

Diabetes Cannot Be Controlled, But It Can Be Managed

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As a diabetes social science researcher and person with type 1 diabetes for more than 24 years, I cringe when my health care providers (HCPs) suggest that I need to “control” my diabetes. I know exactly what they are saying; however, I have come to accept that control is beyond my capability. Merriam Webster defines “control” as, “to direct the behavior of something to do what you want; to have power over” (1). If only I had this super power! On the other hand, the definition of management is, “to handle or direct with a degree of skill” and “to take care of and make decisions about” (2). This is something I can do!

Let me illustrate the difference. If you have children, you may believe you are controlling your children when they do what you are asking them to do. However, you only have the illusion of control. The children maintain control over their actions; they just decide to cooperate and to do what you want them to do. Diabetes is very much like a child. You may believe you have control because your glucose was in a healthy range at a given time. Diabetes may have cooperated, but it was not controlled.

My earliest recollection of balking at the notion of control was about 24 years ago, when I was ordered to avoid sugar at all costs, with the associated promise that my glucose would be fine. Please keep in mind that this was before we understood insulin-to-carbohydrate ratios. I refused to

eat anything that contained sugar. I obediently maintained my regimen of two injections of NPH insulin daily and 5 units of regular insulin three times daily with meals. To my dismay, my blood glucose inexplicably soared after some meals and plummeted after others. How could this be? I was doing what I was told. My doctor gave me the look that told me he was certain I was “cheating.” I knew better. This was when I knew I could not control diabetes.

Today, we know that diabetes is a multifaceted disease, with numerous factors interfering with consistent blood glucose management. These factors include diet, physical activity, medication, stress, illness, hormonal changes, dehydration, and pain (3). Polonsky et al. (4) resonate with me as they characterize diabetes management as a “complex, demanding, and often confusing set of self-care directives.” Furthermore, current notions of diabetes management place a heavy burden on people to maintain healthy blood glucose levels. This expectation of controlling blood glucose has contributed to an atmosphere laden with stigmatization of people with diabetes (5). On occasion, loved ones or complete strangers have winced when I have checked my blood glucose and questioned my dietary choices with a prying, “Can you eat that?”

People with diabetes have two primary self-management strategies: proactive and reactive. The proactive approach requires a person with diabetes to attempt to prevent extreme

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blood glucose levels. For example, lowering your pump basal rate while exercising could prevent hypoglycemia; counting carbohydrates instead of using fixed dosing for meals may allow you to maintain your blood glucose in a healthy range. The reactive approach requires retrospective problem-solving. If the blood glucose is currently high, taking correctional insulin will assist in lowering it. Conversely, if blood glucose is falling, drinking juice can be used to avert or treat a hypoglycemic event.

My husband describes diabetes as the math problem that never ends. I count my carbohydrates, calculate insulin based on my insulin-to-carbohydrate ratio, and add in any correctional insulin needed before taking the dose. In reality, after many years of performing such calculations, the dose I take is still just my best estimate. Even dietitians cannot always calculate carbohydrates accurately, so what hope do I have? It is unreasonable to expect control over something if we do not know all of the factors influencing a given phenomenon. Thus, the notion of controlling diabetes places an impossible burden on both patients and their HCPs.

It is important that patients have an accurate expectation of diabetes self-management to achieve optimal outcomes. Furthermore, illness representations predict self-management behaviors, lending support for constructing an accurate representation of diabetes and the ability to manage it (6). In addition, Richardson et al.

(7) found that diabetes-related perceptions were related to A1C. Toward this end, the power of words cannot be denied. In the patient-physician relationship, words must be thoughtfully chosen to convey intended meaning. Rowe et al. (8) suggest that patients and providers likely have differing expectations in clinical encounters, shaped by their personal beliefs, fears, and attitudes.

Patients carry their HCPs' words and perceived expectations from the exam room to their home, where the treatment plan is implemented. Indeed, even when patients with diabetes have applied self-management strategies, diabetes has a mind of its own and will not be controlled; there is the very real possibility that blood glucose levels will unexpectedly rise or fall. There are factors beyond patients' control and awareness, such as counterregulatory hormones and insulin sensitivity, that may vary throughout the day.

I submit that terminology used in health care settings has evolved over time, reflecting providers' current beliefs and attitudes about patient care. For example, Tilson (9) suggested replacing the term "compliance" with "adherence" to better reflect the desire to promote shared decision-making between health care providers and patients. Thus, I propose that a similar shift from "controlling" to "managing" diabetes would be appropriate to more realistically reflect the current understanding of diabetes treatment.

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Duality of Interest

No potential conflicts of interest relevant to this article were reported.

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