Self-management and fear of hypoglycaemia in adolescents with type 1 diabetes

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Aims: To explore the relationship between diabetes self-management, and behavioural and emotional responses to hypoglycaemia in children and adolescents aged 8–15 years with type 1 diabetes via self-report measures. *Methods:* Data were collected at an overnight diabetes camp and endocrinology clinic on 127 participants who responded to two self-administered measures: the Diabetes Behavior Rating Scale (DBRS) and the Children's Hypoglycemia Index (CHI). Descriptive statistics and linear regressions were analysed to detect significant relationships. *Results and conclusions:* Five items from the DBRS were found to predict 80% of the variability in self-management. Five items on the CHI predicted 90% of the variability in fear of hypoglycaemia. Children aged 11–15 years with repeated (>2 years) diabetes camp attendance were found to have less fear of hypoglycaemia.

In children and adolescents with type 1 diabetes, self-management of the condition inevitably begins through adherence to a prescribed regimen started at the time of diagnosis. Physicians, nurses and other healthcare providers remind them of their goal: aim for a target HbA_{1c} level of <7.5% (NICE, 2004). They are taught to monitor and regulate their diet, physical activity level and insulin dosage, and some learn to manage episodes of hyper- and hypoglycaemia with minimal parental assistance.

Although self-management of diabetes is challenging at all ages, adolescents in particular have been found to have difficulties in adhering to their regimens. Some studies have shown that diabetes management and glycaemic control actually declined as children progressed through adolescence (Anderson et al, 1990; Thomas et al, 1997; Hamilton and Daneman, 2002; Iannotti et al, 2006).

The type of insulin regimen used may add to the complexities of type 1 diabetes self-management. The prevalence of insulin pump therapy (or continuous subcutaneous insulin infusion [CSII]) and multiple daily injection (MDI) regimens have increased 10-fold since being recommended by the DCCT (Diabetes Control and Complications Trial; DCCT Research Group, 1994). Although the

Article points

1. The aim of this study was to explore the relationship between diabetes self-management and fear of hypoglycaemia in young people with type 1 diabetes.
2. Associations between self-management and fear of hypoglycaemia, HbA_{1c} level, age, gender, method of insulin administration and diabetes camp attendance were assessed.
3. Lower self-management scores were associated with higher HbA_{1c} levels.
4. Children aged 11–15 years who attended the diabetes camp for more than 2 years were found to have less fear of hypoglycaemia than those who attended for 2 years or less.

Key words

- Adolescents
- Hypoglycaemia
- Insulin pumps
- Self-management
- Type 1 diabetes

Authors' details can be found at the end of this article.

Page points

1. With less cognitive ability and emotional maturity than adults, children and adolescents are at risk of developing a fear of hypoglycaemia.
2. The purpose of this study was to explore the relationship between diabetes self-management and fear of hypoglycaemia in children and adolescents aged 8–15 years with type 1 diabetes by means of two self-report measures.
3. The Diabetes Behavior Rating Scale includes items covering a wide range of self-management behaviours, and some assessing regimen adherence at varying levels of symptomatology.

DCCT reported a three-fold increase in severe episodes of hypoglycaemia with insulin pump use, later research has demonstrated improved glycaemic control and reduced frequencies of hypoglycaemic episodes (Boland et al, 1999; Danne et al, 2001; Maniatis et al, 2001; Plotnick et al, 2003; Alemzadeh et al, 2004). Research on the transition from MDI to CSII regimens (Conrad et al, 2002; Mednick et al, 2004; Cogan et al, 2007) has reinforced the medical benefits of reduced hypoglycaemia and improved glycaemic control while recognising the need to balance them with the potential disadvantages of weight gain, hyperglycaemia caused by dislodgement of catheters, site infections, pump malfunctions and hypoglycaemia (Boland et al, 1999; Berlin et al, 2006).

Occasional episodes of hypoglycaemia remain inevitable and the frequency may increase as the young adolescent becomes more physically active and spends more time away from parents. With less cognitive ability and emotional maturity than adults, children and adolescents are at risk of developing a fear of hypoglycaemia (Irvine et al, 1994; Marrero et al, 1997; Kamps et al, 2005). An understanding of how they respond to hypoglycaemic episodes, both behaviourally and emotionally, can assist nurses in developing effective interventions.

Aims

The purpose of this study was to explore the relationship between diabetes self-management and fear of hypoglycaemia in children and adolescents aged 8–15 years with type 1 diabetes by means of two self-report measures. Self-management includes skills that must be performed daily (i.e. blood glucose monitoring and insulin administration) and adherence to a lifestyle regimen including regulation of diet and physical activity levels. Associations between self-management and HbA_{1c} levels, age, gender, method of insulin administration and diabetes camp attendance were also explored.

