A Patient’s Journey: Navigating Life with Type 1 Diabetes

Maram Dalab
PERSONAL NARRATIVE

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ABSTRACT

We are all patients. This article represents my views from my personal experience with type 1 diabetes for 25 years, in combination with my professional experience over the past 10 years as I have worked in patient support, health promotion and improving the patients’ experience. I aim to provide an outlook on the patient perspective, how the physician encounter translates to them and finally, what are some gaps that need to be filled in order to have a better experience and better health outcomes as a result. As I wrote the article, I shared my perspective building on my personal encounters and reflected on what I personally believe could be added to the journey of patients in order to improve it.

Keywords: Patient experience, Health literacy, Patient empowerment, Healthcare encounter, Shared decision making, Health coaches, Adherence, Patient education

1. Intent of the essay

In this narrative, I intent to share my personal story of living with type 1 diabetes, shedding light on the challenges encountered and the profound insights gained. As both a patient and a health promotion practitioner, my goal is to emphasize on the significance of patient-centered care and advocate for improvements in the overall patient experience, driven by a deeper understanding and empathy cultivated through patient stories combined with the power of scientific knowledge.

My aim out of sharing my experience, is to inspire healthcare professionals, policymakers and the wider community to actively engage in improving patient care by understanding the patient perspective, practicing healthcare in a truly caring way and empowering individuals with chronic conditions like diabetes.

2. Introduction to the narrative

Having lived with type 1 diabetes since 1999 has been a journey of approximately almost 9000 days. According to the calculation I did through JDRF DiaDigits Calculator, I did more than 71,000 blood sugar checks, received more than 62,000 insulin injections, lost more than 200 days of sleep and spent more than 12,000 hours in correcting hypoglycemia episodes. The numbers could be perceived as overwhelming, but I find that this is a very interesting calculator that visualizes to me my strength in overcoming such numbers. It is also a reminder that this experience has equipped me with the ability to navigate life’s complexities, honing skills in multitasking, emotional intelligence, and project leadership. My journey has been a testament to resilience, illustrating that every day presents an opportunity to move towards a better future.

My experience with diabetes inspired me to pursue a career where I would be able to change lives, help educate the community and support patients. Not only that, but has also heightened my awareness of clinical and hospital settings and health systems.

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3. Synopsis

In this narrative, I will navigate through topics that I found important yet burdening in my experience as a patient. I will also reflect on potential ways to improve such encounters with an aim of enhancing the journey as a whole. Starting with the importance of ensuring patients’ comfortability to share, express and eventually get empowered, moving to the importance of shared decision making. Reaching to the very critical point of the impact of time limitation and its compounding effect and finally highlighting the impact of complex healthcare systems and their impact on adherence and disease management.

4. General narrative

Through more than 24 years of encounters, certain elements have emerged as crucial in defining positive and progressive clinician-patient interactions.

To begin with, I or any person living with any disease, need to feel safe and comfortable with their care providers. This “safe space” feeling is pivotal as we are most vulnerable when we are questioned about our disease care, how do we take care of ourselves and what are the actions that we take to manage this unwelcomed guest that we have. Patients need to be able to express themselves comfortably, freely and in a judgement-free way. This not only helps the patient feel comfortable, but it also helps the physician, nurse or educator to have a realistic understanding of the patients’ daily experience and take the informed medical decisions accordingly. It also enables the patient to become open and accepting of guidance and accordingly, confident in handling situations and feeling in-charge of their case.

As an adolescent with diabetes, I had a physician who was highly knowledgeable and capable of managing my case. The challenge was that I felt judged and heavily challenged for not following specific instructions. I accordingly dreaded the visits, felt that I was unable to share my thoughts comfortably and sometimes adjusted my sugar log book to appear better than my actual results. Looking back, I obviously realize the impact of such actions on creating suboptimal care plans. Nonetheless, I believe that such a result can be a natural repercussion for an unhealthy relationship between some care providers and patients. While I highly note the burn-out that care providers go through, the norm needs to be that an open and a comfortable setting needs to be availed for patients.

This leads me to the second important element, “Shared Decision Making”. Once the patient is in-charge and empowered, they become able to participate in their condition’s care. With the right guidance and support from their healthcare team, the patient plays a very important role, not only in managing their disease, but in also providing the clinician with the right information that they require. This helps put the patient on the right disease management plan and supports them in taking the lead on daily basis.

I had this experience with a physician who drastically improved my disease care, even during highly challenging times, such as pregnancy. The difference with this physician’s approach, was that she was keen on establishing a strong connection between us and that she was highly informed with the technology that I used for my disease care. We worked together as a team, she enabled me to make suitable choices for my life, ensured that I was educated & aware and was available to contact when I needed her consult between visits.

