centre, randomized clinical trial (3), proved that intensive management using multiple daily injections can reduce the devastating long term complications of diabetes by reducing blood glucose fluctuations and targeting average blood glucose values as close to normal as possible. This requires a considerable degree of discipline and even though the daily management of type 1 diabetes may be burdensome, with the spectre of metabolic decompensation ever present, the short term goals are to ensure normal growth and development, while minimizing complications such as hypoglycaemia and hyperglycaemia.

The long term complications of neuropathy, retinopathy, nephropathy and cardiovascular decompensation (in type 2 diabetes), are commonly highlighted in clinical and academic settings, however cognitive impairment is a serious yet less recognized complication of diabetes that is not sufficiently addressed, especially in children, in whom the impact is greatest (4,6). Although much research has been done looking at the impact that diabetes and neuro-cognitive function has on each other, the findings are of a contradictory and inconsistent nature.

1.4 Cognitive dysfunction in diabetes

Studies in the field of diabetes-related cognitive dysfunction have shown that children with type 1 diabetes, compared to age-matched peers, performed poorly on intelligence scores, processing speed of timed tasks, executive function, self monitoring, long term memory and attention skills (3-6). These deficits have been recognized as early as 2 years after diagnosis and are progressive (4). Early onset of disease (before the age of 4 to 5 years) was found to be the strongest risk factor for such neuro-cognitive sequelae (4,5,7), with learning and memory abilities (both visual and verbal) being the most affected. However, some studies have shown that duration of disease does not correlate with cognitive function scores and patients who develop diabetes after the age of 5 years, have detrimental deficits in cognition as well (4,8-11).

Other studies have looked at the association between cognitive function and metabolic control, as measured by the HbA1c level (3,5,9). HbA1c is the fraction of haemoglobin that is glycosylated. It is abnormally elevated in diabetic patients with chronic hyperglycaemia and is used as a marker to assess the diabetic patient's metabolic control over the preceding 3-4 months. A target level of HbA1c for good control is less than 7.2% (12).

The DCCT (3), which encompassed an 18 year follow-up, also showed that patients with an HbA1c level of less than 7.4% performed significantly better on tasks of motor speed and psychomotor efficiency than those with levels greater than 8.8%, who showed slowing of all cognitive functions, increased mental subtraction errors, loss of inhibition and focus as well as deficits pertaining to attention, processing speed and working memory.

McCarthy et al, also verified an association between metabolic control and academic performance in children with type1 diabetes (9).

Besides the psychological impact that this disease has, it has been shown that children with type 1 diabetes exhibit greater rates of school absenteeism, as well as behavioural and mood disorders, ranging from social withdrawal to overt aggression (13). This may be due to metabolic instability, with fluctuating blood glucose levels and emotional stressors playing a pivotal but not exclusive role. All of these factors impact significantly on the child's education as well.

In order to evaluate the degree of cognitive impairment, neuro-cognitive and neuropsychological tests have been used as the gold standard. Although many of these tests are well validated, some do not have adequate reliability data and almost all have a high rate of intra-subject variability (6). Another limitation is that in order to administer these tests, it is presumed that the participant has some degree of literary and numeracy skills.

1.5 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' (14). Nowhere, is this more pertinent than in the life of the diabetic child and his family, who utilize these skills daily. Those may include calorie or carbohydrate counting, insulin dose calculations and corrections, number sequencing, pattern recognition, rounding, estimating, fractions, addition, subtraction, multiplication and division. Not only do these vital skills assist in the patient's

understanding of the disease, but also impact on their disease management and health outcomes.

Health literacy is ‘a reflection of the complex interface between a patient’s ability and the literacy pre-requisites of participating in one’s health and interacting with the health care system’ (14). Low health literacy is common among patients with diabetes. A growing body of evidence supports the association between limited health literacy and numeracy and poorer diabetes outcomes (14,15).

It has been proven that patients with diabetes and limited health literacy or numeracy are more likely to have poorer disease knowledge and symptom recognition, poorer glycaemic control, greater difficulty interpreting food labels and estimating portion sizes, lower self-confidence in diabetes management (self-efficacy), fewer self management behaviours and poorer communication with health care providers (16).

In fact, analyses comparing the influence of low literacy and numeracy together on glycaemic control suggest that numeracy is more closely related to glycaemic control than literacy (14-16). In the field of diabetes, numeracy skills can be assessed by evaluating the level of basic quantitative skills, referred to as “general numeracy” or by evaluating applied quantitative skills within the context of diabetes care, referred to as “diabetes-related numeracy” or both (16).

1.6 Assessment Tools

A Diabetes Numeracy Test (DNT) has been formulated to assess numerical skills in adult diabetics. The DNT is an assessment test designed by Vanderbilt University to investigate the numeracy skills in adult patients with diabetes (14,17). Question development was guided by reviewing validated math and literacy tests. It can be administered as an oral or written exam by health care practitioners in the clinical setting. It consists of 43 questions in 5 domains that include nutrition, exercise, blood glucose monitoring, oral medications and insulin. In addition, the scale consists of 8 math problem domains that include addition, subtraction, multiplication, multi-step mathematics, time, counting and number hierarchy (17).

It was found that patients with higher diabetes- related numeracy, as measured by the DNT, had significantly greater diabetes knowledge and better self- efficacy related to diabetes management. A modest association between higher diabetes- specific numeracy and better glycaemic control (lower HbA1c values) was also observed (16). The DNT 15 is a validated shorter version of the DNT that includes 15 items from the original scale and has better practical utility (16,17).

In addition to the DNT, the Diabetes Literacy and Numeracy Education Toolkit (DLNET) was developed to meet the need for diabetes education and management materials for all diabetic patients, but especially for those with low literacy or numeracy. The DLNET consists of 24 distinct modules. Core modules cover basic information about prevention of diabetes- related complications, hypoglycaemia awareness and management, blood glucose monitoring, exercise, foot care and nutrition (16).

However, both the DNT and DLNET were specifically devised for adult diabetics and no such tests have yet been devised for diabetic children. Tests that have been used in previous studies to assess literacy in children include the Rapid Estimate of Adult Literacy in Medicine (REALM), a validated measure of reading ability that correlates with reading comprehension (14). General numeracy has been previously tested using the math section of the Wide Range Achievement Test, 3rd Edition (WRAT- 3), a validated instrument that evaluates calculation skills whereas, diabetes- related numeracy has been evaluated using a modified version of the DNT (14, 16).

1.7 Caregiver Literacy

Even though most children with diabetes are actively involved in their diabetes management, with respect to monitoring glucose levels, carbohydrate counting, minor dose corrections, it is in actual fact the caregivers that are involved in day to day critical decision making such as diet and portion monitoring and modification, major dose adjustments and sick-day management. Studies have shown that literacy and numeracy skills of caregivers, significantly influences the glycaemic control of children with type 1 diabetes (18). Thus, assessing these skills adequately in patients and caregivers and addressing deficiencies may be crucial in optimizing glycaemic control and diabetes outcomes.

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, as not only do caregivers form an integral part of the diabetes team, but they are responsible for the day to day management of this disease, especially in our younger patients. We formulated our own

questionnaire, specifically designed for children (but can be used by adults as well), based on the South African national mathematics curriculum (19).

1.8 South African Mathematics Curriculum

The aim of the Tirasano Revised National Curriculum Statement (RNCS) is to "develop the full potential of each learner as a citizen of a democratic South Africa. It seeks to create a lifelong learner who is confident and independent, literate, numerate and multi- skilled, compassionate, with a respect for the environment and the ability to participate in society as a critical and active citizen" (19).

