Hypoglycemic Confidence in People with Diabetes and their Loved Ones: The Dietitian's Role in Accentuating the Positive

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Abstract

Hypoglycemia, including severe hypoglycemia, is recognized as a substantial burden to persons with diabetes (PWD), their partners, and family members. Worries and fears about hypoglycemia, or low glucose, contribute to not achieving the glucose goal and impaired quality of life. Hypoglycemic Confidence (HC) is the degree to which an individual feels able, secure and comfortable in his or her ability to stay safe from hypoglycemia-related problems. Assessing HC in PWD and their loved ones can be the catalyst for conversations that engage persons to prepare, optimize medications, and select tools that can provide comfort and security to master hypoglycemia-related problems.

Introduction

Robert and his wife Betsy admit their lives have been turned upside down since his type 1 diabetes (T1D) diagnosis last year. Robert's regular exercise routine has become much more burdensome and less enjoyable because of constant insulin and food adjustments to prevent severe hypoglycemia. Even worse, Betsy had to call 911 for a serious low following a particularly active day. As a result, Betsy now sleeps poorly as she worries his blood glucose will fall dangerously low during the night. Robert now secretly takes less insulin than prescribed and snacks more to both avoid those frightening lows and get Betsy off his back. The result is a higher HbA1c, weight gain, frustration, and a lot of stressful disagreements between the two of them.

Hypoglycemia, and particularly severe hypoglycemia, are primary contributors to diabetes-related emotional distress in PWD, their partners, and family members (1,2). Fear of Hypoglycemia (FOH) and its concerns are often even greater in partners and family members than in PWD (3). More than two-thirds of partners and family members of PWD say they are exhausted by worrying about hypoglycemia (4). This should come as no surprise as treating severe hypoglycemia is demanding, immediate, frightening, and can leave partners traumatized.

Any PWD using insulin, T1D, type 2 diabetes (T2D) on basal/prandial, and T2D on basal, is at risk for hypoglycemia and, potentially, severe hypoglycemia (5-7). Severe hypoglycemia occurs at all ages and all levels of glycemic management. A 2019 study in PWD with T1D (T1 PWD) ages 1 to 93 years found that 3-14% of PWD experienced a severe low in the past three months (8). The greatest frequency was found in those with A1C <7% and >9%. The use of real-time continuous glucose monitor (CGM) systems lowered the incidence

of severe hypoglycemia in the previous three months from 7% among non-users to 4.5% among users. Compared to those using multi-daily injections, pump users had a lower incidence of severe hypoglycemia (9% vs 5%) (8). Although technologies could help to lower the occurrence, they were not able to entirely eliminate severe hypoglycemia.

Until recently, healthcare professionals have focused on assessing and alleviating diabetes distress (DD) and FOH in PWD and their loved ones. New evidence, however, suggests that it may also be valuable to focus on a third element: the opposite side of fear, Hypoglycemia Confidence (HC). HC is distinctly different from hypoglycemia fear in both PWD and their partners. The Hypoglycemia Confidence Scale (HCS) and the Partner-HCS are reliable and validated measures that can be used in PWD and their partners (3,9). Registered Dietitian Nutritionists (RDNs) have unique relationships and conversations with PWD and their families that frequently focus on hypoglycemia concerns and issues. These conversations can be enriched when tools such as the HCS are employed to help identify overall confidence as well as individual contributors to HC. Together with PWDs and their loved ones, RDNs can inform and explore ways to build HC. Here we will review the research behind the HC concept and components, who should be assessed, and what can be done to help improve HC.

Hypoglycemia Confidence in PWD

Diabetes care and education specialists and healthcare professionals are familiar with helping PWD develop the confidence to adopt self-management behaviors that lead to optimal health and quality of life (QOL). A certain degree of confidence, or self-efficacy, is critical to successfully perform most self-management tasks and to cope with the demands of living with diabetes.

Enhancing HC by helping an individual feel able, secure, and comfortable in his or her ability to stay safe from hypoglycemia-related problems can be part of any educational intervention when there is a concern of hypoglycemia. As previously noted, we now have validated reliable tools for assessing HC in T1D adults, T2D adults using insulin, and T1D spouses/partners (3,9). Furthermore, though not yet formally validated, we strongly suspect that the tool for T1D and insulin-using T2D adults will be usable by older teens, and that the tool for T1D spouses/partners will be equally applicable for the spouses/partners of insulin-using T2D adults.