Methods

The study participants comprised children and adolescents with type 1 diabetes, recruited through a diabetes overnight camp (n=97) and an endocrinology clinic (n=30) in Atlanta, Georgia, USA. Eligibility criteria for enrolment included a disease duration of ≥9 months (to eliminate newly diagnosed individuals who would be adjusting to an insulin regimen), fluency in English and willingness to independently complete the two measures.

Of the 97 participants who had attended the diabetes camp, 75 (77%) had attended for ≤2 years, and 22 (23%) for >2 years. The two measures were completed on the first day of camp or at an office visit (those who attended the clinic), and took approximately 20 minutes to complete. The most recent HbA_{1c} level for each camp participant was recorded.

The Diabetes Behavior Rating Scale (DBRS) (Cook et al, 2001) includes items covering a wide range of self-management behaviours, and some assessing regimen adherence at varying levels of symptomatology. Behavioural frequencies and, in some items, the child's degree of responsibility for their behaviour is assessed. This scale also measures specific behaviours in response to blood glucose levels that are too high or low.

The DBRS score is calculated as a proportion of the maximum possible score; higher scores reflect greater regimen adherence. In this study, a revised version (that included pump-specific items) of this tool was used and its psychometric properties were consistent with previous versions; internal consistency (Cronbach's alpha) was 0.84 (0.86 for the original version) (Iannotti et al, 2006). Both versions of the DBRS are significantly related to HbA_{1c} levels. One-week test–retest intraclass correlations for youth responses reflect good reliability (Cronbach's alpha 0.71) (Iannotti et al, 2006).

The Children's Hypoglycemia Index (CHI) is a scale designed to measure fear of hypoglycaemia, and is a revision of an earlier scale for adults (Green et al, 1990). Items on the CHI assess behavioural and emotional responses to hypoglycaemic episodes in various everyday-life situations. The CHI contains 24 items, and responses are rated on a five-point Likert scale (from "not afraid" to "extremely afraid" or "never" to "all of the time"), with higher scores representing greater levels of fear.

Table 1. Descriptive data on participants (*n*=127).

	Mean	Standard deviation	Confidence interval	Range
Age (years)	11.8	2.1	11.5–12.2	8–15
Duration since diabetes diagnosis (years)	4.5	3.2	4.0–5.1	1–13
Most recent HbA_{1c} level (% [mmol/mol]) (*n*=97)	8.0 (64)	1.0 (10.9)	7.8–8.2 (62–66)	6.1–10.7 (43–93)
Diabetes Behavior Rating Scale score (%)	66.5	11.5	64.5–68.5	24.1–87.0
Children's Hypoglycemia Index total score (%)	25.9	14.6	23.3–28.4	0–79.2

The validity of this measure has been supported through confirmatory factor analysis. It was also significantly correlated with established measures of anxiety and fear of hypoglycaemia in children. The internal consistency for the total score is 0.89 (Kamps et al, 2005).

A data set was constructed, and all data were entered twice and cross-checked for accuracy. The cleaned data were imported into SAS version 9.2 and statistical analysis was conducted using linear regression models and significance was assessed based on Type II sum of squares. Model fit was assessed using the F-statistic, and R-square values. Quantitative variables were modeled in several ways and the best fit chosen for the relationship being described.

Results

The study population consisted of 127 children and adolescents with type 1 diabetes. The mean age was 11.8 (range 8–15) years, 59% were female and the mean duration since diabetes diagnosis was 4.5 (range 1–13) years (*Table 1*). The sample was racially diverse, consisting of white (*n*=84), Hispanic (*n*=2), and black (*n*=41) youths. A CSII regimen was being used in 53% of the youths. Descriptive data on the participants and scores on the two measures are presented in *Table 1*.

Total DBRS and CHI scores did not indicate an association between self-management and fear of hypoglycaemia. However, responses to one item on the DBRS, "Out of the last five times that the amount of exercise you did changed, how often were your meals and snacks changed?", were associated with better self-management and greater fear of hypoglycaemia (*Figure 1*). When compared with participants who had adjusted their meals and snacks four or five of the last five times after they exercised, the DBRS score was 7.7%, 11% and 16% lower for those who responded three times, twice and once or never, respectively. In addition, two-thirds of participants changed meals and snacks four or five of the last five times they exercised and the average total hypoglycaemia fear (CHI) score among these youths was 9.6% and 10.8% higher than that for those who had adjusted meals twice and three times, respectively.