It was revised by the Department of Education in 2005, in order to take into consideration the educational deficiencies of the past and to create a new, coherent and comprehensive curriculum that seeks to embody the principles of social justice, equity and democracy. With respect to mathematics, the new curriculum urges teachers to teach this subject in ways that are meaningful to learners and links with their everyday realities (20).

Each subject within the school curriculum, has certain 'learning outcomes' that are defined and each of these outcomes has to meet specific 'assessment standards'. An example pertaining to mathematics is as follows:
Learning outcomes include the actual numerical skills, such as counting, estimation, graphic interpretation and problem solving. Assessment standards provide details of what learners should be able to complete in each grade. Each learning programme is directed at a different level of learners, starting at the foundation phase and progressing to the intermediate and senior phases (19).

These learning outcomes and guidelines were applied to the formulation of our questionnaire, with questions being arranged according to each grade level (in the basic math section) and according to the actual numeracy skill tested (in the numeracy section), (Appendix B and C).

1.9 Hypothesis

Children with type 1 diabetes encounter difficulties with basic mathematics and numeracy, thus our population of type 1 diabetic children would perform poorly on formal math and numeracy testing and those with low numeracy would have poorer diabetes control (as measured by the HbA1c level).

1.10 Objectives of the study

1. To assess the level of numeracy skills (basic math and diabetes- related) in type 1 diabetic children and their primary caregivers, attending the paediatric out-patient diabetic clinics at the Chris Hani Baragwanath Academic and Charlotte- Maxeke Johannesburg Academic Hospitals and to ascertain if there were any deficits in these skills (relative to participants' highest grade achieved).

2. To establish if there was an association between the level of numeracy skills and the degree of metabolic control achieved in our participants (using the average HbA1c value, taken over the preceding year).

CHAPTER 2: MATERIALS AND METHODS

2.1 Study design and sample

A cross-sectional descriptive study was conducted in a group of 53 children with type1 diabetes and 37 primary caregivers, attending the paediatric out-patient diabetic clinics at the Chris Hani Baragwanath Academic and Charlotte- Maxeke Johannesburg Academic Hospitals, from March 2009 to September 2009. Both hospitals are large teaching facilities attached to the University of the Witwatersrand, providing primary, secondary, tertiary and quaternary care to the people of Gauteng, as well as patients referred from other provinces and neighbouring African countries. Both centers deliver similar standards of care and were included so as to generate adequate numbers for our study population.

The study group comprised 32 females (60.38%) and 21 males (39.62) and 37 primary caregivers, comprising 6 males (16.22%) and 31 females (83.78). The reason as to why there were more children than caregivers was that some children were 18 years and over and were able to consent on their own.

2.2 Inclusion criteria

1) Children with type1 diabetes diagnosed at least 6 months prior to being tested.

This was used as a cut-off period to allow for caregivers and participants to have completed diabetes education and to become familiar with diabetes related tasks. It has

also been proven that adequate medical and nutritional therapy (MNT) of diabetes can be effectively achieved within 6 weeks to 3 months, from the time of diagnosis (12,21).

Participants were considered to have 'type 1 diabetes' if they presented with symptoms of diabetes (such as polyuria, polydypsia and loss of weight) and had random plasma glucose concentrations of greater than or equal to 11.1 mmol/litre (1,2).

2) Children attending school or college/ university (if they have completed school), who attend the stipulated diabetic clinics. Candidates were below the age of 20 years (range of between 9-19 years).

3) The availability of primary caregivers involved in the day to day management of diabetes, mainly for those children under the age of 18 years. Those children that were equal to or over the age of 18 years, attended the clinics on their own.

'Primary caregivers' refer to those family members or guardians who are responsible for the majority of the day to day care of the participants.

2.3 Exclusion criteria

1) Children with pre-existing neurological diseaseas, such as epilepsy or cerebral palsy or a known learning disorder such as attention deficit hyperactivity disorder (ADHD).

2) Candidates younger than 8 years were excluded as they required constant parental supervision and could not comprehend instructions independently.

2.4 Procedure

Consecutive children attending the stipulated clinics between March 2009 to September 2009, who fitted the inclusion criteria were considered for enrolment in the study, based on parental consent (if they were younger than 18 years of age). Children over and including the age of 18 years, usually attended the clinics on their own and were able to give consent. Upon arriving for their routine clinic visit, patients and caregivers were informed about the study and the nature of their potential involvement. Those who consented then received a questionnaire to complete, as well as health record release forms.

2.5 Methods

A supervised Diabetes Math Questionnaire (Appendix B) was completed by each participant and patient records were accessed to obtain clinical data (such as insulin regimens and HbA1c levels). In this study, the Tirisano Revised South African National Curriculum Statement (RNCS) for Mathematics was used to formulate the mathematical questionnaire and mathematics teachers in both the private and public sector schools, as well as teachers at the Charlotte- Maxeke Johannesburg Academic Hospital, were consulted. Thus, the questionnaire was based on current national standards.

The questionnaire took approximately 30 minutes to complete. Verbal assistance or explanations were rendered when needed. A language interpreter was also available and a calculator was provided for those questions that required it.

2.5.1 Questionnaire Data

Information included:

- Demographic data (such as age, sex and base hospital)
- Current level of education or highest level/grade achieved
- Duration of diabetes
- Average HbA1c level (over the last year)
- Meal plan (specifically enquiring if the patient used carbohydrate counting)
- Insulin regimen
- Presence of existing diabetic complications

The same questionnaire was used to assess the basic math skills of each individual tested and the application of these skills in diabetes management (referred to as 'numeracy'). This took the form of problem solving exercises and assisted in determining if these numerical skills were appropriate for the current grade or the highest level of education achieved by each participant.

The mathematical section of the questionnaire was subdivided into 2 sections:

Section 1 of the questionnaire tested basic math such as addition, subtraction, multiplication, division, estimation, matching and sequencing. The questions were

arranged according to grade appropriate tasks (for example, questions 1 to 5 was equivalent to grade 1, 6 to11, equivalent to grade 2 and so forth). Grades 1 through 6 were tested in both participants and caregivers. Table 1 delineates how the questions were stratified according to grade levels and the scores for each section. Table 2 subdivides each question further, according to the grade- appropriate mathematical skill assessed.

Table 1: Basic math section: stratification of questions.

GRADES (Sections)	1	2	3	4	5	6
QUESTIONS (equivalent to each grade)	1-5	6-11	12-17	18-24	25-31	32-35
SCORES (for each section)	10	12	12	14	14	8

Table 2: Basic math section: Stratification of questions and skills assessed.

Grade	**Questions**	**Numerical Skills Assessed**
Grade 1	1-5	Simple sequencing, word interpretation, basic shapes, 1-2 digit addition and grouping common objects.
Grade 2	6-11	Sequencing, basic fractions, 1-2 digit sums, time and grouping.
Grade 3	12-17	Sequencing, word sums, 2-3 digit sums, time conversion and general knowledge.
Grade 4	18-24	Rounding, descending order, graphical fractions, double digit sums, rearrangement of sums and 3D diagram construction.
Grade 5	25-31	Triple digit sums, sequencing, equivalent fractions, rounding, time, concepts (doubling, halving), decimal and calculator sums.
Grade 6	32-35	Percentages, interpretation of complex word sums, money conversion sums and rearrangement of sums.

Section 2 of the questionnaire tested numeracy, 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. Table 3 stratifies the section 2 questions according to grade levels.

Table 3: Numeracy Section: stratification of questions.

Minimum grade tested	**Question number**	**Numerical skill assessed**
Grade 3	1-2, 5-9,11-13,16-18	Addition, multiplication, division, rounding, time, mixed sums and number hierarchy.
Grade 4	3-4, 10,14,19	Graphical fractions, complex multiplication, time, data grouping and interpretation.
Grade 5	15, 20	Rounding, Averages, use of formulae and calculator.

