Working Effectively with Those Who Struggle with Type 1 Diabetes Self-Management: Lessons Learned from a Courageous Population

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Abstract

Working with people with type 1 diabetes (T1D) who struggle with their diabetes self-management can be both challenging and rewarding. To truly help these people in the most meaningful way, it is important to develop a nonjudgmental approach, good listening skills, empathy, and an atmosphere of trust in order to identify barriers to good management. It is furthermore critical to form a partnership with patients in a joint effort to help identify challenges and develop goals that are practical, attainable, meaningful, and sustainable.

Additionally, it is necessary to have a broad understanding regarding insulin, technology, and the differences between T1D and T2D for effective disease management.

Introduction

Living with a chronic disease is exhausting, but there are few diseases that are as time consuming, demanding, and a never-ending marathon as T1D. Multiple decisions about food and insulin need to be made several times each day, including at every meal and snack, when exercising, during times of increased stress, and when sick. These complex management requirements can cause significant diabetes distress (1,2). It is normal for diabetes self-management to wax and wane for most people with T1D. Having a good understanding of the many challenges facing people with T1D is necessary to effectively help them develop successful self-management skills and improve their diabetes management. It is also essential to possess a thorough understanding of T1D pathophysiology, insulin types, insulin action, insulin storage, rotation of sites and insulin injection technique. Additionally, understanding glucose meters, insulin pumps, continuous glucose monitoring systems (CGMS), and report interpretation in the context of their usual diet is critically important. Collaborating with patients and meeting them "where they are at" is paramount to success. The words "noncompliance" or "nonadherence" are pejorative and should never be used (3).

Diabetes Self-Management is Never Static

Times have certainly changed from when people with T1D had only one visit with the registered dietitian nutritionist (RDN) and were given an "exchange diet." Previously, there existed little or no differentiation from those with T2D as all patients essentially received the same meal plan. With today's flexible insulin regimens and rapidly-changing technology, people with T1D can live free from the rigid schedules and meal plans of the past, those which dictated when and how much a person ate. There is no need to follow a consistent carbohydrate diet with multiple daily injections and insulin pumps. There is strong evidence that using a carbohydrate counting meal planning approach results in improved glycemic control. The focus therefore should be on how to adjust insulin doses for planned carbohydrate intake (4). This doesn't mean, however, that people do not continue to struggle with diabetes self-management. Those with longstanding T1D may have developed his/her own ways of managing diabetes that may not necessarily be optimal but changing these habits can prove difficult as they have adhered to such for many years. For examples, a patient may have never met with an RDN, or it may have been several years since their last visit with an RDN, and as such, they may be using outdated information in their diabetes self-management. And, indeed those with TD1 often need more than just a carbohydrate counting review to help them improve their diabetes self-management. There are a number of factors that affect blood glucose in addition to carbohydrate intake (stress, illness, medications, and exercise), therefore perfect control of diabetes is not the goal (Table 1). Diabetes can be overwhelming at times and ultimately, patients need to accept life with diabetes. As professionals, we can best help our patients by going the extra mile and encourage a collaborative effort towards improving their diabetes self-management using available tools that support making life with diabetes a bit easier.

Where to Begin

When patients seek your help, a good place to start is to ask them how you can help them, and what they specifically want to accomplish in their visit with you. They live with their diabetes daily and they usually can identify where they specifically struggle. Establishing a positive rapport with patients and developing a steady atmosphere of trust is a vital component of professional practice as it will encourage the open exchange of this very information. Be sure to also address their questions specifically during your session.

If a patient has not brought food records to a visit, always start with a thorough review of eating and lifestyle habits. It is essential that you keep an open mind free from judgements about what they eat so they can share with honesty. Be sure to obtain information about meal times, snacks and beverages typically consumed, where meals and snacks are consumed, daily routines/ schedules, foods consumed during the workday versus non-work day, other scheduled activities they may have, restaurant frequency and type, alcohol intake, and sports/exercise regimens in order to obtain an accurate patient overview. Additionally, for females, be sure to collect information regarding menses onset and duration.

