

Patient-centered care at Joslin: Reflections of a mirror

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ABSTRACT

This personal communication describes the practical aspects of patient-centered care (PCC), as viewed by a person with diabetes, who is also a diabetes educator. He describes his encounters with two leading diabetologists, who practiced the real essence of PCC. The author also explains the impact these patient-centered doctors had on him, and how it has shaped his personal as well as professional life, over the past half century.

Key words: India, patient empowerment, patient values, shared decision making, USA

INTRODUCTION

“Patient-centered care” (PCC) is the buzz word in modern diabetes care. We continue to hear and learn more about PCC, and its multiple dimensions.^[1,2] Having the patient as the leader member of their diabetes team, many of us believe, helps patients understand how to balance their life with diabetes optimally. The PCC model has the patient in the center, while we, the diabetes providers, walk by their side. We educate, support, and empower them to help ensure the fullest of health, both psychological and physical. This fuller health allows our patients to live productive lives with their families and friends, grow in their careers, progress in their schooling, their sports, maintain their mental health, and excel in all aspects of life.

I have been fortunate to experience PCC from both sides of the table as a person with diabetes, as well as a diabetes educator. This has helped me understand and internalize the concept of practical PCC, as opposed to just knowing the theory of this approach to diabetes care. Being on both sides of the patient-provider encounter has allowed

me to look at PCC through a two-way mirror. In this brief communication, I hope to share my reflections on PCC, as learnt as a patient, and then a counselor, at Joslin.

Staying focused on PCC, let me share with you two exceptional examples of this approach that I have benefited from. One episode is from the day that I was diagnosed with type 1 diabetes, some 51 years ago. Another powerful example of PCC is from my first day as the first ever full-time psychologist/counselor at the Joslin Clinic in Boston.

DIAGNOSIS DAY: I CAN SKI

When Dr. Leo Krall told my parents and me that I had diabetes, my mother’s eyes filled with tears. I remember looking at my father, the pinnacle of strength for our family, and noticing the tears running down his cheeks. My father was a bright man with an outstanding academic record. He had graduated from Harvard near the top of his class, and even he did not understand what this new diagnosis meant. I could only imagine that if my tearful father did not know that something must be very wrong. Even today so many people know very little about diabetes. If they do know something about diabetes this limited knowledge all too often focuses on the sad stories; the disabling complications of diabetes.

My father then grabbed Dr. Krall’s arm and led him out of the room into the hallway. His words still ring in my ears today, more than 50 years later, ever so clearly. “What does this mean? Will my son be able to stay active and play

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with the other children? We are supposed to go skiing next week; will he be able to ski?"

Within seconds, Dr. Krall came back into the clinic, with my father. I remember Dr. Krall telling me that if I along with my parents would work with him and the team at Joslin, to learn about balancing my diabetes, I would become the best skier ever. I do not remember anything more about that first appointment. In fact that first discussion with Dr. Krall was very short. I did not need to hear anything more from him at that time. I heard what I needed to hear; that if I was willing to learn how to balance my diabetes, I truly would become the very best skier. On this scary, emotionally draining day, this is exactly what I needed to hear!

LEARN TO BALANCE

I had learned on my diagnosis day the most important lesson of all: If I balance my diabetes, then I could be the very best I could be! This simple message along with the love, support, and patience of my family and friends, as we learnt about diabetes together, allowed me to grow. I was able to expand this "being a great skier" belief into understanding that I could be the best in whatever I chose to go after in life! I have grown with this belief from the very beginning, and try to share it with all people with diabetes that I come in contact with.

PATIENT-DRIVEN EDUCATION

This first unplanned diabetes experience serves as a constant, powerful reminder for me, as a diabetes educator, that our teaching must always focus on what the patient needs rather than what the outline says should be covered. This requires that we, diabetes professionals, encourage and allow our patients to help set the agenda. We are clearly the experts regarding the knowledge of diabetes treatment, but the patient is the expert relative to their needs. Our role is to guide, coach, educate, and support them so that they are best equipped to meet the multiple challenges their diabetes presents every day.