2.5.2 Scoring of Questionnaire

The mathematical sections of the questionnaire were scored as follows (Appendix C):

-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 section 1 (basic math) a percentage score of 50% was set as the minimum competency level for each grade. Thus, if a candidate scored 50% or higher, the candidate was assessed as having passed that particular set of questions or grade. Section 1 had a total score of 70. Section 2 (numeracy) comprised 20 questions, each with a total value of 2 (scored as above). Thus the total score was 40, which was subsequently converted to a final score of 80.This facilitated the entire questionnaire to be scored out of 150 (Appendix C).

2.5.3 Definitions of actual grade and functional grade

The difference between the actual grade (current school grade or highest level of education achieved) versus grade achieved on testing (referred to as the 'functional' grade) in section 1 and section 2 were also analyzed. 'Functional grade' was the maximum grade attained by completing each section and achieving a score of greater than or equal to 50% in each section. The testing sections were also analyzed according to each core competency skill such as addition, multiplication, division, subtraction, estimation, sequencing, averaging, data interpretation, fractions and time concepts.

2.6 Data Analysis

Data were captured using Microsoft Excel 2007 spreadsheets and data was then imported into Statistica statistical software, version 7.0 (Stasoft, USA). Most results were descriptive, but standard statistical measures were used where appropriate (such as chi-square and t-tests).

The Student paired t-test was used to compare the means of variables such as the percentage scores between basic mathematical skills (section 1) and numeracy skills (section 2), and actual versus functional grade levels. Pearson correlation coefficient was calculated to ascertain the relationship between the test scores in each section and to assess the relationship between the test scores and the participants' metabolic control (using the HbA1c level). Non- parametric data (such as demographic data and base hospital) were assessed using the Mann-Whitney U Test. A p-value of <0.05 was considered to be statistically significant.

2.7 Ethics clearance

Ethics clearance was obtained from the Human Research and Ethics Committee of the University of the Witwatersrand; clearance number M 090315 (Appendix A).

2.8 Limitations of Study

The following limitations in our study need to be acknowledged:

1) The study questionnaire was not piloted or tested on normal children, as the Tirisano Revised South African National Curriculum Statement (RNCS) for Mathematics was taken as the "gold standard" and questions were based on national grade-specific learning outcomes. As a result, there was no control group.

2) Even though all of the children had blood glucose testing (haemostix) done 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.

3) The test was designed to measure participants' existing math and numeracy skills (as related to diabetes), but may reflect differences in diabetes knowledge or prior diabetes education and differences in provider management and communication.

4) Questions were formulated until grade 6 level, as the minimum required numeracy competency skills needed for diabetes management are incorporated in the learning outcomes of this level. By making the questionnaire more comprehensive and including subsequent individual grade questions, this would have lengthened the questionnaire.

5) Each section of questions should have been equally weighted with respect to number of questions, so as to facilitate more equal distribution of questions which would impact on the final grading and score.

6) Language of testing was not always in the child's or caregiver's vernacular, but assistance was available and language issues were taken into consideration and participants were not penalized if translation was required. Everyday real world scenarios were used during testing.

7) Even though attempts were made to delineate the actual person responsible for managing the diabetes (on history), it was not possible to delineate exact role- players as there is much overlap in the day to day management of diabetes.

CHAPTER 3: RESULTS

3.1 Data analysis

The mean age of the children was 12.92 ± 2.96 years (range 8-19 years) and the mean age for the caregivers was 35.78 ± 6.78 (range 19-47 years), demonstrating a wide range, as some patients were looked after by older siblings and others by grandparents (Table 4). The group comprised children and adults from different racial and ethnic backgrounds. 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 (Table 5).

The majority of caregivers were interviewed at the CHBAH (67.57%) and the number of children at each hospital was almost equal (49.06% at CMJAH and 50.94% at the CHBAH respectively). The mean HbA1c level for the diabetic children was 12.84% ± 3.04 (range 7.1-17.5%). A total of 5 participants were excluded from the study, 3 refused consent because of time constraints and 2 were too young and not attending school as yet.

Table 4: Stratification of caregivers.

Primary caregivers	**Number in each group (percentage of total)**
Parents	40 (75.47)
Siblings	2 (3.77)
Grandparents	2 (3.77)
Placement (Childrens' Home)	3 (5.66)
Self- Care (> or = 18 years)	6 (11.32)

Table 5: 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)
HbA1c level (range)	12.84 ± 3.04 (7.1-17.5)	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 adults fell between the ages of 26 and 40 years (70.27%), with only 6 participants (16.23%), having completed some form of tertiary education (Table 6).

Table 6: Stratification of participant's ages.

Children		**Caregivers**	
Age groups (years)	**n (%)**	**Age groups (years)**	**n (%)**
8-11	18 (33.96)	**19-25**	3 (8.11)
12-15	23 (43.40)	**26-40**	26 (70.27)
16-17	6 (11.32)	**>40**	8 (21.62)
18	4 (7.55)		
> 18	2 (3.77)		

The subsequent bar graphs delineate the ages of the participants in their respective groups (Figures 1and 2).

