

Our Journey with Type 1 Diabetes for over a Half Century: A Dialogue between Patient Spouse and Her Physician Caregiver

Linda Severidt, Larry Severidt*

Broadlawns Medical Center, Regional Dean Des Moines University, University of Iowa, Des Moines, Iowa
Email: *lseveridt@broadlawns.org

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Abstract

A personal perspective and a narration by a patient and her Physician spouse caregiver regarding coping with evolution in therapeutic modalities including ongoing changing insulin formulations and insulin administration devices. Narration also encompasses and establishes the utility of the improving glycemic monitoring tools in assisting in attaining desirable glycemic goals.

Keywords

Insulins, Insulin Pumps, Glucometer, Continuous Glucose Monitoring System (CGMS)

Dialogue:

Larry

Our story begins over 50 years ago. I was a premedical student at Iowa State University and had the good fortune to meet a beautiful young coed on campus. On one of our first dates I asked Linda if she would like to join me for a pizza after I finished doing some studying. Thankfully she said yes but I was quite surprised when she told me that she could not eat pizza at 9 PM in the evening or for that matter any time. This is when I first learned that she had developed diabetes at age 16. I was intrigued with this information but at that point knew absolutely nothing about diabetes.

Linda presented to her family doctor at age 16 with polydipsia, polyuria, and weight loss. He immediately diagnosed her with diabetes mellitus type 1 and she was admitted to the hospital where she spent the next 1 week. She learned how to give herself insulin injections and her diabetic education was to say the least very interesting. She was told that she would likely die at a

young age and that she would likely be unable to have children. Also the prospect of kidney failure and blindness were discussed. Fortunately then as now she was determined to take good care of herself even before we understood that good control could minimize and eliminate many complications of diabetes.

Linda

At the time I was diagnosed the only available insulins were NPH and regular. For the first few years I was controlled nicely by taking 12 to 14 units of NPH insulin each morning along with following a diabetic diet. In retrospect I had a “honeymoon phase” and was likely still making some of my own insulin during that time period. Several things that we now take for granted such as home glucose testing, continuous glucose monitoring, long-acting insulin, insulin pumps, were not available. Monitoring consisted of seeing my family physician (there was no endocrinologist in the city where I lived) monthly for fasting and post-prandial blood glucose done by venipuncture. Home testing consisted of urinary test tape to look for evidence of glycosuria and if acutely ill to look for evidence of ketones in my urine.

Eventually a single shot of NPH did not adequately control my sugars and I started taking a combination of NPH and regular in the morning and evening. Adjustments were difficult in the absence of careful blood sugar monitoring but I seemed to get along quite well. As Larry progressed in his medical career he was paying close attention to current literature regarding the care for diabetics. In 1982 the DCCT (Diabetes Control and Complications Trial) was begun [1]. It is hard to believe but before this study many medical experts did not feel there was a relationship between control and prevention of complications [2]. In essence they were saying that this disease will be running its course and there is not much you can do about it [2]. This was not particularly good feeling for a young and otherwise healthy diabetic like myself.

Larry

The DCCT trial was a large multi-center randomized controlled trial that looked for and compared complications in diabetics that were put on a strict regimen to control their blood glucose levels versus routine standard care [1]. The trial was terminated early because of the profound decrease in complications for those patients who were under good control. Over the next several years the concept of intensive conventional therapy was developed. Long acting insulins became available and Mayo Clinic was promoting more intensive therapy. Linda and I discussed this type of treatment and she subsequently went to Mayo Clinic where she was started on an intensive conventional therapy of long-acting insulin plus regular before each meal. Also this was around the time when home glucose testing became available and hemoglobin A1c testing became available for routine clinical practice. All of these advances made management of Linda’s diabetes much easier and much more effective.

