The key to managing diabetes in children and adolescents

Lori Laffel[†]: Information about the interviewee

Q What initially drew you to working in the field of diabetes management?

The management of diabetes offers so many challenges and the approach to caring for a person with diabetes has so many opportunities. Working in the area of diabetes clinical care and research we can provide ways to manage and live with diabetes, there is so much hope for future improvements in care and preservation of health and there are certainly opportunities for future approaches that may near a cure.

My first exposure to diabetes was in medical school at The University of Miami (FL, USA), which has had a very strong diabetes program for many years. As a medical student I attended a diabetes camp and lived in a cabin with children with diabetes, and I was able to witness how these individuals were doing their best to manage their diabetes. Through multidisciplinary approaches all of the staff at the camp were working together for the single goal of creating a safe and successful experience for the kids. It allowed me to see how these patients were children first, and yet children who were living with a very demanding and chronic medical condition. This allowed me to have an emotional attachment to the management of diabetes and this combined with my intellectual curiosity about ways to optimize diabetes care and advance the field. While we had opportunities then, there were certainly many challenges and I wanted to be a part of making things better for these children.

Q How did you career lead you to the Joslin Diabetes Center?

In diabetes care, a clinician will tend to self-select whether they want to take care of pediatric patients or adult patients, and I always had an affinity for working with children, having been a councilor before I attended the diabetes camp. In addition, I had an intellectual curiosity in endocrinology and mechanisms involved in understanding the physiology as well as the pathophysiology of the endocrine system and endocrine diseases,

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particularly diabetes. I have a quantitative background in mechanical engineering and the notion of the feedback systems that help us understand the endocrine system was a natural match to my intellectual inclinations; so I thought of training in pediatrics, after which it was only natural to seek some specialty training in pediatric endocrinology. I then did my general pediatrics training at the Children's Hospital in Boston and my specialty training in pediatric endocrinology at both the Children's Hospital in Boston and the Joslin Diabetes Center, where I have remained ever since.

Q What do you consider to be the greatest achievement in your career so far?

While we continue to try to master diabetes therapy, we recognize that we have not reached the finish line yet, so it is imperative that there is another generation of very talented people who are entering the field of pediatric endocrinology. My greatest achievement in general diabetes research, clinical care and clinical investigation, and what I call 'paving forward', is that I have the wonderful opportunity of mentoring the younger generation of college students, medical students and research assistants. These individuals will hopefully make another great impact in conquering this disease, so I continue to be very involved in mentoring and attracting young scientists and investigators to the field of biomedical and behavioral research in diabetes. That is, I would say, my greatest achievement.

Q The Joslin Diabetes Center is a world renowned centre for its research & clinical care; how does it feel to be part of this organization?

I feel privileged to have had my training at the Children's Hospital in Boston and the Joslin Diabetes Center and to have become a staff member after my training. It allowed me to feel like I am a part of a group of individuals who are trying to push the inside of the envelope and find new ways to manage, reverse, cure and prevent complications. Working at the Joslin Diabetes Centre has allowed me to work with colleagues looking into areas different to my own but with one single mission and vision, which is to make the world a better place for people living with diabetes. I certainly feel like my colleagues and I are participating in the effort to advance the field of diabetes.

Q How have you seen the Pediatric, Adolescent & Young Adult Section evolve in the years that you have been working there?

I have seen our unit quadruple in size, both in terms of the number of patients and families coming in for care, and in terms of our staff. We now have a staff of almost 40 members, in both our pediatric research and clinical endeavors. The great contribution we make in delivering care is that we provide research efforts alongside the care we deliver, so it's very much a two-way street: we learn from the families and the families appreciate that they are getting state-of-the-art care and are contributing to research to try to make sure that care is not only better for their own families but also for others as we all gradually work for a cure.

Q What is the age range of diabetic patients that you treat at the Joslin Diabetes Center & how does your care differ between the age groups?

At our center we work across the spectrum of young children, school-aged children, teenagers and adults; these different stages of development require very particular approaches to care as there are very unique targets for glycemic control and for the screening and management of the potential for developing complications of diabetes.

The young children are challenging because they cannot communicate their symptoms, if their sugar is out of their control then they are totally dependant upon their family members for their care. On the other hand, because their parents are a captive audience, the care provided is often superb because parents want to do the best for their children. We stress the importance of family care in diabetes, regardless of the age of the child. We do not expect a child to manage his or her diabetes on their own.

When a child reaches adolescence they want to be doing much more independent thinking and activities; however, the

challenges of adolescence are multiple because during pubertal growth in early adolescence the blood sugar becomes harder to control. We never want adolescents to feel guilty about their blood sugar being out of range because they may be in the midst of puberty, so we try to surround them with the notion of family and teamwork in diabetes management. We recognize that adolescents truly have much more free time and have to begin to undertake and accept the approaches to their self-care or shared self-care with their family members. Often people say that adolescents are not motivated to care for themselves; there is no question that adolescents are extremely motivated, but often their diabetes is not at the top of the list. We have to continue to be supportive of adolescents and appreciate that they are juggling many challenges. We need to provide a safety net, ongoing family support and teamwork to help shepherd teens through the challenging period of adolescence.

There is fourth stage called 'conversion to adulthood', which is when the older teens or young adults are now leaving their home, and are either attending college or working on their own. At this time we see even more challenges in terms of making sure that the adult is engaged in managing their condition and seeking the medical care that they need from their diabetes team. For this reason, we are very involved in trying to understand the period of transition of emerging adulthood. We are very fortunate at Joslin Diabetes Center, in that we have the depth and breadth in diabetes so that we can stand and appreciate these unique and demanding developmental stages.