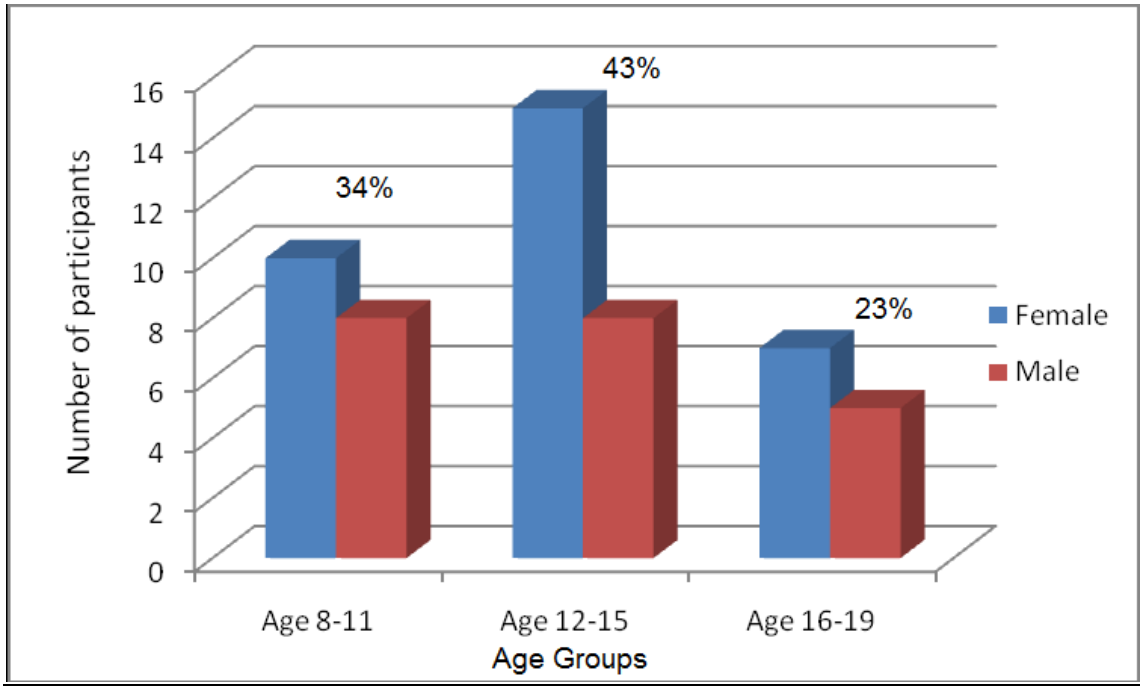

Figure 1: Bar graph depicting sex and age groups in the children's sample

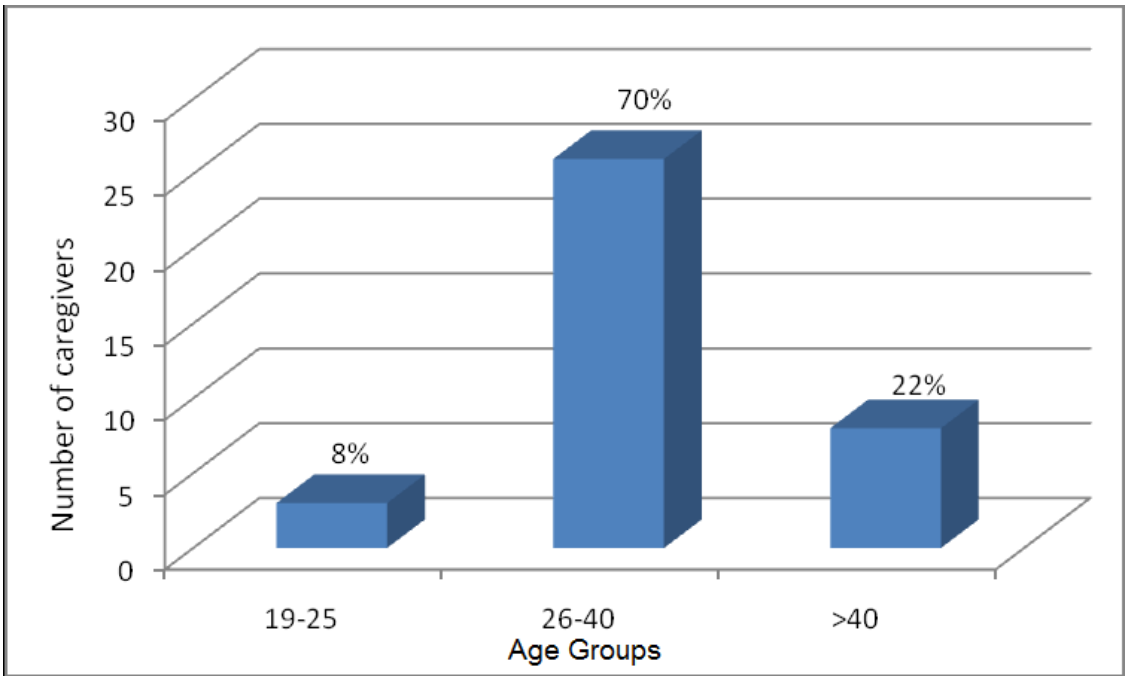

Figure 2: Bar graph depicting age groups in the caregiver sample (there were only 6 males in the total sample)

3.2 Questionnaire Outcomes

3.2.1 Comparison of the percentage scores for section 1 and section 2

The children's mean percentage scores for the basic math (section 1) and the numeracy (section 2) were 69.30% (SD ± 18.62)) and 56.63% (SD ± 27.82) respectively and the caregiver mean percentage scores for the same sections were 73,30% (SD ± 15.92) and 60.71% (SD ± 23.61) respectively (Tables 7 and 8).

Analyses also revealed that there was a significant difference in the percentage scores of the basic math (section 1) and the numeracy (section 2) achieved by children ($p<0.001$) and their caregivers ($P<0.0001$), with participants scoring less well in the numeracy

questions (Figure 3). Thus they did better in basic math, but were unable to apply these skills in relation to diabetes related scenarios.

Table 7: The means of the percentage scores in each section in the children's group

Section	Mean score	Confidence Interval (-95)	(+95)	Standard deviation (±)
Section 1	69.299*	64.266	74.333	18.262
Section 2	56.627	48.958	64.297	27.825

- P <0.001 between section 1 and section 2

Table 8: The means of the percentage scores in each section in the caregiver group

Section	Mean score	Confidence Interval (-95)	(+95)	Standard deviation (±)
Section 1	73.281*	67.973	78.590	15.922
Section 2	60.709	52.836	68.583	23.615

- P < 0.0001 between section 1 and section 2

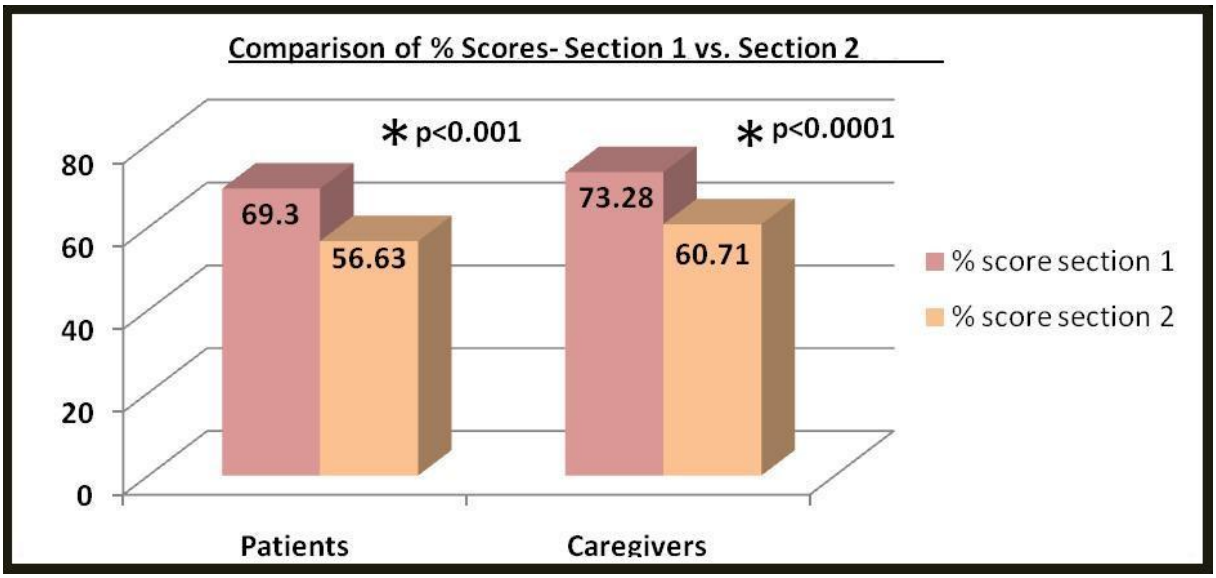

Figure 3: Comparison between the percentage scores for the basic math (section1) and the numeracy (section 2) for both children and caregivers. The values on the actual bars represent the mean.

A good correlation was also found between the percentage scores of the basic math (section 1) and the numeracy (section 2), implying that the numeracy skills questions were appropriately leveled to the basic math skills questions. This was found in both the children ($r=0.82$, $p<0.0001$) and caregiver ($r=0.81$, $p<0.0001$) groups. (Figures 4 and 5)

