Original Research

Pediatric Type 1 Diabetes: Patients' and Caregivers' Perceptions of Glycemic Control

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ABSTRACT

Objectives: (1) to describe pediatric patients with T1D and their caregivers' perceptions of measures of glycemic control (hemoglobin [A1C] and blood glucose [BG] levels) and (2) to determine the relationship between patients' and caregivers' perceptions of measures of glycemic control with actual A1C levels and adherence to diabetes self-care behaviors.
Methods: Patients (8 to 18 years) with T1D and caregivers completed questionnaires that queried their perceptions of (1) what the A1C level assesses, (2) the ideal A1C target, and (3) the ideal BG range. Point-of-care A1C levels were measured for each patient. They also completed the Self-Care Inventory Revised (SCI-R) to assess adherence to diabetes self-care behaviors.
Results: Among 253 dyads, the frequencies of patients compared to caregivers who could accurately describe what the A1C level assesses, identify the ideal A1C target, and identify the ideal BG range were 20 vs. 66, 31 vs. 56, and 72 vs. 76%, respectively. Patients' accuracy in reporting ideal targets for glycemic control was significantly associated with caregivers' accuracy. There was a trend for lower median A1C levels in patients who were part of a dyad wherein both had accurate perceptions of glycemic control.
Conclusions: Patients and caregivers had accurate knowledge of ideal BG range but were less knowledgeable about the meaning of A1C levels and ideal A1C targets. Nevertheless, whether glycemic control was perceived as an A1C measurement or a BG range, A1C levels trended lower for patients when both they and their caregivers had accurate perceptions of glycemic control.

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RÉSUMÉ

Objectifs : 1) Décrire la perception des enfants et des adolescents atteints du DT1 et de leurs soignants sur les mesures liées à la régulation glycémique (les concentrations de l'hémoglobine [A1c] et de la glycémie [G]) ; 2) Déterminer la relation entre la perception des patients et des soignants sur les mesures liées à la régulation glycémique par rapport aux concentrations actuelles de l'A1c et à l'observance aux autosoins diabétiques.
Méthodes : Les patients (de 8 à 18 ans) atteints du DT1 et les soignants ont rempli les questionnaires qui visaient à connaître leur perception sur : 1) ce qu'évalue la concentration de l'A1c ; 2) la valeur cible idéale de l'A1c ; 3) la fourchette de G idéale. Les concentrations hors laboratoire de l'A1c de chacun des patients ont été mesurées. Ils ont également rempli la version révisée de l'Inventaire des capacités à prendre soin de sa personne (SCI-R, de l'anglais *Self-Care Inventory Revised*) pour évaluer l'observance aux autosoins diabétiques.
Résultats : Parmi les 253 dyades, les fréquences des patients par rapport à celles des soignants qui pourraient décrire avec exactitude ce qu'évalue la concentration de l'A1c, déterminer la valeur cible idéale de l'A1c et déterminer la fourchette de G idéale étaient respectivement de : 20 % *vs* 66 %, 31 % *vs* 56 % et 72 % *vs*

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76 %. L'exactitude des patients à rapporter les valeurs cibles idéales de la régulation glycémique était significativement associée à l'exactitude des soignants. Il existait une tendance à des concentrations médianes d'A1c plus faibles chez les patients qui faisaient partie d'une dyade où les deux avaient des perceptions justes sur la régulation glycémique.

Conclusions : Les patients et les soignants possédaient des connaissances précises sur la fourchette de G, mais en possédaient moins sur la signification des concentrations d'A1c et des valeurs cibles idéales de l'A1c. Néanmoins, que la régulation glycémique soit considérée comme une mesure de l'A1c ou une fourchette de G, les concentrations d'A1c montraient une tendance à la baisse chez les patients lorsque ces derniers et leurs soignants avaient des perceptions justes de la régulation de la glycémie.

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Introduction

The test for hemoglobin (A1C) provides information about a person's blood glucose levels over an 8- to 12-week period (1). It is arguably one of the most important outcomes to monitor when managing diabetes because the level is exponentially related to the risk for developing micro- and macrovascular complications (2,3). Lower A1C levels attenuate risk but must be weighed against an increased chance of hypoglycemia; the *Canadian Diabetes Association 2013 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* recommend an A1C target of 7.5% or lower for children 6 to 12 years and 7.0% or lower for youth 13 to 18 years, with the caveat of tailoring the target to the individual (4,5).