The DBRS score was found to be a predictor of HbA_{1c} level; for every 1% increase in total DBRS score, the HbA_{1c} level was reduced by an average of 0.02 percentage points (0.2 mmol/mol) (P<0.05). When controlling for race, the average HbA_{1c} level for "good" self-managers (DBRS score of ≥70%) was 0.4 percentage points (4.4 mmol/mol) lower than that for those with a DBRS score

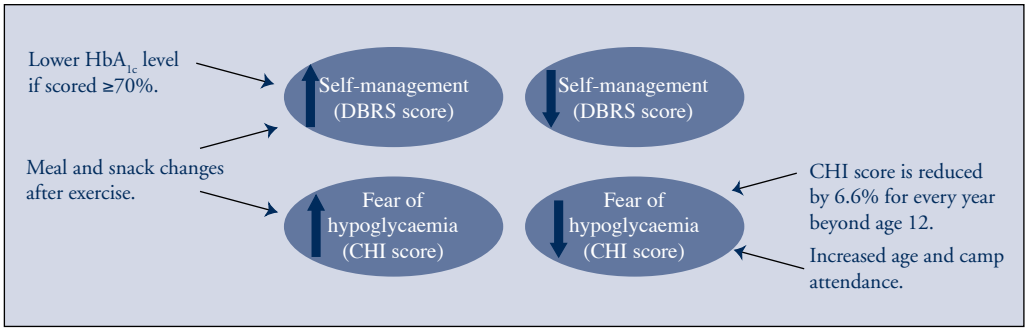

Figure 1. Schematic representation of factors found to predict self-management or fear of hypoglycaemia. No significant relationship was found between self-management and fear of hypoglycaemia.

Page points

1. After controlling for age, total Children's Hypoglycemia Index (CHI) score was reduced by an average of 7.4% for repeat campers (those attending >2 years) compared with those who had attended the camp for ≤2 years.
2. Total CHI score was reduced by 6.6% for every 1-year increase in age beyond 12 years.
3. In this study, lower self-management scores were associated with higher HbA_{1c} levels.

of <70%. Age, gender, method of insulin administration and diabetes camp attendance were not predictors of HbA_{1c} levels (*Figure 1*). Using a linear regression model, five items from the DBRS were found to predict 80% of the variability of total DBRS score (*Box 1*).

Gender, duration of diabetes and DBRS score were associated with CHI score. Although there were no significant differences in CHI score between diabetes camp attendees and those who had not attended, participant age, together with the number of years of camp attendance, was found to predict fear of hypoglycaemia. After controlling for age, total CHI score was reduced by an average of 7.4% for repeat campers (those attending >2 years) compared with those who had attended the camp for ≤2 years. This finding applied to youths aged 11–15 years. After controlling for camp experience, total CHI score was reduced by 6.6% for every 1-year increase in age beyond 12 years. Using a regression model, five items on the CHI predicted 90% of the variability in total score (*Box 2*).

Box 1. Items from the Diabetes Behavior Rating Scale predicting 80% of total score variability.

- How often was your blood sugar checked at the time of day it was supposed to be?
- Out of the last five times that the amount of exercise you did changed, how often were your meals and snacks changed?
- Out of the last five times that you needed help for your diabetes in school, home, or social settings, how often was help obtained?
- Out of the last five times that you had symptoms of being "LOW", how often was your blood sugar checked within 20 minutes after having taken "fast sugar"?
- Out of the last five times that you had symptoms of being "HIGH", how often was insulin dose changed based on the results of a blood sugar test?

Box 2. Items from the Children's Hypoglycemia Index predicting 90% of total score variability.

- Having low blood sugar when I am out with a group of friends makes me feel …
- Passing out from low blood sugar makes me feel …
- Making a mistake at school because my blood sugar is low makes me feel …
- I don't like to be alone because I am worried that my blood sugar might get low.
- I eat more food than I should because I don't want my blood sugar to get low.

Discussion

In this study, lower self-management scores were associated with higher HbA_{1c} levels, as shown previously (Danne et al, 2001; Iannotti et al, 2006). Stewart et al (2003) found a significant relationship between self-reported adherence to a medical regimen and glycaemic control. A later study showed that the most important predictor for HbA_{1c} level was the adolescent's report of making adjustments to keep blood glucose levels in the normal range (Stewart et al, 2005). The relationship between regimen adherence and HbA_{1c} level is unclear; some adolescents managing their diabetes may adhere to more aspects of their regimen than others. Inaccurate reports of adherence, emotional stress and biological factors (such as pubertal changes that affect the response to insulin) are other reasons for the complex relationship between regimen adherence and HbA_{1c} level.

The items in the DBRS regression model (*Box 1*) indicate that performance of monitoring and regulatory behaviours (i.e. adjusting meals and snacks according to activity level and checking blood glucose after responding to a "low") were the most important contributors to overall self-management. These aspects of self-management involve higher-level cognitive skills than simply adhering to healthcare providers' directives. Young people of this age group cannot be expected to have the cognitive ability or the emotional maturity to consistently plan ahead and make decisions about adjusting their diabetes regimen. The nurse's advice relating to physical activity should emphasise the importance of careful planning and attention to detail when making regimen adjustments. Developing these skills should be an emphasis of diabetes education during pre-adolescence and the teenage years.