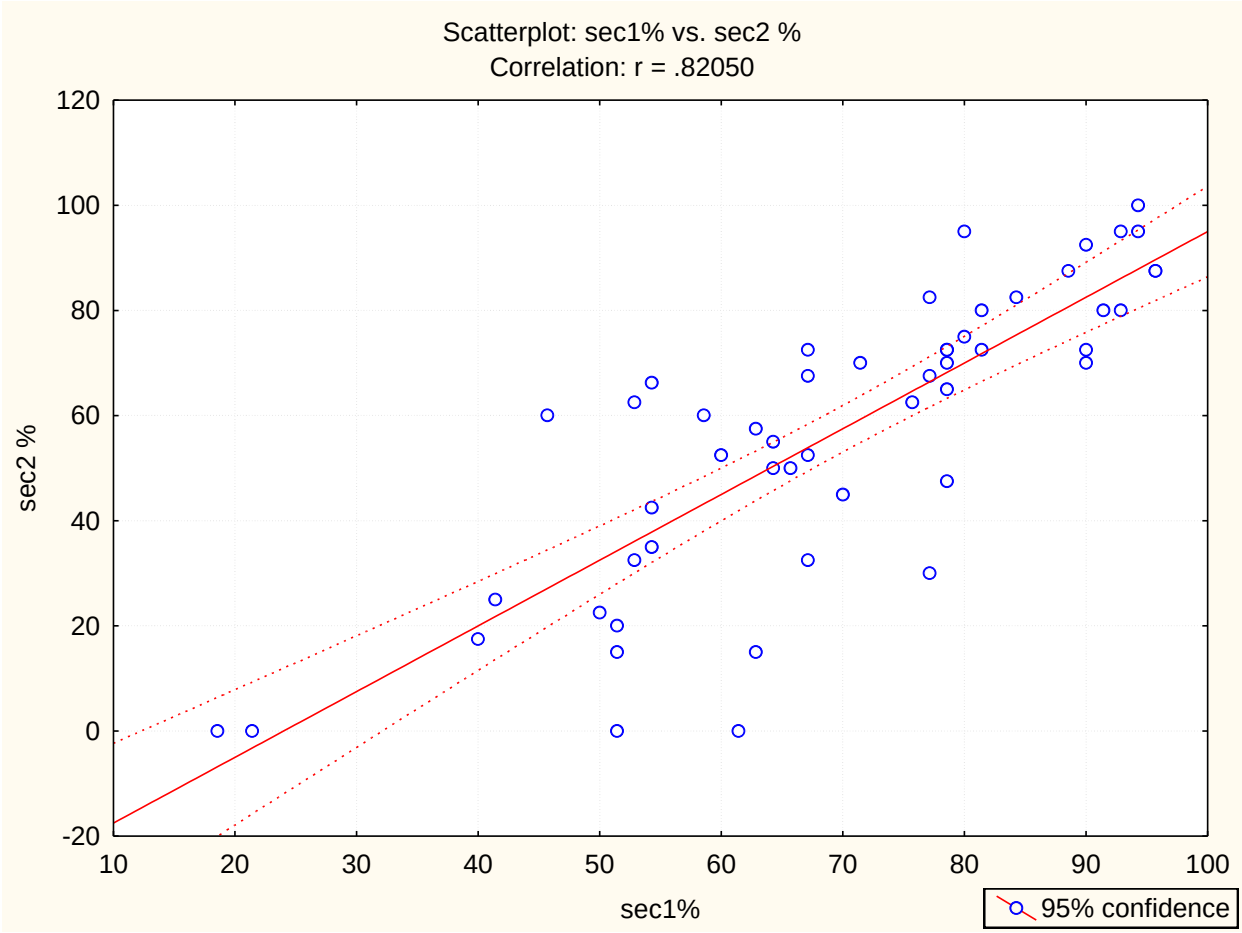

Figure 4: Scatterplot showing the correlation between section 1 and section 2 scores (children's group)

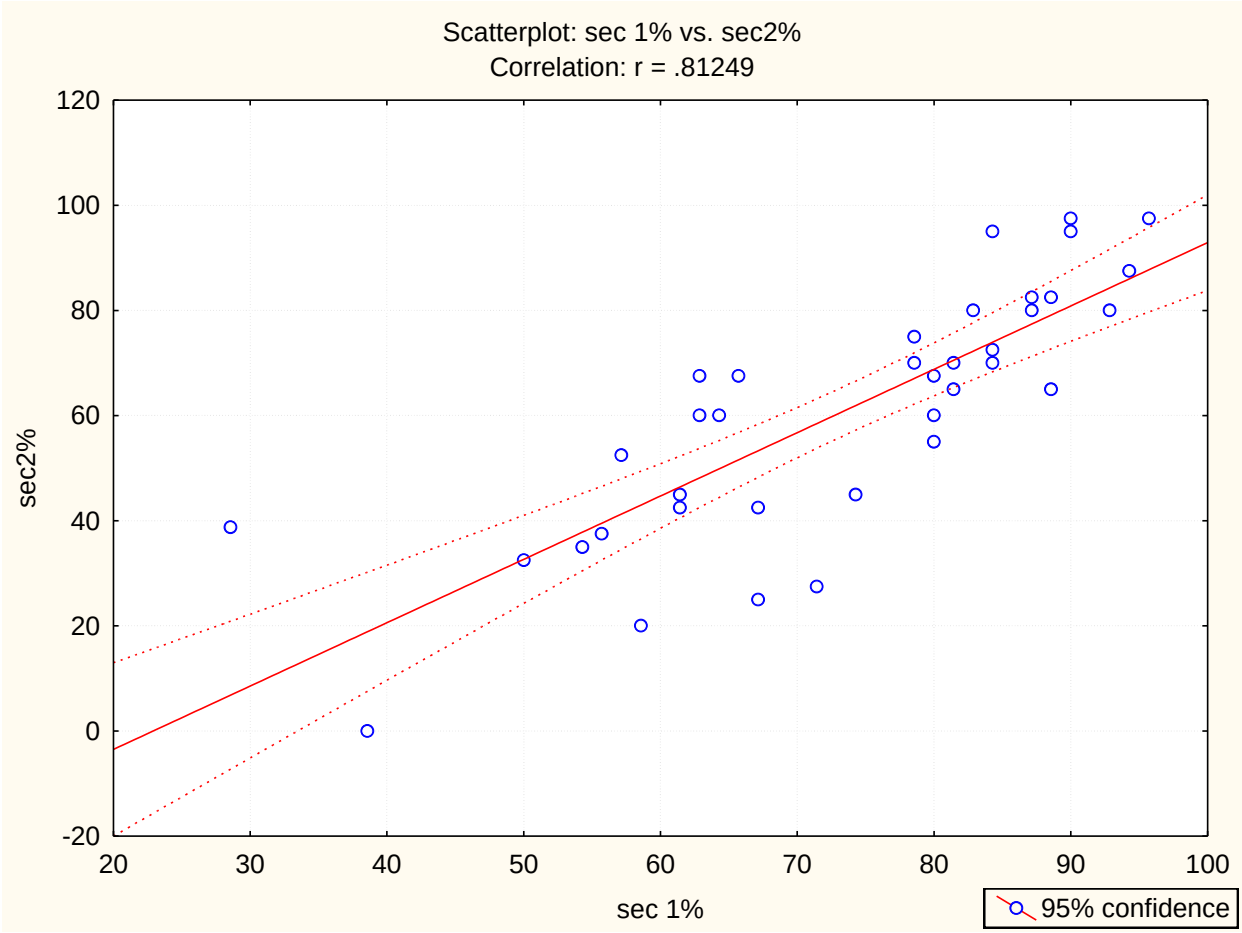

Figure 5: Scatterplot showing the correlation between section 1 and section 2 scores (caregiver group)

3.2.2 Comparison of the actual and functional grades

Tables 9-11 demonstrate that most children and caregivers performed below their expected potential, with participants' 'functional' grades being less than their actual grade levels. However the small numbers in each group may account for the lack of statistical significance in individual groups. When comparing the overall means of the actual and 'functional' grades, a significant correlation was however found between the actual and 'functional' grades of the children (r=0.345, p=0.014), 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 6).

