TO ZERO
Co-creating a path to end
childhood sexual violence

solutions insights lab

“It’s an open-source development community” Mi-Young Kim of the Korean Type 1 Diabetes Association on leveraging technology and utilizing media strategically.

Yubin Kang
September 9, 2024

Yubin Kang: Please introduce yourself, including your name and the organization you work for.

Mi-Young Kim: I’m the head of a patient group called the Korean Type 1 Diabetes Association. Our group specifically deals with type 1 diabetes, which is different from the commonly known type 2 diabetes, in which the onset period is not fixed and can be diagnosed in people of all ages from childhood to the elderly. The hormone insulin is needed in our body, but the beta cells of the pancreas that secrete insulin are destroyed by an autoimmune mechanism. It is a much more severe disease than the commonly known type 2 diabetes, and one cannot survive without injecting insulin.

I don’t have type 1 diabetes myself, but my son was diagnosed at the age of 3, and he will soon be 16. Thanks to him, I learned about it and the difficulties people with type 1 diabetes face. We shared those in our online community, and rather than just sharing among ourselves and feeling upset, we decided to make this our voice, create an organization, and convey our situation to the government and stakeholders around us to receive institutional and policy support.

It started as an online community called Sugar Tree, around October 2015. Sugar Tree has many meanings. Sugar is just sugar and Tree is also an abbreviation for the treatment tree. It means treating sugar, and our hope is for it to be cured, so we named it with that in mind.

There were limitations in raising our voices in government governance, so in July 2017, we established the official patient group. You can think of Sugar Tree as the name of an online community where patients can communicate. When we're active externally, we operate as the Korean Type 1 Diabetes Association.

Yubin Kang: Could you explain how your approach differs from those organizations, and how it is different from the Korean Diabetes Association (KDA)?

Mi-Young Kim: Overseas, there are active patient groups and groups that are financially well-off and support researchers' research funds. However, in Korea, most patient groups are poor. The origin of patient groups in Korea is to gain access to new expensive drugs. We have insulin, but innovative medical devices to manage blood sugar levels are much more helpful, such as continuous glucose monitors and insulin pumps, which in October 2015 were not available in Korea.

To introduce and actively utilize these medical devices, patients shared their know-how within the online community. The methods of importing them and translating guides written in English into Korean. In this way, patients helped each other and a community was created. Our organization was created to introduce innovative medical devices to prevent and manage diseases that can lead to a decline in quality of life.

We have a global type 1 diabetes community and a Korean patient group. It's an open-source development community. We develop new applications or algorithms using medical data collected through existing medical device apps. Our patient association develops together with the global type 1 diabetes community, and we collect patients' medical data separately digitally.

We manage it more scientifically, by using my data to extract various statistics that can help with future management, or by looking at real-time trends. That differentiates us from other domestic patient groups or the Global Type 1 Diabetes Association.

Yubin Kang: What prompted you to do that, could you explain more?

Mi-Young Kim: Before my son was born, I worked as a developer at the Korean branch of Motorola, a company in the US that used to develop feature phones, not smartphones. Then I moved to Samsung Electronics' wireless division and worked as a smartphone developer. Because I had some IT knowledge and a background in development, it was easy to access open-source projects in the global type 1 diabetes community.

When I worked at Samsung, my son was diagnosed with type 1 diabetes. For the first year, I measured blood sugar by drawing blood from his fingertips. At that time, he was 3 years old, and I checked his blood sugar 10 to 24 times a day. In the case of type 1 diabetes, blood sugar levels go from low to high. Low blood sugar levels can be fatal if they last for 30 minutes, and high blood sugar levels can cause various difficulties in life due to complications if they accumulate over the long term, so I had no choice but to check his blood sugar levels frequently.

Even though I organized the slightly analog data at home after work, digitally using Excel, and drew graphs, it was volatile and would become too much work. The need for digitized data that could be collected automatically, grew bigger. I had a vague idea that it would be nice to automatically measure blood sugar without me having to check it, transmit it to the device via wireless technology, such as Bluetooth, upload it to the cloud and transmit it to parents who are remote via the network.

A year after my son was diagnosed, I searched the global community and found that they were doing open-source development activities. If I had no IT knowledge at all, I would have just vaguely imagined it, but now the global community was doing it, and I could go in and understand it. I used a lot of open-source projects in Korea.

Yubin Kang: There must have been various efforts and approaches you've used to achieve your goals, is there a good example where it was effective?

Mi-Young Kim: In many patient groups, young children have difficulty expressing themselves or raising their voices externally. That is why, when they are young, their parents take their place, and when they become adults, they speak up in patient groups on their own. However, there are cases where the parents and adults of these children do not get along well. The parents of the children say, “Since they are young, please give them some support first.” Or the adults say, “We have the same disease, so why do you keep dividing us by age and giving support only to children? It is difficult for us too.”