If a patient is seeing you specifically to review carbohydrate counting, make sure to focus on the carbohydrates usually consumed in their diet. If the patient struggles with carbohydrate counting and is not adept at using computers or smart phone apps, make a chart together listing the foods and beverages typically consumed alongside the portion-specific carbohydrate amount consumed. If the patient frequents restaurants of which do not readily provide nutrition information, assist the patient in estimating the carbohydrate content of those foods usually ordered and document this information accordingly. Encourage patients to take pictures of usual food, meals and nutrition labels with a phone or tablet so that you may review during future visits to help identify carbohydrates consumed. To further explore eating habits with your patient, you may ask them to bring some food from home to your next appointment. If financially feasible, encourage patients to purchase a digital nutrition scale for home use to help with accurate carbohydrate counting. If you identify overall diet quality is an issue, and the patient is willing to make positive changes, work with them to make self-determined and realistic improvements. If a patient adheres to a fixed insulin regimen, create a few days of sample menus featuring consistent carbohydrate content using foods customarily eaten. Use food pictures, food models, empty food packages and containers, measuring cups and spoons, or any resources necessary to aid in the visualization of concepts discussed. If a patient is unable to carbohydrate count, work alongside the patient's medical provider to determine fixed rapid-acting insulin doses for different meals consumed with varying carbohydrate based on insulin-to-carbohydrate ratios.

The Value of Diabetes Technologies and Data

It is both very important and useful to download blood glucose meters and/or pumps and/or CGMS and to review glucose readings and insulin types, doses and times taken (bolused). Patients can alternatively upload their devices at home and bring that information to the appointment. Some meters, pumps and CGMS offer "provider side" data viewing. Examining the detailed diet history and daily routines together is extremely useful in teaching patients pattern management and how to effectively identify any trouble-spots. Partner with your patients to help optimize their lives with diabetes using these wonderful technologies. When issues or challenges are identified, the appropriate education needs and goal setting can be formulated.

Table 1 highlights some situations that can affect diabetes management.

Problem-solving and Motivating

Use motivational interviewing techniques, ask open-ended questions and work with patients to identify barriers based on the information you have reviewed together (for example, the diet history and meter/pump/CGMS downloads). Individualized medical nutritional therapy (MNT) is needed to help patients improve glycemic management; therefore, assisting patients to do the best they can within their ability is significantly more important than striving for perfection. Problem-solve together with the patient but be sure to have the patient *set his/her own goals* moving forward so that they feel they can succeed and accomplish all targets addressing the identified issues. Remind patients that fewer goals are more attainable, whereas setting multiple goals at once is less

Table 1. Common factors affecting diabetes self-management in people with T1D

• Inaccurate carbohydrate counting, guessing, eating directly from packages, not reading labels, or not measuring food portions
• Not accounting for the delayed effects of high-fat/high-protein meals with adequate insulin or possessing unfamiliarity with extended bolus options use in pump
• Alcohol intake: type, amount, frequency
• For women: hormonal effects of menses, pregnancy
• Missing insulin injections/boluses – forgetting, or possibly related to not wanting others to know about their diabetes
• Infrequent self-monitoring of blood glucose (SMBG)
• Overcorrecting hyperglycemia or stacking rapid-acting insulin doses resulting in hypoglycemia
• Not using CGMS correctly; ignoring alarms or turning off alarms; not calibrating as directed
• Over-treating hypoglycemia with subsequent hyperglycemia
• Not compensating for exercise/unplanned activity by decreasing insulin or consuming additional carbohydrate necessary to prevent hypoglycemia
• Fear of hyperglycemia, allowing glucose levels to run too low
• Fear of hypoglycemia, allowing glucose levels to run too high
• Hypoglycemia unawareness
• Frequent travel/eating out
• Erratic work schedules; shift work
• Not rotating injection sites causing poor absorption of insulin, not injecting properly
• Outdated or damaged insulin, improper insulin storage
• Not changing pump sites/sets often enough, causing poor absorption of insulin
• Limited numeracy, literacy skills
• Language or cultural barriers
• Difficulty understanding
• Depression/anxiety/cognitive dysfunction or other psychosocial factors
• Poor social support
• Financial insecurity
• Disordered or disruptive eating behaviors or eating disorder
• Sustained insufficient diabetes education