Table 9: Stratification of actual and 'functional' grades in the both groups

Children				**Caregivers**			
Actual grade	n (%)	**Functional grade**	n (%)	**Actual grade**	n (%)	**Functional grade**	n (%)
3	5 (9.43)	**<3**	2 (3.77)	**5**	1 (2.70)	**3**	5 (13.51)
4	4 (7.55)	**3**	7 (13.21)	**6**	3 (8.11)	**4**	7 (18.92)
5	9 (16.98)	**4**	16 (30.19)	**>6**	33 (89.19)	**5**	5 (13.51)
6	9 (16.98)	**5**	8 (15.09)			**6**	3 (8.11)
>6	26 (49.06)	**6**	6 (11.32)			**>6**	17 (45.95)
		>6	14 (25.42)				

Table 10: Percentage of children that performed below their actual grade level

Actual grade levels	**Total number in each grade**	**Percentage of children equivalent to or greater than actual grade n (%)**	**Percentage of children less than actual grade n (%)**	**P values**
1	0	0	0	-
2	0	0	0	-
3	5	5 (100.00)	0	**0.023**
4	4	2 (50.00)	2 (50.00)	0.680
5	9	3 (33.33)	6 (66.67)	0.253
6	9	4 (44.44)	5 (55.56)	0.525
>6	26	12 (46.15)	14 (53.85)	0.887

Table 11: Percentage of caregivers that performed below their actual grade level

Actual grade levels	**Total number in each grade**	**Percentage of caregivers equivalent to or greater than actual grade n (%)**	**Percentage of caregivers less than actual grade n (%)**	**P values**
3	0	0	0	-
4	0	0	0	-
5	1	0	1 (100)	0.541
6	3	1 (33.33)	2(66.67)	0.562
>6	33	16 (48.49)	17 (51.51)	0.366

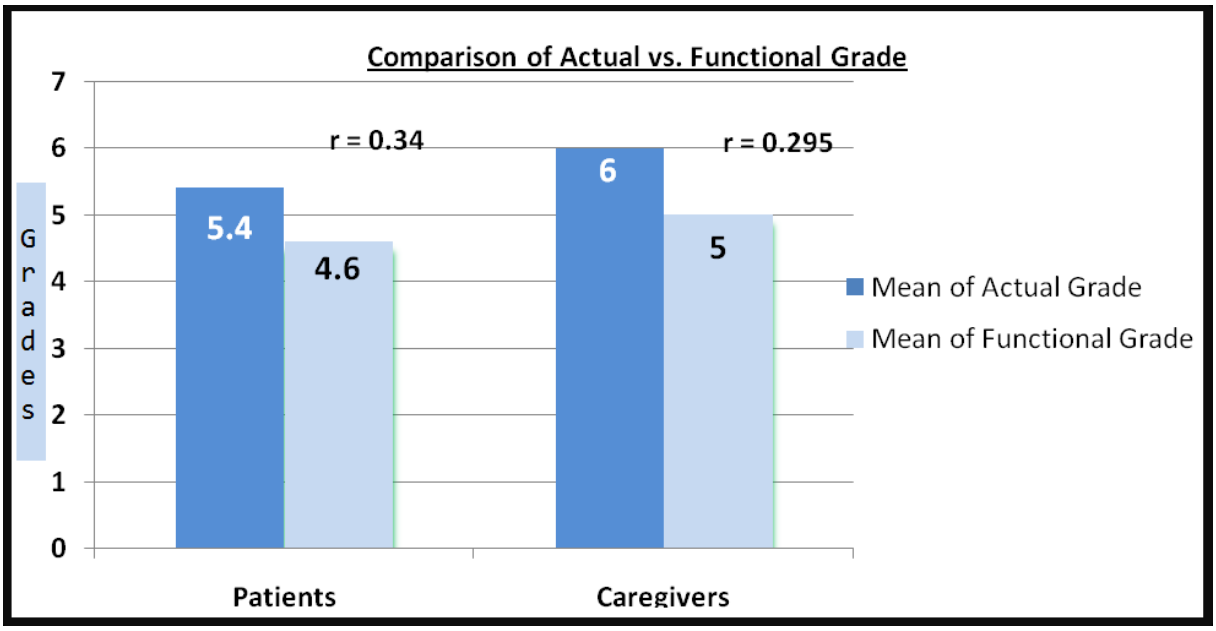

Figure 6: Comparison of the actual vs 'functional' grade levels. Values on the actual bars represent the mean.

3.2.3 Correlation between actual and 'functional' grades and percentage scores for both sections

A positive correlation was found between actual grade and percentage scores for both basic math (section 1) and numeracy (section 2) as can be seen in table 12. This was found in the children and caregiver groups. An even stronger correlation was found between the percentage scores for both sections and the 'functional' grade, thus implying that the 'functional' grade was a better indicator of the participants' actual basic math and numeracy skills than actual grade. When comparing actual to 'functional' grade, a significant correlation was found in the children's group only ($p = 0.001$ and $r = 0.4478$) but not in the caregiver group ($p = 0.777$ and $r = 0.482$).

Table 12: Correlation statistics - actual and 'functional grades' vs percentage scores for both sections (both groups).

Grades in relation to section 1 and section 2 scores	Children p value (r value)	Caregivers p value (r value)
Actual grade		
Section1	**0.019 (0.320)**	0.055 (0.318)
Section 2	**0.015 (0.332)**	**0.015 (0.396)**
Functional grade		
Section 1	**0.000 (0.500)**	**0.000 (0.858)**
Section 2	**0.000 (0.500)**	**0.000 (0.732)**

3.2.4 Correlation of scores with age

A significant correlation was found between the age of the children and percentage scores in both sections, with children of advancing age performing better that their younger peers (as would be expected), as they progressed through the grades ($p = 0.006$, $r = 0.375$) (Figures 7-8).