There always seem to be issues about the priorities of policies, but in our organization, it was the parents of patients and young children who started it at first, and they contacted us because of the enforcement ordinance of the Elementary and Secondary Education Act. There were a lot of cases where very young children were denied admission to kindergarten because they had to get insulin shots and there was a risk of hypoglycemia and hyperglycemia.

We revised the Infant and Toddler Care Act, and if you look at the revised version, type 1 diabetes is included in the priority of care. Children with type 1 diabetes can receive extra points and be admitted first. Our patient association promoted this, we worked hard to inform the media, and we visited members of the National Assembly. When we tried to revise this law, adults in particular said, "Why are you guys doing that on your own? Is that what your children want? We don't want to reveal our diseases."

We tried to persuade those adults and consistently explained, “If we don’t speak up, no one will know about our difficulties and pain. In a way, we need to show our handicap to be considered and let the public know what we need.” When our community was first created, mostly by the parents of type 1 diabetes, the adults didn’t share our views, but as we continued to work for all type 1 diabetic patients regardless of age, they saw our sincerity.

Now, about 55% are parents of children with type 1 diabetes, and 45% are adults with type 1 diabetes. The ratio is much more balanced than before, and what I've been moved by recently is that many of those adults are actively participating in the activities of the patient association. Whether it's online activities or offline activities, they work hard.

I gave a lecture to about 500 health teachers nationwide, both online and offline. There were a lot of adults with type 1 diabetes, almost more than parents. I thought, "Why did these people take vacation days to hear this health teacher lecture?"

Firstly, they wanted to support the representative who worked so hard, and the second reason is that when they were in school, they didn't receive medical support from the health teacher, so they came out to tell the health teacher about the difficulties they had during their school days for the juniors to receive support. I was touched when they showed up there.

Yubin Kang: Were you moved by the fact that things built up over the past seven years, and some change has occurred?

Mi-Young Kim: I'm acting as the representative, but we have about 18 executives nationwide. This is a disease that is difficult to manage, it is difficult for the children, and the guardians, and many people complain of mental difficulties. The regional representatives go to those who struggle mentally and help them with blood sugar management. Patients receive a lot of comfort from that group, and the overall direction of our patient association is not to pursue some kind of profit or do something political, but to truly do it for the patients.

Yubin Kang: Could you explain the results of the various development activities and data-related analysis activities you mentioned as points of differentiation?

Mi-Young Kim: If we only use medical devices made by existing medical device companies, the data is fragmented. For example, in the case of my child, we use medical devices called A and B. Medical device A is stored on the server of medical device company A, and medical device B is stored on the server of company B. However, we need to integrate this to help with blood sugar management.

Through an open-source project, we integrated the various data manually entered by people from these two, stored them in one Amazon Web Service (AWS), and created personal storage space. We were able to utilize it, and we did it because our patient association was the only one in the world. Patients can see reports on how many months of data they analyzed, how much insulin they're currently injecting, how much when they eat, how much overall, and how it is daily, and an environment has been created where they can manage their blood sugar better.

Secondly, we are creating such data because, in the medical field, real-world data is important. When you are hospitalized, clinical data is collected and it comes from a different environment than daily life, so there is bound to be some bias. However, there was no way for hospitals or researchers to collect such data from patients who were not hospitalized. Since we are collecting it, researchers said that they would conduct a study on it, and we were able to use it to study patients' blood sugar management patterns.

Collecting medical data by patients like this is not done globally, nor by patient groups, so the Ministry of Health and Welfare and the Ministry of Science and ICT have recently become very interested in collecting individual citizens' data, called MyData. The government has not yet properly promoted collecting medical data, but the Ministry of Science and ICT has become very interested.

Yubin Kang: Among the many things you've done, if there's a case that didn't work out that well, but still left an important lesson, please tell us about it.

Mi-Young Kim: Rather than a failure, it was a trial and error where I proceeded without knowing much. One situation was when the medical device measuring the continuous glucose meter wasn't approved in Korea, I first saw it in an overseas community. When I went to the site, people in my country couldn't buy it, later I used Virtual Private Network but at that time, I imported the medical device through acquaintances who lived overseas.

Under the medical device law, some laws prohibited the use of medical devices that were not approved in Korea. We didn't know there were such laws. As a result, we were reported to the Korea Customs Service, and the Ministry of Food and Drug Safety investigated it. I violated the law but was not seeking profit or harming others, so I was suspended from prosecution, and it was settled. However, even before receiving the suspended prosecution, as the situation became known, many citizens shared opinions such as, "The law should be changed to make patients do such difficult things on their own." We received a favorable ruling of suspended prosecution.