Q What kind of techniques do you use in order to encourage adolescents & young adults to prioritize managing their diabetes?

We have multiple approaches, and we individualize these to the patients. While we recognize the importance of targets in the national guidelines, we acknowledge the patients' needs, and what we seek from patients is involvement and improvement. Individuals will have competing demands in their lives, and we want to keep diabetes as a part of those demands, but we want to be realistic. In order to do this, we work closely with individuals and find ways to understand the other demands in their life so that we can try to fit diabetes into their lives, not their lives into diabetes. We recognize that these are people first, who happen to have diabetes, and we try to find ways that the program can fit into the lives of these young and talented individuals. We provide realistic expectations and do not place any unnecessary demands on our patients that would be impossible for anyone to meet within a short period of time.

Certainly we want to achieve optimal glycemic control in patients; however, our main goal is for patients to feel engaged in their care. When you look at the risk factors for diabetes complications there is no question that glycemic control is a potent risk factor; however, the greatest risk factor is likely to be losing patients from the care environment. This is why we focus on ensuring that we are a welcoming environment for children, teenagers and adults of all ages, so that they never have to be ashamed or embarrassed if they feel like they are potentially missing the mark or the expectations for their diabetes care. We always want the young adults to be able come in and talk to us about that. We can then problem solve together; we can understand what is working and what is not working, then tailor the diabetes program to the needs of the individual.

Q So providing a supportive environment is definitely a big priority at the Joslin Diabetes Center?

It truly is. We are in a very fortunate environment at the Joslin Diabetes Center that has the breadth, depth and focus on diabetes. In our team we have pediatric endocrinologists, an adult endocrinologist who works in our transmission program, nurses, practitioners, pediatric dieticians, psychologists, social workers, pediatric medical assistants and child life specialists who from a very young age actually help children to want to come to their medical appointments because they are greeted in a very playful and nurturing environment

in which they are learning about their diabetes and feeling supported and engaged at the same time. We have office staff who know the individuals when they answer the phone, so being at the Joslin Diabetes Centre we are fortunate to have been blessed with this opportunity, and as the head of the program I have been able to help build this environment that really is family focused and provides a multidisciplinary approach to carry this out.

Q Any there any specific research projects that you are working on at the moment?

Yes, we are working on a number of projects. The main basis of my research is to try to understand the barriers that exist for achieving optimal glycemic control, and once we understand the dietary interventions to overcome the barriers to optimize glycemic control, we can maintain normal growth and development in children, prevent chronic complications and most of all preserve and protect the futures of the children growing up with diabetes.

Once we identify barriers, we design interventions. Most of these are family-focused behavioral interventions, which focus on teamwork in diabetes management, this is important even for something as commonplace as checking blood sugar. We have to put in a tremendous amount of work focusing on the importance of the language we use so that people never feel ashamed or blamed for their results. So we have devised interventions focused on the language surrounding glucose monitoring and family teamwork.

We have also designed a lot of approaches to using technology as an aid to optimize the adherence to the HbA1c diabetes management test, which will in turn improve glycemic control. We developed one of the initial approaches to the wireless transfer of blood glucose data, to a central server and have also worked to develop blood glucose reminders, for example text messaging to remind teenagers to check their blood sugars. We have done a lot of work in trying to understand approaches that could be implemented in continuous glucose monitoring technologies in pediatric patients.

We have a long history of previous work, but I'll just share with you two main studies that we are working on right now. In one study, we are trying to address a return to looking at nutrition and helpful eating. We all know that diabetes management requires the orchestration of diet and exercise and that means influencing the foundation of education and glucose monitoring, but with this new era of "carb counting" and being more flexible in meal planning, we are taking a back seat to focus on "carb counting". With colleagues from the National Institute of Health we have been designing and implementing an intervention that enhances the quality of carbohydrates in the foods that children with diabetes eat. Our goal is to devise behavioral interventions, and motivational interviewing and problem solving techniques, creating a curriculum in which we are focusing on overall healthy eating. The key goal here is that we will improve glycemic control and recognize the epidemic of childhood obesity, so by encouraging healthy eating we will have more favorable outcomes and improvements in body composition and other measures of nutritional status such as lipid biomarkers.

The second study is on new technology for continuous glucose monitoring. I have the privilege of being the co-chair of the Juvenile Diabetes Research Foundation continuous glucose monitoring multicentre trial, which demonstrated continuous glucose monitoring to be efficaciously reduced in adults with Type 1 diabetes. There was an improvement in children and adolescents, but only with those that used the technology consistently. The current study that we are about to recruit for and that we have been designing, funded by the National Institute of Health, is to employ a family-focused behavioral intervention to encourage consistent views of continuous glucose monitoring technology in children and adolescents with Type 1 diabetes. This is because we want children and adolescents to benefit from the same improvements in glycemic control and the same prevention of reduction in hypoglycemia as adults who use the technology have been able to experience. We hope to be able to share what we learn with the wider diabetic community.

Q What developments do you hope to see in the field of diabetes management over the next 5 years?

Recognizing that we have had tremendous advances in technology with improvements and availability in glucose monitoring, I am certainly optimistic that we will see a greater emergence in technology with approaches to the artificial pancreas. Certainly at this stage in time we will see greater advances in how we can predict how diabetes will develop, but I certainly hope to progress our knowledge so that we may find ways to preserve pancreatic functions.

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