A few years ago, my endocrinologist and I decided that seeing a certified diabetes educator (CDE) was the best move to help my diabetes management.

Unfortunately, my insurance company had a different view: The powers-that-be didn’t think diabetes education was necessary and denied my claim.

This certainly isn’t unique to CDE requests, or even diabetes care. It’s a systematic healthcare failing that irks many people – why is my insurer deciding what’s best for my health, and not listening to what my doctor and I have already decided is needed?

My doctor appealed and helped my insurer see the “medical necessity” of a CDE. However, when the bill arrived, I couldn’t help but be amazed that the CDE was charging me $65, which was twice as much as it cost me to see my endocrinologist who my insurance considered a “specialist.”

I ended up seeing this CDE once, and after that decided it wasn’t worth paying double the amount of a regular endocrinologist office visit. As someone living with type 1 diabetes (T1D) for roughly three decades at the time, it wasn’t critical enough for me to have that insight for what I was forced to pay.

Fast forward to 2016: I’m dealing with this exact same issue with a new health maintenance organization (HMO) insurance plan that is a bit picky on things like this.

The only choice I have for diabetes education and fine tuning my diabetes management is to consult someone from outside of my endocrinologist’s office. With my HMO insurance configuration, in order to work with a CDE elsewhere, it requires a referral from my insurance-mandated Primary Care Physician, and out-of-pocket costs for the larger “specialist” co-pay that is higher than what it costs to see my endocrinologist. For now, I have to say, “No, thanks.”

It’s not worth the time and hassle for me to make this happen right now, despite the likelihood of a CDE helping me achieve better diabetes results. I do think I’m lucky that I don’t need a CDE as a key part of my D-management routine. For me, today, having a CDE is a “nice to have” more than a “need to have.” A combination of my own diabetes experience, access to good doctors, and peer-support from the diabetes online community (DOC) are all big parts of keeping me healthy.

However, one diabetes complication, one life-altering low blood sugar requiring emergency assistance, or one episode of diabetic ketoacidosis (DKA) from hyperglycemia, and that story changes. “Nice to have” then becomes “medical necessity,” and shifts the acute goals of my diabetes management from “preventative” to “responsive.”

Imagine those who are not living with decades of T1D experience, but are newly-diagnosed with any particular type of diabetes. They are scared, overwhelmed, and need support and basic education that goes beyond the typical few minutes with their clinician during an endocrinologist visit.

These folks are just starting the world of diabetes management, which is 24 hours a day, 7 days a week, 365 days a year, for the rest of their lives. It’s overwhelming. It’s overwhelming even if you have lived with diabetes for more than three decades like I have. Yet, we are asking them to take these new demands on life and all of this new information, with the expectation that they will simply figure it out.

I wonder about these people who need access to a CDE but can’t afford it. Or those who are told insurance won’t cover
the visit, and they don't know the decision can be appealed. Where do they get advice from? What do they do? How do they figure it out?

We already know that people with diabetes don’t have good enough access to CDEs. The latest data from the American Association of Diabetes Educators (AADE) shows an amazingly small percentage of people with diabetes routinely see a diabetes educator.

You have to wonder why that is. Personally, I think that access and affordability are big barriers to diabetes education.

Reaching out to my current endocrinologist about this, he pointed out that “nothing with insurance companies surprises me any longer.” And my former endocrinologist in another state told me his office just started charging for diabetes education in March, because the time has to be justified to the payers.

I get it. Really, I do. Diabetes care is a business, and our providers need to get reimbursed and make a living just like everyone else. Still, the cost of CDE coverage by insurance doesn’t seem to make much sense – to me, there’s no reason why a CDE visit needs to cost more than the endocrinologist’s office visit co-pay.

When it comes to costs, this is baffling. We could prevent so many incidents of diabetes emergency response if we simply had better training and more information. This same argument applies to continuous glucose monitoring, and soon even closed-loop insulin pump systems. As it is with these technologies, time with a CDE seems like a small investment for such a grand payoff in cost savings of diabetes emergency care and diabetes complications.

The AADE and the American Diabetes Association continue to advocate for better access to diabetes educators. Data from a recent study published in Patient Education & Counseling shows that diabetes education, when added to usual diabetes care, lowers HbA1C and leads to better health outcomes, yet insurers don’t seem to be listening.

Whether we are patients, clinicians, or researchers, it’s easy to agree that more education about the best practices and strategies of managing diabetes of all types is preferable to ignoring actions that can lead to positive results. Now more than ever, research and reputable sources are confirming that diabetes education is beneficial to long term success with all types of diabetes.

If this education is so important, I shouldn’t be forced by my insurance company to pay more for a CDE visit than what it costs to see my endocrinologist. Maybe I could be a bit healthier and even cost my insurance company less money if they simply offered better coverage for quality diabetes education. Maybe I could recommend diabetes education to my peers in the diabetes online community. Seeing an educator can be just as important, if not more, than many other parts of a person’s D-management. Maybe we could live longer, more productive, and healthier lives without diabetes complications and even cost less for insurers and the overall health system.

Maybe in the near future diabetes education will become the standard for all people with diabetes, instead of the exception. Maybe sooner than later.

FURTHER READING