Our incident led to the creation of the National Institute of Medical Device Safety Information in 2018. The institute created a system where, like our situation at the time, even if it wasn't approved in Korea, it was approved overseas, and if patients wanted to use it, they could exempt them from the requirements, or they could import it and deliver it to patients. Rather than saying it was a failure, we should have checked various laws before proceeding, but we didn't, so we experienced some difficulties, and it was a blessing in disguise.

Yubin Kang: I would like to ask about some of the limitations. Other than the funding issue, what was the biggest difficulty or limitation you faced?

Mi-Young Kim: Most people think that patient groups receive government support. They think we speak on behalf of the government or are manipulated by it. But we are not like that. On the contrary, we are a group that strongly demands or criticizes the government.

Whether we express an opinion and relay it to the Ministry of Welfare, the National Health Insurance Corporation, or the Ministry of Food and Drug Safety, or conduct a survey at our patient association, people are not very interested. Instead, when a bad case becomes a big issue and is reported in the media, or when some politicians take an interest something moves.

It takes a long time to solve a problem, and sometimes, if the timing is good, a member of the National Assembly asks a question during the state audit, and it's solved. When that happens, I feel grateful, but we need to continue raising our voices.

Yubin Kang: Public health or safety campaigns often require changes in people's behavior and mindset. But I think your work also includes changing cultural norms. What is the most effective strategy or solution for changing social awareness of a certain issue?

Mi-Young Kim: Before my son was diagnosed with type 1 diabetes, I didn't understand the lives of patients or their families. In the past, I didn't even know that there were diseases that couldn't be cured. I had to give injections and deal with hypoglycemia and hyperglycemia as a non-medical person, it broke the mold of what I had previously thought of as a patient.

Diseases like ours can't be managed daily unless the patient has the same medical and IT utilization knowledge as the medical staff. In general, patients are very passive beings who receive medical services and there is a strong perception that they cannot do anything on their own. We need to break the general concept of patients.

During the pandemic, we were diagnosed with COVID-19 but we couldn't go to the hospital. In the end, the recovery status changed due to how well we managed ourselves, the prescriptions, and how much rest we took. Regarding new infectious diseases, shouldn't we change the existing image of patients and the definition of a patient?

I also lecture a lot in university departments related to IT. If we get contacted by major or small media outlets, if they want to include our voices, we accept almost all of them. And we conduct awareness-raising campaigns for our association every year. We make videos, publicize them, and are moved when we realize they were well-made. But when they are delivered to non-diabetics, even 3 minutes is too long.

Our association made a type 1 diabetes family musical and toured the country. When the audience came to see the musical, they learned about type 1 diabetes, but when we asked them about it they said, "What is this disease?". They didn't watch it. Next year, a movie called "Sugar" will be released. It's based on the actual activities of my family, and our patient association. The Korean Film Council recognized the quality of the scenario, and we received support for the production cost. My role is played by actress Choi Ji-woo. It is an opportunity for the general public to learn about type 1 diabetes, like in dramas such as "Marathon" or "The Strange Lawyer Woo Young-woo". The patient association strives to change people's perceptions in various ways, from the perception of patients to the perception of what type 1 diabetes is.

Yubin Kang: Who are your main partners, and how do you form and maintain cooperative relationships?

Mi-Young Kim: Our patient association is active in the Korean Patient Association which supports several patient groups. We mainly deal with issues related to our disease, but when we speak out about overall healthcare issues or the various systems surrounding our disease, we work together in this organization.

There are also academic societies for medical professionals like The Korean Diabetes Association and the Korean Endocrine Society. When it comes to specific characteristics of patients' diseases that they don't know about, they ask us. In August, there was a session at the International Diabetes Association of Korea to present about the stigma of patients and the difficulties of type 1 diabetes patients, and the professor of the association asked me to provide the data because he didn't know much about it, so I made it for him.

When the patient associations speak out together or if experts and patients agree, it gives more power. There are many committees within government ministries, such as the Public Health Review Committee, the My Health Way Committee, and the National Bio-Integrated Big Data Committee, which I've been going to recently. In the past, clinical drugs or medical devices were mostly developed based on the opinions of medical professionals, but now they ask the patients' opinions.

At first, when we visited, we were often treated with disdain. But recently, the so-called experts, the medical staff, invited us, and when I speak, other people say, "Oh, you pointed out things that we hadn't thought of, things that we had missed." It took seven to eight years, but there's now an atmosphere of recognition.