likely to result in lasting behavior change. People are more likely to make changes when the recommendations are personalized versus being given standard recommendations, and indeed, individualized care is one of the main points in the American Diabetes Association (ADA) 2013 nutrition position statement (4) and reiterated in the current 2018 ADA Standards of Care (5).

If you have permission or authority from the referring provider to change insulin doses or pump settings (insulin-to-carbohydrate ratios, correction factor, basal rates) and such alterations are if warranted in the identification that insulin dose changes are in fact needed, make dose changes during the visit, and communicate your changes or insulin dosing recommendations with the appropriate health care provider. It is absolutely critical to document any changes in the patient's medical record. It is moreover important to establish a good relationship with your colleagues, so a patient feels that they have a strong team of support. Refer patients to other team members as necessary, especially if psychosocial factors are identified as an interference to self-care.

For follow up, if patients are willing, encourage them to fill out a few days of records across meal and snack times, insulin doses, blood glucose readings, food/beverage portions and carbohydrate amounts, activity/exercise, and stress/illness/medications. Reassure patients in using whatever format is most convenient for them (paper, electronic, apps, etc.) keeping in mind the patient burden for this record-keeping. For ongoing support, ask patients to upload their pump and CGMS data and share accordingly so that you may continue to monitor progress and use said information for further interventions. Schedule follow-up appointments for ongoing education, support, and goal setting, and always give positive feedback to patients for even the smallest change they successfully make.

The 2018 ADA Standards of Care have identified four critical time points when the need for diabetes self-management education and support is to be evaluated by the medical care provider and/or multidisciplinary team, with referrals made as needed (5):

1. At diagnosis
2. Annually for assessment of education, nutrition, and emotional needs

3. When new complicating factors (health conditions, physical limitations, emotional factors, or basic living needs) arise that influence self-management
4. When transitions in care occur

Additionally, the Academy of Nutrition and Dietetics revised Standards of Practice and Standards of Professional Practice for RDNs in diabetes published May 2018 provides valuable guidance (6).

Nutrition Diagnosis Codes and PES Statements

Using the appropriate Nutrition Diagnosis Codes and PES (problem, etiology, signs, and symptoms) statements, the RDN can accurately identify the nutrition problem(s) and intervention(s) or treatment (7,8). Table 2 provides some examples of nutrition diagnostic codes and PES statements that can be used when working with patients with T1D.