The challenge that I found with Shared Decision Making, is that it would be challenging when patients are not at a high level of health literacy. And here, from a professional perspective, I would say then it is our role as professionals to ensure that we provide all the possible routes for health education and disease awareness, to help ensure that community members are well educated to understand their own healthcare needs. This starts from educating children in schools, up-to the highest levels of education in universities, even if the course of study is not health related.

The third element is related to time limitation and its compounding effect. To ensure education, means that time needs to be spent with the patient to understand and learn. Time limitation is one of the biggest barriers when it comes to a healthcare encounter. As patients, we have a limited time to spend with the treating physician, a lot of that time is spent on typing information into the system for my medical record, another part of it is spent on physical examination and finally a limited time, of the 20-25 minutes, is dedicated to sharing the concern, feeling, experience and opinion of what has been happening for at least the last 3 months.

The challenge with sharing in this small window of “time to share” is that it doesn’t do justice to how the patients feel. Patients feel anxious about their medical condition, with worries about “how can it evolve?”, “what else could it impact physically?”, “would I lose
my job?”, “will it affect my family?”. They then need to translate this emotional luggage to only focus on the physical symptoms that are to be shared with their healthcare practitioner. In the case where the HCP has empathy, they don’t only provide medical guidance, but they also move to a deeper level and try to assure the patient and then involve them in taking the best medical care decisions in order not to burden them with their condition management.

I highly appreciate the partnership type of patient-physicians relationship. It enables room for assurance, engagement and understanding. But also, in my opinion, this needs to have a collaborative team effort where educators, mental health experts and perhaps “Health Coaches” would get involved with the patient to improve their experience.

The last element that I will reflect on in this narrative is the complexity and inconvenience of some health systems. It is one of the most elements that burden me in my disease care, and I admit, affects my adherence too. The need to have multiple visits, long waiting hours and several locations to see my healthcare team every couple of months leads me to prioritize the most important visits, and sometimes postpone the lesser important ones to a later time. Now, I fully acknowledge my accountability to dedicating this time in-between visits for better health outcomes, but I also believe that a system or a process needs to be simplified and can be rolled out with more convenience.

5. Recommendations

Simple tweaks can drastically change the patient experience and make life with the disease a bit easier, and this could start with putting the phone on silent and establishing a caring connection with the patient. To increasing patients’ comfortability and engage them in their care plans, I recommend for healthcare professionals to utilize soft toned words and point out issues in disease management without judgement. This can be also supported by health organizations through continuous soft skills, empathy and coaching trainings delivery to healthcare professionals. Establishing a partnership with the patient is critical. This can be done by setting roles and responsibilities in alignment with the patient, this empowers the patient and adds accountability to their perception of their role in their experience. Involving patients through shared decision making and co-design methodologies are highly effective in achieving this level of empowerment.

Time limitation and it compounding effect is a common pain amongst both patients and healthcare professionals. Putting systems in place such as telehealth with support teams or digital tools where patients can log their complains, remarks and experiences prior to their visits, can serve as a pre-read for the healthcare professional before the visit and accordingly set a common ground for the discussion where the patient can feel that the HCP is aligned and set an effective action plan accordingly. Finally, the complexity and inconvenience of the healthcare system might lead to lack of adherence. I would accordingly recommend starting with tailoring personalized plans based on patients need and lifestyle and then utilizing technology to create a hybrid setup of face-to-face visits for critical elements, digital platforms to increase health literacy, patient reporting and online consultations with the support team and home delivery for their medications.

With the combination of empathy, empowerment, education and innovation, a lot can be accomplished in improving the interaction and experience of both the patient and the clinician. This should not only be on the shoulder of the clinician; it takes a team. Therefore, patients need to be actively involved to play their critical role in improving their experience as well.

6. Reflections

Having said the above, I must acknowledge the amazing healthcare practitioners that I had throughout the years, with the support and care they gave, I was able to navigate many hardships in my journey. But I believe, that there is a lot to be done, as I have also encountered some healthcare teams sharing personal opinions/phrases such as “Oh My God you are too young to have diabetes!” or simply not providing me with the listening ear that the support I need is beyond just medicine prescriptions and lab tests.

7. Conclusion

Through my narrative of living with type 1 diabetes, I hope to shed light on the importance of patient-centred care. By empathizing, understanding and tailoring the approach, we can improve the healthcare system to make sure it truly meets the needs of patients. As I believe that only through these measures can we enhance the patient experience and ensure better outcomes for all stakeholders in the continuum of care.
While on the profession, I often like to provide myself with a reality check. I will share this with you as well, ask yourself the question: Who Are Patients? The answer will provide us with the guidance that we need. For patients are us, our parents, our children and our friends... Therefore, we need to deploy our care to patients with the same value and care that we would apply when caring for our loved ones.

Reference