Yubin Kang: What insights and lessons can others gain from your experience?

Mi-Young Kim: Actually, I never thought of becoming a representative, nor did I think of organizing an organization. At first, I just wanted to find a way to manage my child's blood sugar, who has type 1 diabetes. I didn't plan on organizing a group or anything like that, but my child had to live healthily, and as a parent, I thought I had to make the world a little more comfortable for him until the day he died. All children with the same disease as my child had to do well, and we had to unite and speak out.

We created it without any foundation at all, with the sole purpose of creating a world where people with type 1 diabetes can live comfortably, the rest of the things naturally came about out of necessity. The purpose has to be clear, and if you do the activity with sincerity, the rest will follow.

Yubin Kang: What efforts did you make to encourage and unite companies, local communities, and organizations to work together on this issue, and what did you focus on?

Mi-Young Kim: First of all, we communicate a lot with companies. We think about not only the products we use but also the social contribution projects. When we do awareness campaigns, we tell them to refer to it.

We have a partnership with the diabetes-related business division of a pharmaceutical company but it also makes various functional foods and other things, such as the diagnosis and treatment of eye disorders, ophthalmology. Because complications can arise in ophthalmology, the ophthalmology business division sponsors us with nutritional supplements. There is only one company I have a bad relationship with, a medical device company. When we asked them to improve their products, they didn't respond. So we issued a statement criticizing the company, and after that, I was sued 18 times.

Our patient associations are located nationwide. If there are people with influence in the area, they knock on the doors of local councils and have them change regulations. Each local government has a chronic disease center. We brought about changes in providing support, such as supplies or medical expenses.

In the case of institutions, some are linked to government ministries. The Korea Health Industry Development Institute, the Korea Institute of Health and Medical Research, and the Health Insurance Review and Assessment Service. They ask us for advice or review, and we get recognition.

Recently, the government has been doing something called the National Integrated Bio Big Data Construction Project, done by all departments. We're collecting bio data from 1 million people in the entire country, specimen data. The United States has the All of Us Research Program, and other countries are doing it too, but our country started a little later. The National Health Insurance Corporation wanted to do some Environmental, Social, and Governance (ESG) activities and come to our organization for volunteer work. When the organization creates a research request for proposal (RFP) or asks for research-related advice, we provide opinions.

We also visited companies that didn't seem related to diabetes first. For example, when we have low blood sugar, we have to drink juice. There was a company that made healthy juice, they made a special product that sells juice at a 40-50% discount, so I contacted the CEO and bought them at half the price. The product is called Lotte Zero. The sugar content is low. We have partnerships with companies like that - they also have a social responsibility to donate - so we are able to make full use of them.

Yubin Kang: You work with the government a lot, what do you do to elicit the government's interest and participation?

Mi-Young Kim: Many patient groups protest in front of the Ministry of Food and Drug Safety and the Ministry of Health and Welfare. We protested once, but when we did, the other party felt bad. Instead, we try to persuade them by using various media, or if we cite statistical data, research results, or overseas research results, we make announcements and use evidence-based data to give them an image that says, "This is what the patient group says."

Recently, we said that we were collecting medical data through open-source and a civic group criticized those activities. It was a ghost patient group created by the medical device company we were not on good terms with. Various laws can prove that there are no problems with the medical device data we're using.

We went to the Ministry of Food and Drug Safety with those laws and explained there is no problem with individuals using it for their own health. We said, "Let's conduct a research project on how the Ministry of Food and Drug Safety can approve the open-source app." It seemed an innovative case, so we submitted a proposal on how we could research our open-source activities. The acceptance or rejection of the proposal has not yet been decided, but we must always be careful about what we assert in that form, otherwise, in fact, the sincerity of our organization may be misunderstood.

Yubin Kang: Is there anything else you would like to add?

Mi-Young Kim: What we think is meaningful is that it's not easy to put a single disease name in the law. That's why we said that it was included in the Infant and Toddler Care Act. This time, Type 1 diabetes was also included in the Enforcement Decree of the Elementary and Secondary Education Act. We've knocked on the door a lot to add these things to many bills, things that Type 1 diabetes patients need, but in the end, only two were included.

Recently, we've been trying to have Type 1 diabetes recognized as a disability, and fortunately, the Ministry of Health and Welfare is reviewing 16 diseases from last year to this year to recognize them as disabilities, and our type 1 diabetes is included in the review. In the US, there is a 504 Plan that almost recognizes type 1 diabetes as a disability. So we are now persuading the government based on that, and we are also providing advice to institutions that are conducting research. The results will come out early next year.

Yubin Kang: Thank you for taking the time for this interview.

***This conversation has been edited and condensed.*