Linda

Larry and I were married before he began medical school at the University of

Iowa. After 3 years of marriage we decided that if we were going to have children it would probably be best to manage a diabetic pregnancy at a major tertiary Medical Center. I was under the care of the perinatal team at Iowa under the direction of Dr. Frank Zlatnik with whom we both became well acquainted. Controlling my diabetes consisted of twice weekly appointments with Dr. Zlatnik at which time I would present fasting for a venous glucose test and then have some breakfast and have a 2-hour postprandial blood glucose drawn after eating. The pregnancy went well and at 37 weeks gestation I was hospitalized for elective induction. After 2 days of Pitocin and not making significant progress a cesarean section was done and our son Mathew was born. Mathew's weight at 37 weeks gestation was 9 pounds and 9 ounces. Obviously my glucose levels were not tightly controlled but certainly I did not have any severe episodes of hyper or hypoglycemia during the pregnancy. We subsequently had a second beautiful baby girl Mary during Larry's second year of family medicine residency. Interestingly Mary also weighed 9 pounds and 9 ounces at 37 weeks gestation.

Larry

After residency our family moved to Manchester Iowa where I began my family practice career. Linda did well and continued to be active and healthy without complications of either retinopathy or renal disease. In the mid-1990s Linda began to experience her first complication of diabetes, that being hypoglycemic unawareness. She was unable to sense low blood sugars which put her at high risk for hypoglycemic events. Fortunately home glucose testing was then available and she managed by testing herself multiple times daily to determine what was happening with her blood sugars.

Linda

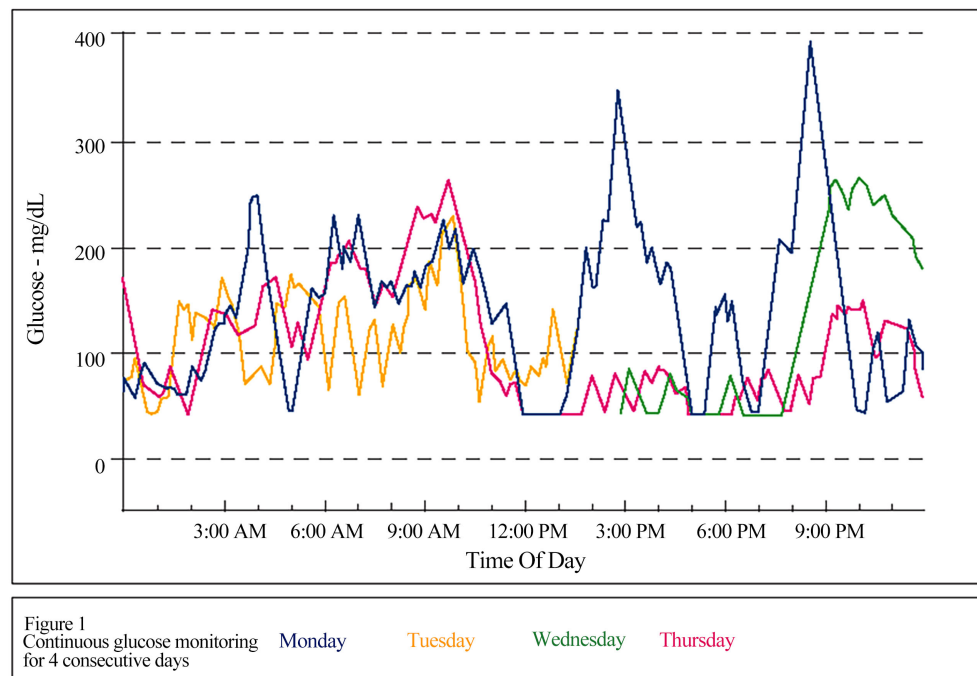
Eventually this became a disabling problem. I did not feel safe in driving other than for very short distances by testing my blood sugar before I got in the car and then retesting wherever I arrived. The same routine was needed for the trip home. I also worried about my own safety and the safety of my children should I experience an unanticipated hypoglycemic episode. Home glucose monitoring was not available but through laboratories you could arrange to have 3 days of blood glucose monitoring. As you can see, my glucose levels were fluctuating significantly (**Figure 1**).

Larry

This is about the time when Linda got her first insulin pump. This resulted in the minimal improvement in the control of her diabetes and hypoglycemic unawareness.