The majority of youth with type 1 diabetes do not meet recommended A1C targets for age (6,7). One possible reason might be that youth with type 1 diabetes do not consistently set goals for glycemic control. They might not know what A1C levels measure, and even if they do, they are unlikely to report an accurate A1C target (8,9). They may also struggle with relating the daily glucose levels they view on their glucometers with a measurement that is done quarterly and in different units (mmol/L vs. percent, respectively). Younger children with type 1 diabetes may have even more difficulty than adolescents with conceptualizing glycemic control as an A1C measurement. Less cognitively and developmentally mature, they have had less practice with numeric skills, may not be as readily able to process abstract concepts and are more likely to rely on their caregivers to understand these concepts for them. Blood glucose levels, as determined by self-monitoring, provide immediate documentation of hyperglycemia and hypoglycemia and may be a more accessible means of perceiving glycemic control (10). It has been reported that children can predict their metabolic control correctly, irrespective of their actual A1C levels, possibly by perceiving glycemic control through other ways, such as blood glucose (BG) levels (11).

Pediatric diabetes care is distinguished by the fact that youth depend on caregivers to supervise and implement their diabetes care. A surfeit of studies has demonstrated the influence of parental knowledge, attitude and involvement on children's sense of self-efficacy and adherence to diabetes care behaviours (12). Parental involvement includes an awareness of diabetes-management activities, direct behavioural involvement in the daily management of diabetes and a posture of warmth and acceptance (13). Yet it is not fully known how much caregivers understand the meaning of the A1C test compared to their children nor how their perceptions might impact their children's understanding. Extrapolations from studies of adults with diabetes suggest that adults are also imperfectly aware of A1C targets (14).

There are data to suggest that youth and their caregivers who set goals in diabetes care have more optimal A1C levels. The cross-sectional study by Boot et al sought to assess the impact of parents' glycemic goals on A1C levels in children and adolescents with type 1 diabetes (15). They found that the A1C levels of children and adolescents were lower when parents reported A1C goals of 8% or lower versus 8% or above. They also observed that A1C levels were higher for youth whose parents reported BG goals of 10 mmol/L or higher. They acknowledge, though, that they did not ascertain children's and adolescents' goals. The Hvidoere Study Group on Childhood Diabetes observed that adolescent patients and their caregivers who reported lower A1C targets were more likely to achieve those targets (16). Moreover, in this multicentre survey, they were more likely to attend a clinic where the health-care provider had also reported lower A1C targets. Consistent messaging of shared, stringent A1C targets was associated with achievement of lower A1C levels. Other studies have reported a similar trend of lower A1C levels in adolescents who were able to report the recommended A1C levels for themselves, but these studies have also shown an overall lack of understanding of the A1C test by most youth (8,9). Less than 10% of youth were able to relate BG levels with the A1C values, reflecting a disconnect between daily BG testing and A1C-level targeting.

In this study, we sought to describe how youth with type 1 diabetes and their caregivers perceive glycemic control, whether it be through recognition of BG numbers, A1C targets, or a combination of both. We hypothesized that patients with accurate perceptions of glycemic control would be more likely to have caregivers who also had accurate perceptions. We also aimed to determine the relationship between patients' and caregivers' perceptions of various measures of glycemic control with the outcomes of actual A1C levels and adherence to diabetes self-care behaviours.

Methods

This study was conducted in the Stollery Children's Hospital Pediatric Diabetes Education Centre, University of Alberta, Edmonton, Alberta, Canada. The centre implements a multidisciplinary-team approach to patient care with a pediatric endocrinologist, dietitian, nurse, and social worker available at every visit. Routine follow-up visits occur every 3 to 6 months, and the centre serves approximately 1000 unique patients per year. The study was approved by the Health Ethics Research Board at the University of Alberta.

Patients and caregivers were recruited consecutively between June 1, 2015, and April 30, 2016, during routine clinic visits. Requirements for participation included duration of type 1 diabetes for more than 1 year, patient age of 8 years or older, and the ability to read and understand English. The adult accompanying the youth also had to be the primary caregiver (parent or legal guardian) since the time of diagnosis. Demographic and clinical data for each patient, such as age, duration of diabetes, and insulin regimen, were collected. We also collected data about number of clinic visits as a reflection of potential opportunities for messaging about glycemic control. From previous demographic information, we estimated that approximately 250 patients would meet eligibility requirements. Clinics occur every day of the week, and the research associate variably selected 2 to 3 days per week to recruit participants.

The research associate administered 2 identical questionnaires to each patient and caregiver, who responded independently. The