The items in the CHI regression model (*Box 2*) highlight the importance of understanding fear of hypoglycaemia in terms of interactions with others. Berlin et al (2006)

Page points

1. Although age was not found to be significantly related to the Diabetes Behavior Rating Scale score, it was a predictor of fear of hypoglycaemia.
2. The social support and informal education provided by the camp in this study may have positively influenced behavioural and emotional responses to hypoglycaemia.
3. Nurses can be influential in promoting diabetes camps to children who are hesitant to attend, or parents who find it difficult to encourage their child's diabetes self-management.

reported that the most frequent problematic situations in children and adolescents with type 1 diabetes involved self-care in social and peer contexts. Young people with diabetes may have concerns about embarrassment and having others misinterpret their behaviours. The treatment of hypoglycaemia, with its effects on mental status, often requires assistance from others. Although the physical symptoms are usually most prominent, poor motor coordination, mental confusion, and altered mood states of argumentativeness and irritability can be especially distressing to young people of this age group. The CHI item about fear of hypoglycaemia when alone was also a significant contributor to fear of hypoglycaemia. When alone, children may be fearful of being unable to take care of themselves during a hypoglycaemic episode, especially if it occurs quickly.

Although age was not found to be significantly related to the DBRS score, it was a predictor of fear of hypoglycaemia. The finding that hypoglycaemia fear decreased with age should be cautiously interpreted, as it could indicate carelessness. In a qualitative study by Walker and Bradley (2002), only four of 15 adolescents with type 1 diabetes who completed a quality of life (QOL) questionnaire rated the diabetes domain as being important to their QOL. Diabetes management may not be a priority for adolescents when compared with social, academic and athletic pursuits. Alternatively, a "healthy" fear of hypoglycaemia that does not cause a child to keep blood glucose levels elevated is a favourable trait. If a child fears hypoglycaemia, he or she may be more apt to make adjustments to keep glucose levels normal.

The method of insulin administration was not found to be significantly associated with self-management or fear of hypoglycaemia. CSII or MDI is the standard of care for children aged >7 years with type 1 diabetes in the USA (American Diabetes Association, 2005) and those aged 11–18 years in the UK (NICE, 2004). Future research should explore the effects of longevity of pump use on self-management in young people with type 1 diabetes.

Finally, repeated attendance at the diabetes camp among participants aged 11–15 years was associated with less fear of hypoglycaemia. The social support and informal education provided by the camp in this study may have positively influenced behavioural and emotional responses to hypoglycaemia. Research studies and numerous anecdotal reports have attested to the social support and educational benefits of the diabetes camp (Cheung et al, 2006; McAuliffe-Fogarty et al, 2007; Santiprabhob et al, 2008). Nurses can be influential in promoting diabetes camps to children who are hesitant to attend, or parents who find it difficult to encourage their child's diabetes self-management.

The following limitations of this study are acknowledged. The participants were a convenience sample from one large diabetes camp organisation and one endocrinology clinic, and their ages ranged broadly. Socioeconomic data on the participants were not collected and such data might have shed light on parental support, method of insulin administration and diet content. This may have impacted the findings of reduced hypoglycaemia fear and HbA_{1c} levels, although these reductions were relatively small, which is consistent within the authors' models and with other researchers' findings.

Conclusion

At present, there are few studies with reliable and valid reports of adolescents' diabetes self-management, yet it is known that increasing self-care by the young adolescent is a strategy for improving metabolic control. This study describes a complex interplay between self-management, regimen adherence and responses to hypoglycaemia. The results indicate specific areas of emphasis for diabetes nursing that can be helpful in supporting self-management of type 1 diabetes in older children and adolescents, and ultimately in controlling disease progression.

Education focused on hypoglycaemic episodes in various situations can help young people learn how to use their blood glucose levels to plan ahead for problems, and be equipped with potential solutions. In addition, the use of self-assessment tools can stimulate discussion and predict readiness for self-management, especially in young people who are less verbal.

"Education focused on hypoglycaemic episodes in various situations can help young people learn how to use their blood glucose levels to plan ahead for problems, and be equipped with potential solutions."

Children aged 11–15 years who attended the diabetes camp for >2 years were found to have less fear of hypoglycaemia. The social support and education provided at the diabetes camp can assist young people in coping with the stress of diabetes self-management.

The finding that much of the variability in CHI and DBRS scores was explained by five questions from each of the tools may facilitate healthcare practitioners in more rapidly assessing patients' fears or ability to self-manage. More research is needed on this possibility. ■

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