HC illustrates the importance of not just focusing on the negative (e.g., fear), but considering in parallel the positive aspects of a PWD's experience. Feeling safe and confident is not merely the absence of fear and worry, it is a sense that hypoglycemia can be generally avoided and managed, if not mastered. The 9-item Hypoglycemia Confidence Scale (HCS) self-report tool was studied in T1 PWD and PWD with T2D (T2 PWD) on basal/prandial insulin or basal insulin only. Higher HCS scores were significantly associated with measures of diabetes-related QOL, including lower levels of DD and FOH in all three groups (3). Higher HCS was associated with better glycemic management in T1 PWD and T2 PWD on basal/prandial insulin. The failure of HC linked with glycemic management in PWD on basal insulin only may be due to fewer hypoglycemia events and thus less hypoglycemia experience (3).

As noted, real-time CGM (RT-CGM) and insulin pumps have reduced the prevalence of hypoglycemia and severe hypoglycemia. Can RT-CGM also serve as a tool to enhance HC in PWD? In two recent clinical trials, HCS rose significantly in T1 PWD after RT-CGM was introduced (10,11).

Hypoglycemic Confidence in Partners of PWD

Nearly 65% of partners of PWD report being moderately to extremely worried about hypoglycemia in contrast to 40% of PWD (2). Since partners and family members are often more distressed and anxious about hypoglycemia and severe hypoglycemia than PWD, a 12-item self-report Partner-HCS was developed to study if HC is present in T1 partners (9). As expected, greater partner HC scores were associated with lower levels of DD, FOH, and general anxiety. Greater partner HC was related to the PWD experiencing fewer severe hypoglycemia episodes in the past six months and partners not having to directly assist in helping PWD recover from severe hypoglycemia. This suggests that HC results from individual experiences with hypoglycemia. Having glucagon available for the treatment of severe lows and confidence in the ability to use glucagon were also linked with greater HC scores (9).

In the Partner-HCS validation study, more than one in three partners (38.5%) had low HC, which was surprisingly high since 92.2% of T1 PWD were using CGM (9). These data underscore the complexity of HC and the importance of gauging the partner or family member's

confidence and comfort in dealing with hypoglycemia and severe hypoglycemia since their beliefs and concerns can influence the support that they provide to their PWD. For example, a partner like Betsy could appear to be nagging their PWD to check blood glucose levels more frequently or even encourage them, directly or indirectly, to keep blood glucose levels higher than recommended.

Addressing HC in Clinical Practice?

Since every PWD on insulin is at risk for hypoglycemia, clinicians need to be diligent in recognizing the problem exists and that hypoglycemia avoidance tactics may be impacting behaviors of the PWD and their loved ones. Even clinicians are not immune to hypoglycemia avoidance tactics. Therapeutic inertia, the failure to escalate therapy when glycemic goals are not met, is receiving considerable emphasis as the number of individuals achieving glycemic goals has stagnated over the last 10 years (12). Concern regarding hypoglycemia is identified as a major barrier to escalating glycemic therapy and therapeutic inertia in PWD and their clinicians.

Sharing in decision making with PWD and their loved ones.

1. Discuss hypoglycemia concerns with PWD and loved ones. Consider asking the PWD: *"How confident are you that you can avoid or address serious problems with hypoglycemia?"* Ask a second question to a loved one: *"How confident are you that your partner will be able to avoid or address serious problems with hypoglycemia when you are not around?"*
2. Consider using the full HCS for PWD and/or Partner-HCS to identify specific elements of hypoglycemia to focus on in the discussions. Demonstrate your desire to *talk about what concerns them most*. Refer to team members to address issues when needed.
3. Advise PWD and loved ones to *talk to each other* about hypoglycemia concerns. Ask children if they have talked to their friends about how to help them when needed.
4. Discuss CGM and the *value of checking blood glucose* results to evaluate issues they can then seek help in problem solving.
5. Evaluate medication regimen together to *problem solve* around dosing and timing. Watch for overbasalization in T2 PWD who may be trying to avoid prandial insulin.
6. Evaluate and *discuss prevention strategies*, especially around vigorous or unusual exercise bouts or changes in food intake or timing.
7. Evaluate and *discuss hypoglycemia treatment strategies*. Be nonjudgmental in how PWD reacts to lows and severe low; PWD may find them embarrassing, frightening, and physically and mentally draining. The 15:15 rule (see details on page 1) is a place to start but all PWD eventually develop their treatment algorithm based on how low and how rapidly their blood glucose falls.
8. Emphasize the goal of being confident and how confidence can be achieved by *being prepared*. Emphasize what to do and what is needed, including carrying fast-acting carbohydrates and glucagon so that these are available when and where needed, such as school, home, gym or sports venue, or office.