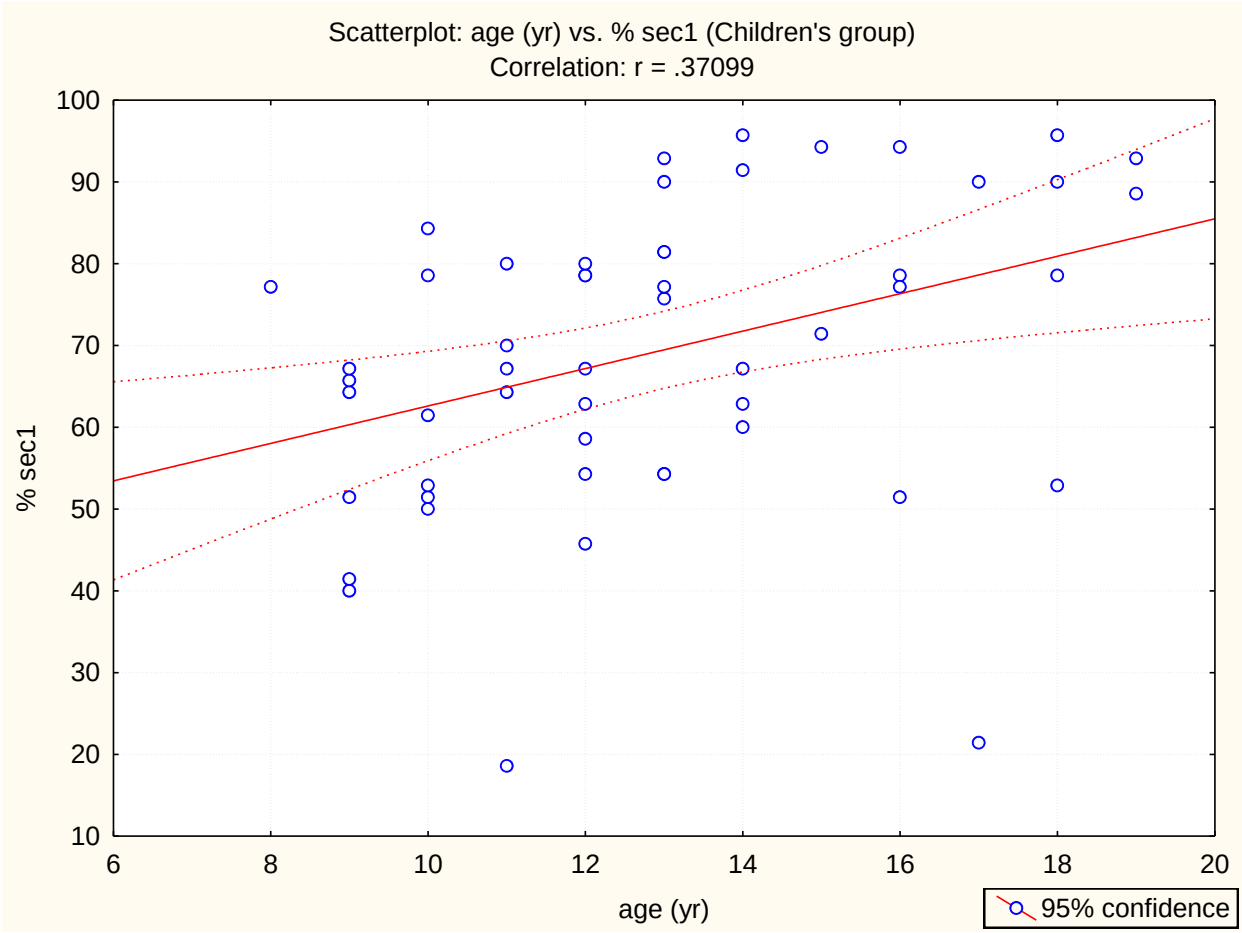

Figure 7: Scatterplot depicting the relationship between section 1 percentage scores and age (children's group)

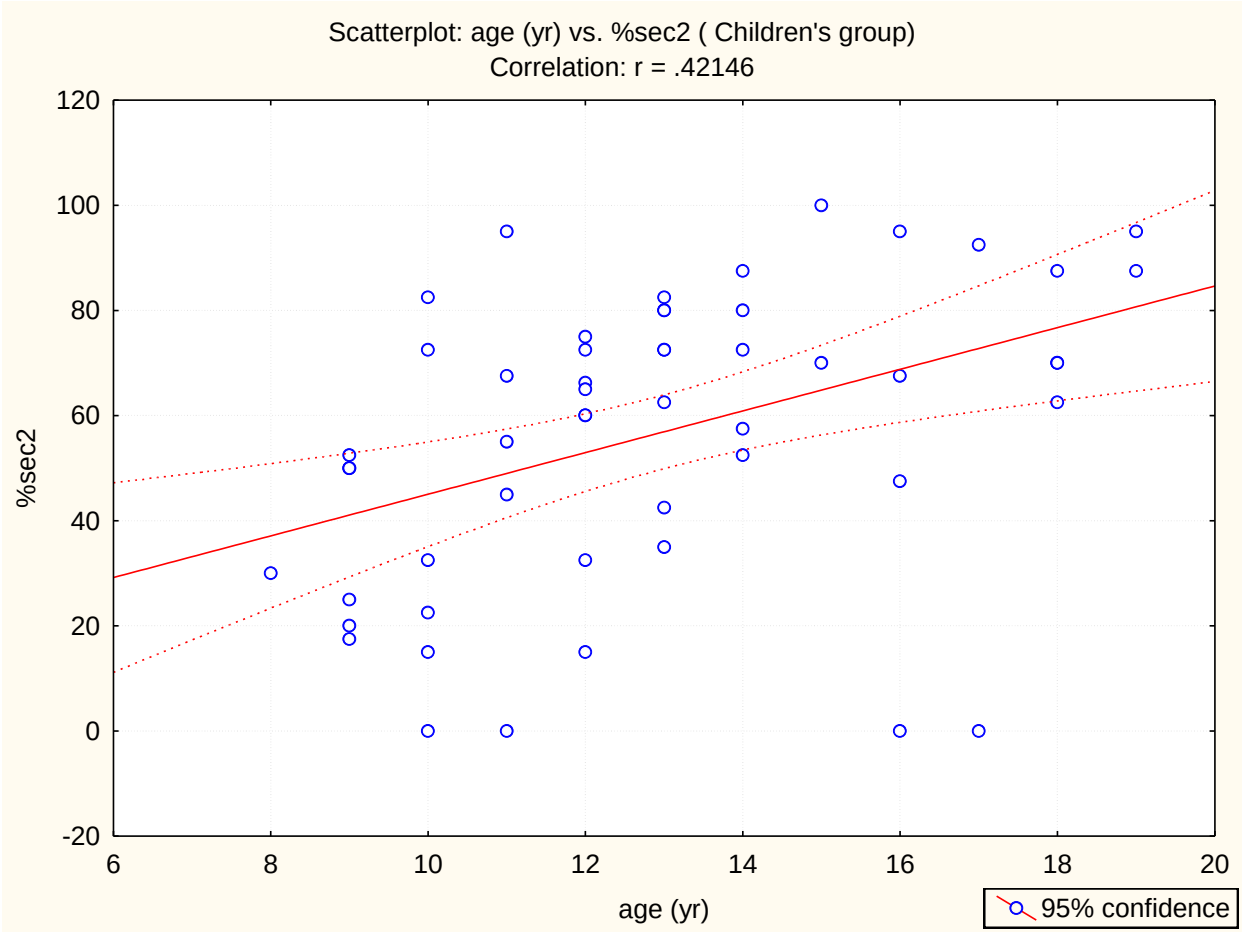

Figure 8: Scatterplot depicting the relationship between section 2 percentage scores and age (children's group)

3.2.5 Actual numeracy deficits

Table 13 highlights the actual deficits in mathematical skills, specifically relating to the numeracy questions (section 2). Both children and caregivers did equally poorly in the tasks of rounding, formulae and data interpretation. Table 14 stratifies each section further and delineates the percentage passed in each individual question, with the children doing poorly in the grade 5 level basic math skills and confirming the above deficits in the numeracy section (the numbers in bold print delineate those sections that had a pass rate below 50%).

Table 13: Pass rates for numeracy questions in patients and caregivers (arranged according to math skills)

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

Table 14: Pass rates for basic math and numeracy questions in patients and caregivers (arranged according to questions)

QUESTIONNAIRE SECTIONS	QUESTION	% PASSED (Children)	% PASSED (Caregivers)
BASIC MATH SKILLS	Grade 1 questions	96.23	97.30
	Grade 2 questions	94.34	97.30
	Grade 3 questions	96.23	100.00
	Grade 4 questions	79.24	81.08
	Grade 5 questions	**45.28**	59.46
	Grade 6 questions	60.38	64.87
APPLIED MATH SKILLS (NUMERACY)	**Question 1**	66.04	78.38
	Question 2	56.60	51.35
	Question 3	83.02	91.89
	Question 4	**47.17**	51.35
	Question 5	90.57	94.59
	Question 6	**37.73**	**35.14**
	Question 7	62.26	54.05
	Question 8	64.15	75.68
	Question 9	69.81	64.87
	Question 10	66.04	70.27
	Question 11	88.68	89.19
	Question 12	71.70	83.78
	Question 13	71.70	81.08
	Question 14	60.38	64.86
	Question 15	**24.53**	**18.92**

	Question 16	69.81	79.97
	Question 17	67.92	83.78
	Question 18	**49.06**	59.46
	Question 19	**26.42**	**32.432**
	Question 20	58.49	56.76

3.3 Medical variables

Relationship between metabolic control (as measured using HbA1c level) and actual test scores

A negative correlation (r = -0.32, p=0.029) was found between the HbA1c levels and the percentage scores for numeracy (section 2) (Figure 9), with those with poorer diabetes-related numeracy scores having higher HbA1c levels and thus poorer diabetes control.