In 2000 Dr. Shapiro at the University of Alberta published an article in the New England Journal of Medicine about islet cell transplantation [3]. This work had been ongoing for many years but Dr. Shapiro developed a new protocol which consisted of new procedures and nonsteroidal immunosuppression. In his study 7 of 7 patients that received islet cell transplantation were insulin free for 1 year after their transplants [3]. This obviously interested me and as I studied the

Sensor Modal Days

Patient: Linda Severidt
ID: 73195457MiniMed Solutions: CGMs sensor
MMT-7319 3.CA

Report Printed: 19-Sep-02 8:25 AM

Figure 1. Extensive variability of diurnal glycemia noted on CGMS.

article I realized that Linda would be a perfect candidate for transplant. Dr. Shapiro was particularly interested in long-term diabetics with minimal complications and hypoglycemic unawareness.

This was still strictly a research project but we were able to reach out initially to the University of Minnesota and subsequently Northwestern University in Chicago and Linda was accepted into a transplant program.

With some divine intervention and the support of wonderful friends and colleagues Linda was able to undergo a series of 3 individual transplants which allowed her to be insulin free for almost 4 years.

Linda

I received 3 islet cell implants; first in 2002 and the last one in 2005. My strongest recollection is a sense of relief, gratitude and wonderment. I was totally aware of the process as I was awake through the procedure performed by an interventional radiologist. To watch islet cells implanted into my body and knowing the result is likely to be a cure was an exhilarating experience. Those of us with type 1 diabetes are instructed to practice self-care to ensure survival, but never taught to expect a cure.

My Implanted cells started producing insulin within 24 hours. One of my first celebrations was to take a 3 mile walk without worrying about a hypoglycemic episode. My glycemic awareness returned almost immediately, and after my first implant I needed very little insulin.

To preserve my islets I was treated with several immunosuppressive drugs,

and since I was part of a study I traveled to the implant site on a monthly basis. I maintained a cure thus not requiring insulin injections for 4 years. Over the next couple of years, I gradually lost the ability the implanted islets to produce insulin. However, I was definitely grateful for not requiring insulin injections and more importantly for the benefit of the return to hypoglycemia awareness from unawareness and the associated risks.

Regardless of my temporary cure I always thought of myself as a diabetic and did not change my eating habits or activity levels. I continued to check my blood sugars regularly for several months to assure myself of the functioning implanted islets. After a few months it was suggested to me that I think about cessation of performing multiple finger sticks per day (this was before CGM systems were available). After sharing this anecdote with an audience of physicians that we were speaking to, a psychiatrist approached me and said that my “diabetic thinking” made sense. After all, he said, “thinking in terms of diabetic self-care is survival for those of us who live with diabetes”.

Therefore, I have always lived with diabetes with constant attention to being compliant in terms diet, exercise and continuous monitoring.

I am hopeful that eventually diabetes will be cured. My experience getting opportunity to participate in the islet cell implant research study has enabled me to experience firsthand the professionalism and dedication of the physicians and staff doing this research and their determination to find a cure.

Larry

Where are we now?

As was likely to occur Linda’s diabetes returned 4 years after her transplants. Fortunately she did not have as much difficulty with hypoglycemic unawareness. She continues to do extremely well and remains very active and to this day has been blessed not to have any retinopathy or renal disease.

Three years ago after attending a play we were walking to our car on a cold winter night. When we got in the car Linda told me that she had some vague discomfort in her chest which was relieved after sitting in the warm car. Rather than go home we went to the hospital and she subsequently had a coronary angiogram which revealed an isolated lesion and she underwent a coronary stent without complications. This is not an unexpected thing to occur in a longtime diabetic but again thanks to advancements in health care this problem was quickly managed.

Linda and I recently celebrated our 48th wedding anniversary. We feel very blessed to have shared this journey together. We had two beautiful children and currently have 2 wonderful granddaughters. We hope that our story gives hope to other diabetics that this disease can be managed and that you can lead a full and fulfilling life while you manage your diabetes. We are also hopeful that with continued research more and better options will become available to manage and hopefully cure diabetes mellitus type 1. It is also our hope that our health-care system evolves to the point where it can provide the latest treatments for all

patients dealing with this disorder regardless of their socioeconomic status. I believe that everyone should be afforded the care and expertise that was available to Linda.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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