Partners and family members need to provide support to PWD, but they also need support themselves; they commonly feel the responsibility to help manage hypoglycemia in the PWD. In a large survey of T1D and T2D family members, respondents said they provided emotional support, helped prevent hypoglycemia, helped treat mild/moderate hypoglycemia, and treated severe hypoglycemia (13). Nearly half (48%) claimed such took up too much energy. Only 20.5% of partners felt they have support from family and friends on these issues and only 12.4% felt support from HCPs.

Peer support from partners, family members and friends is extremely important to overall health and well-being and even more so for the PWD, especially children with T1D (14). Developing resilience in youth with T1D involves promoting protective skills and behaviors, including obtaining support from family and friends. Youth with T1D completing resilience assessments at summer camps scored lowest in their ability to share their diabetes with friends and felt they could not rely on their friends to help with their diabetes if needed (15). This represents a high-risk situation in youth who have frequent episodes of hypoglycemia and severe hypoglycemia. Parents from the same camps concurred that the most important topic they wanted their children to discuss with their friends was recognizing and treating hypoglycemia, yet most said they had not (15).

When to Address HC

When striving to enhance self-efficacy in PWD and their loved ones, healthcare professionals have the opportunity to explore the issue of confidence to manage hypoglycemia.

This can be done periodically by addressing issues directly or referring individuals to appropriate members of the healthcare team to address.

Times to explore and possibly measure HC include:

- At diagnosis. Both PWD and loved ones are overwhelmed at diagnosis, however, T1 PWD or T2 PWD starting insulin are at risk and should be taught how to recognize and treat hypoglycemia.
- When medication dose or timing changes occur, especially if a sulfonylurea or insulin is being introduced, prandial insulin is added, or basal insulin dose is increased. Resistance to medication changes may occur if a PWD has experienced frequent hypoglycemia or has had a severe event that was traumatic for all involved. See "Medication-Related Hypoglycemia: Causes and Treatments "article in this *OTCE* issue for further information about medications that impact hypoglycemia, page 11.
- When glycemic goals have not been achieved in the recommended time frame. Quite often elevated FOH or low HC may result in PWD and loved ones keeping blood glucose levels "running high" to prevent lows.
- When physical activity, food intake, or sleep patterns change. Partners of PWD express they are most concerned about severe hypoglycemia while their loved one is exercising or sleeping. CGM data illustrates that over 40% of nighttime readings are often in the "low range." Clear guidance for adjusting medication and/or food intake to prevent lows at this time is important. Appropriate treatment during an activity such as consuming an appropriate amount of fast-acting carbohydrates and having easy-to-use glucagon available can go a long way to helping everyone feel prepared.

Summary

Hypoglycemic confidence in PWD using insulin and their partners or loved ones is a unique and important dimension of the hypoglycemia experience worthy of evaluation and intervention. All diabetes team members can bring the topic up with a simple question and, if warranted, consider using validated HC measures that can further direct the conversation. The resulting interventions designed to enhance HC can improve an individual's medication experience and skillset to be prepared to prevent and treat hypoglycemia and severe hypoglycemia. The RDN, as a key member of the diabetes team, frequently has more interaction with the PWD than other team members. The RDN can assume responsibility for identifying issues and concerns about hypoglycemia and help PWD and their loved ones enhance their confidence to feel safe and prepared to master hypoglycemia-related problems.

Permission for reprint has been provided for the two scales mentioned in this article: 1) Hypoglycemic confidence scale, 2) Hypoglycemic confidence scale for partners of adults with type 1 diabetes. (Please see the OTCE addendum folder for these these two confidence scales.)

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