Table 2. Sample Nutrition Diagnosis Codes and PES statements

• Unintended weight loss (NC-3.2) related to insufficient insulin doses as evidenced by 10-pound weight loss over the past three weeks and Hemoglobin A1C of 12%.
• Altered blood glucose levels (NC-2.2) related to insufficient insulin doses as evidenced by hyperglycemia despite healthy eating habits and appropriate carbohydrate intake at meals and snacks.
• Intake of saturated fat inconsistent with needs (NI-5.6.3) related to lack of knowledge of saturated fat content of foods as evidenced by patient-reported intake of high saturated fat and LDL-cholesterol levels of 180 mg/dL and total cholesterol level of 260 mg/dL.
• Food- and nutrition-related knowledge deficit (NB-1.1) related to lack of exposure to nutrition information due to frequent travel and eating out as evidenced by inability to calculate carbohydrate intake of meals and snacks.
• Not ready for diet/lifestyle change (NB-1.3) related to unwillingness to calculate carbohydrate intake and utilize insulin to carbohydrate ratio as evidenced by self-reported carbohydrate intake and mealtime insulin dose calculations.
• Disordered eating pattern (NB-1.5) related to restricting high-calorie, high-fat foods as evidenced by self-reported food intake and low weight for height.
• Inability to manage self-care (NB-2.3) related to limited ability to prepare meals and estimate carbohydrate content of meals and snacks as evidenced by self-reported lifestyle history.
• Impaired ability to prepare foods/meals (NB-2.4) related to physical limitations as the result of recent stroke as evidenced by self-reported lifestyle history.
• Excessive energy intake (NI-1.3) related to intake of high-calorie foods during the evening as evidenced by diet recall and 14-pound weight gain over the past six months and Hemoglobin A1C of 8.9%.
• Intake of types of carbohydrate inconsistent with needs (sugars) (NI-5.8.3) related to unwillingness to change eating behaviors as evidenced by regular consumption of large quantities of sugar-sweetened beverages and Hemoglobin A1C of 10.6%.
• Overweight/obesity (NC-3.3) related to excessive intake of energy and limited physical activity as evidenced by BMI of 33 and diet/physical activity history revealing physical inactivity and usual consumption of 2400 kcal per day versus estimated needs of 1900 kcal per day.
• Excessive carbohydrate intake (NI-5.8.2) related to inaccurate carbohydrate counting resulting in inadequate mealtime insulin dosing and postprandial glucose readings consistently greater than 250 mg/dL.

Summary

Living with T1D is challenging and it is common for people to struggle with their diabetes self-management at various times throughout their life. Identifying individual barriers in a non-judgmental, supportive environment is essential for success. Individualized MNT is imperative for improved glycemic control. To optimize the care of patients with T1D, it is necessary to have a good understanding of diabetes pathophysiology, the currently available types of insulins and their action, diabetes devices from blood glucose meters to insulin pumps, and the emerging technologies such as apps. Using these technologies and helping patients recognize how these tools can be of benefit is very helpful to diabetes self-management. Collaborate with your patients and work together to set individualized, realistic, attainable goals for improved diabetes self-management, and remind them that regular visits with the RDN or diabetes educator are beneficial.

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The Diabetes Educator's Role in Insulin Pump and Glucose Monitoring Technology

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Abstract

Type 1 diabetes (T1D) is a disease possessing a multitude of variables (physical activity, the macronutrient composition of the meal, physical and mental stress) that often lead to unpredictable blood glucose (BG) results as well as harboring the potential for a patient to experience increased burden in disease care and management. Insulin pumps and continuous glucose monitors (CGMs) have demonstrated the potential to lessen the burden of diabetes by specifically providing the ability for one to make insulin adjustments "on the fly" reflective of changing circumstances throughout the day, and in response to such, alter insulin requirements as needed. It is the role of the diabetes educator to provide the patient and supporting family members with information on technology options and to furthermore offer educational resources and training on the functional use of said technology and resulting data.

Introduction

In 1976 the first insulin pumps were made available outside of the research setting to individuals in order to publicly enhance the management of diabetes. At that time, rapid acting insulin was not available and did not appear on the market until 1996. However, studies suggested better results than with the other treatments at the time (1).

Rapid acting insulin first became available in 1996 (2), but it was not until 2001 that a rapid acting insulin was approved for use in insulin pumps, specifically for adults, and began paving the way for a more physiologically available external insulin delivery (3). Currently over 1,000,000 people worldwide use insulin pumps (4) prescribed by more than 2,000 physicians.

With a change in the option for insulin delivery, the next challenge facing patient and provider alike became bridging the time interval between self-monitoring of blood glucose (SMBG) checks. Even with frequent SMBG, the question was this: where was the BG trending between finger sticks? In 2005 the first continuous glucose monitor (CGM) for patients' individual use was launched. This provided much needed information to note BG trends over time that could aid in insulin delivery decision making. The sensor reads interstitial glucose rather than capillary glucose, so there is a short lag time compared to finger stick readings of 5-15 minutes. This is particularly true when BG levels are changing rapidly due to changes in fluid flow in the area of the sensor, and sensor signal processing time (5).

Insulin Pumps and CGM, the Present

Fast forward to our current era in