COUNSELING DAY: DR. PRISCILLA WHITE AND THE CAT

Now let me share with you my first day on the job at the Joslin Clinic as Joslin's first full-time psychologist/counselor. I had the distinct privilege of doing rounds with one of my early mentors Dr. Priscilla White, the famous diabetologist.^[3] My practical learning began as soon as we entered the first four-bedded indoor ward. As we walked

toward the room, I remember Dr. White looking at just the front of the patient's medical record. Before we entered the room, she closed the medical record. Right away, Dr. White started to ask this young girl with diabetes, how her cat was doing. The patient's eyes and the excitement in her voice displayed her approval of Dr. White's first question immediately. For what was no longer than 2 min Dr. White powerfully taught me that as a healthcare professional, my care must go well beyond just the insulin dose, exercise, and food. In those brief 2 min, Dr. White connected powerfully with this young patient. Her caring question about something this young patient valued nurtured a powerful level of trust from this patient. The remainder of the discussion was focused on the patient's life with diabetes and she shared her thoughts readily.

SHARING VALUES, SHARING DECISIONS

It was this spirit of affirmation for her patients, knowing some important things that her patients valued, and building a shared value system that was unique to Dr. White. I saw how this focus on the total person, not just the biological person, helped ensure that Dr. White's patients were excited to share with her, and empowered as they made suggestions as to what would be most helpful for them. Dr. White was the expert in the room. However, she displayed humility with her patients. She would support them, and when needed coach them to look at something differently if she deemed this would be better for the patient. The level of trust that she built with her patients allowed the dialogue to be robust and ensure that the patient more readily shared relevant information with Dr. White and the medical team. The terms "PCC", "shared decision making", and "bio-psychosocial model" had not been coined in those days,^[4,5] but Dr. White embodied the very spirit of these concepts.

THE QUESTION IS WITHIN, THE ANSWER IS WITHIN

During those last few years of Dr. White's active clinical practice, I saw numerous times how her positive spirit would invite her patients to so often find answers to their own questions. She and several of my colleagues at Joslin had a unique ability to help the patients to develop and refine their questions, and develop best solutions around the challenges of balancing their diabetes around their lives. As they helped patients manage diabetes, they continued to explore additional questions with their patients and family members so that the patient would so often develop their own answers. Dr. White and these other brilliant colleagues were the experts, and guided

the patients when they did not understand enough about what was influencing their blood sugar management. Powerfully, their questions which were developed by their patients' responses, helped mold the next question ensuring that the patient was taking the lead to develop solutions to optimize their diabetes management.

PATIENT-CENTERED CARE TODAY

After over 35 years as a mental health specialist, there is no question in my mind that colleagues who adopt this patient-centered approach far more often, have a higher percentage of patients who address the daily challenges of their diabetes management in a significantly better and more efficient manner, than the bulk of the patients who are just told what to do.

The PCC does not come easily for many of us. Throughout our schooling and professional training, we are frequently asked to memorize facts and be able to state these facts back to our instructors both verbally and on exams. All of us who are medical professionals have obviously learned how to do this relatively well. To take this important knowledge that we have gained from instructors and from books, we must couple it with a high degree of humility coupled with our sincerity and expertise so that we can be the most dynamic educators and clinicians for our patients.

PATIENT-CENTERED CARE IN INDIA

During my short tour of India, to several cities and top diabetes centers, I have been ever so impressed to meet a number of clinicians who truly embrace PCC. I have seen PCC in myriad forms, in different settings, in multiple

languages. But all these facts of PCC share one common denominator: That of a respectful relationship^[6] between the clinician and the person with diabetes. On behalf of people with diabetes across the world, I applaud you and thank you.

“There are only two ways to live your life.

One is as though nothing is a miracle.

The other is as though everything is a miracle.” Albert Einstein

I am fortunate and thankful that I have so often been able to look at so much of life as my multiple miracles!

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