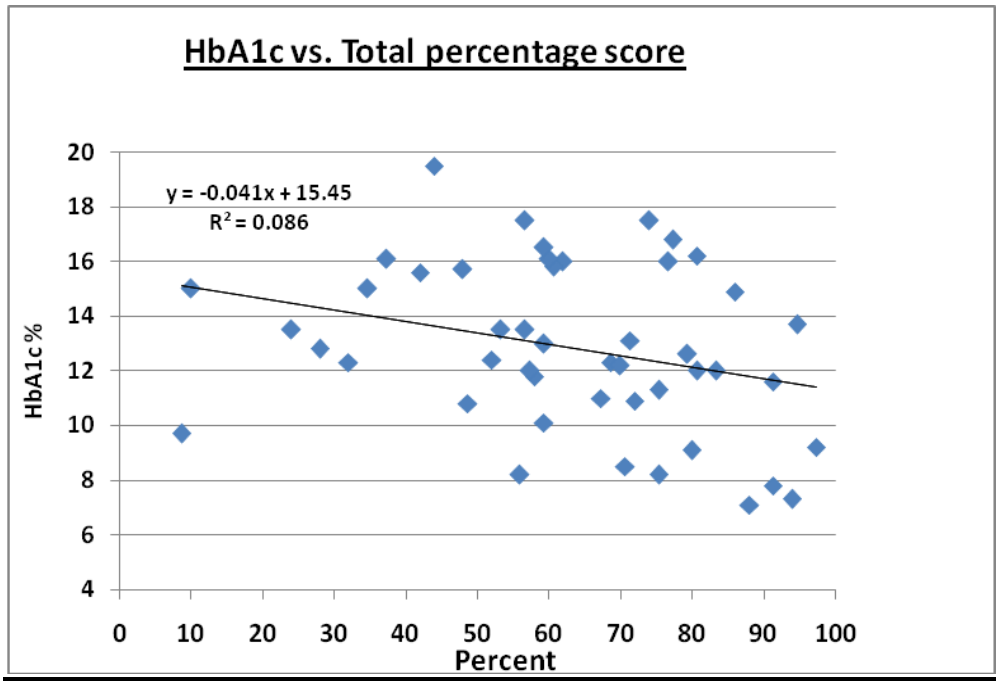

Figure 9: Scatter plot delineating the relationship between HbA1c levels and numeracy scores (section 2).

CHAPTER 4: DISCUSSION

4.1 Background

Type 1 diabetes mellitus is an autoimmune disease with an estimated prevalence of 1 in 400-600 and is the second most common chronic childhood illness (1). Thus the burden of disease is significant, so are the long term complications of this disease, which include neuro- cognitive dysfunction.

4.2 Health Literacy and numeracy: previous studies

Basic Health literacy is ‘the degree to which individuals have the capacity to acquire, process and understand basic health information and services needed to make appropriate health decisions’ (14,22). It has been proven that low health literacy is common among adult patients with diabetes mellitus and that such patients have greater difficulty understanding their disease, have worse glycaemic control and worse clinical outcomes (14,23).

Understanding the reasons behind poor control is pivotal in improving diabetes management. In most instances, it is assumed that patients and their caregivers understand all that goes into a comprehensive diabetes educational programme. However this may not hold true in all cases.

Health numeracy is an important component of health literacy that affects diabetes care. Studies support the association between limited health literacy and numeracy and poorer diabetes outcomes and have also shown that in actual fact, numeracy is more closely related to diabetes control than literacy (14-17).

Diabetic patients need to conquer a wide range of numerically-related tasks on a daily basis, for example, basic mathematics such as addition, subtraction, fractions, multiplication and division are needed for:

1) Calorie counting

2) Adjusting insulin doses

3) Determining food portions and food exchanges

4) Understanding blood glucose measurements and the concepts of 'hyperglycaemia' (blood glucose levels > 7mmol/l) and 'hypoglycaemia' (blood glucose levels < 3mmol/l) (2,12,24,25).

The concept of time is also essential as it impacts on when blood glucose monitoring is done and when insulin is administered, especially in relation to meal times. Interpretation of data (in the form of tables and graphs) and the application of quantitative information assist patients with understanding nutritional labels and applying this information when planning their own meals and thus allowing for variation (12, 14).

Number hierarchy (sequencing numbers in order) allows diabetic patients to understand trends in their blood glucose readings and the application of formulae is needed when determining insulin sensitivity and insulin correction doses. Diabetic patients also need to

understand the concepts of averages as this facilitates their understanding of the relevance of HbA1c levels and its use as a marker of glycaemic control (15).

If these basic mathematical skills are not mastered at an early age, not only will this impact negatively on diabetes management but may also be one of the reasons behind a patient's poor metabolic control and the development of complications, thus creating a vicious cycle (5,6,15, 26-32).

Caregiver literacy and numeracy has also been shown to have a significant impact on the glycaemic control of type 1 diabetic children and that greater diabetes knowledge of the caregivers is associated with better glycaemic control in the children (18).

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4.3 Current Study

In our study, it was found that there were significant differences in the percentage scores of the basic math questions (section 1) and numeracy questions (section 2). Patients and caregivers did worse in section 2, thus indicating that both groups were unable to apply their basic math skills in diabetes related scenarios. The finding of a positive correlation between the section 1 and section 2 percentage scores in both groups, implies that the numeracy section questions were appropriately leveled to the basic math section questions.

Both groups did specifically poorly in those tasks related to multiplication, estimation (rounding-off numbers), interpretation of data from tables and 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, with lower 'functional' scores indicating that on testing they functioned below their expected grade level. A similar correlation was found in the caregiver group but specifically in the numeracy section. This finding could also imply that overall numeracy in both groups was poor. The 'functional' grade was also a more reliable indicator of the participants' actual level of basic math and numeracy skills as compared to actual grade.

In addition a negative correlation was found between HbA1c levels and the numeracy scores (section 2), implying that those that scored poorly in this section had higher HbA1c levels, indicative of poorer metabolic control. Even though this study was not specifically powered 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.

4.4 Conclusions

There have been significant gains in the understanding of diabetes, its management and complications and specifically its effects on cognition. Not only does poor diabetes control affect cognitive function but this in turn impacts on diabetes care, creating a vicious cycle.

Our study confirms what is known in the current literature, namely that type 1 diabetics are known to have poorer numeracy skills (specifically applied or diabetes- related numeracy in our population) and that such patients tend to perform below their expected potential, with our patients having lower 'functional' grades. Also that caregiver literacy does play

an important role in diabetes care and that inadequate numeracy impacts negatively on diabetes control (higher HbA1c levels).

4.5 Recommendations

The challenge in caring for patients with diabetes and limited health literacy and numeracy is that deficits in these skills are not always intuitively obvious to providers and educators, and if these skills are not specifically assessed, then such deficits may go unnoticed (33, 34).

Thus, educational programmes need to be developed so as to assess these skills accurately and to accommodate patients and caregivers with lower numeracy. 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. Not only will this address the issues of diabetes education, but also ensure that the required basic literacy and numeracy skills are attained by learners at all levels.

By formulating such programmes, we hope that not only will patients become empowered to manage their diabetes more effectively but that the long term complications are also avoided. However, future research is needed to determine the exact impact of such numeracy-focused interventions, specifically on diabetes outcome and metabolic control. In fact, a second study is currently in progress at our centre, assessing the effect of a numeracy- based intervention on diabetes management and glycaemic control.

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APPENDIX A

Ethics Clearance Certificate

APPENDIX B

Diabetes Mathematical Questionnaire

APPENDIX C

Scoring System of Questionnaire