Water In and Water Out—Or Just the Opposite? The Need to Understand Our Patients’ Illnesses in Their Own Words

I’m like a sink with an open drain,” my patient explained. “Water in and water out, continuously,” he elaborated. As his doctor, I knew the importance of translating our Latin expressions into layperson’s terms. This interesting description of his disease using the metaphor of a sink was indeed meaningful. It forced me to think of how this patient understands his disease and how he perhaps explained his symptoms to others.

As a child, Hassan* was diagnosed with congenital nephrogenic diabetes insipidus (NDI), a rare inherited disease characterized by unresponsiveness of the kidneys to antidiuretic hormone, resulting in inability of the kidneys to appropriately concentrate urine. These patients usually produce 10-15 liters of urine each day and need to replenish fluid loss with continual water intake to avoid life-threatening volume depletion. For providers and patients alike, NDI may seem a rather simple disease: water in and water out. However, is it necessary to understand that the disease is just the opposite—water out and water in. The dangers of the disease are also just that simple.

As a doctor with a specific interest in this field and a fascination with the physiological processes involved, it has been a privilege to follow and care for Hassan. It has provided me with unique insight into the implications of the disease for Hassan’s everyday life.

At his first visit, my agenda was simple. I wanted him to explain his disease to me using his own words. I expected something straightforward: the kidneys cannot retain water and therefore continuously excrete urine. This water loss is accompanied by compensatory thirst and water intake, which is absolutely necessary to avoid severe dehydration. I realized that I had made a miscalculation. Hassan explained, “I’m just like a pipe. You let the water in, and when there is no cork, it continuously flows out.” I asked him to elaborate, concerned by the misunderstanding this metaphor revealed. He readily continued and told me that his father once tried to “close the water supply” in the evening to avoid bed-wetting several times at night. But, as he recalled, “It did not prevent it.” He recounted that many of his friends and colleagues shared the same view and had offered suggestions to “just stop drinking all the water—then you won’t have to go to the toilet every hour.” With a guilty expression Hassan added, “I have really tried to reduce my water intake … but I can’t.”

That sentence sent chills down my spine. It was only then that I realized how challenging and exhausting his symptoms must have been—to urinate once or twice every hour all day long, even at night, while constantly feeling insatiable thirst. Even more shocking to me was that Hassan felt guilty because he thought his symptoms were self-inflicted. My patient did not understand that his symptoms were not dependent on his water intake, or any of his actions for that matter.

I quickly found a pencil and drew 2 kidneys, the aorta, and the vena cava on a paper. I expanded the drawing with 2 parallel lines from the kidneys to the bladder illustrating the ureters and emphasized that this simple circuit is crucial for the body. With my pencil I sketched how blood constantly flows from the aorta to the kidney and back to the vena cava while explaining that the purpose of the kidney is to remove unnecessary substances from the blood in addition to some water and eliminate this through the urine. “But,” I added, “the kidneys need to withhold most of the water and return it to the body.” He nodded to indicate that this was easy to understand. I continued, “Your disease is very simple, you lack the channels needed to retain water.” He reviewed my drawing in detail. “Does this also happen even if I don’t drink?” he asked after a while. “Yes,” I replied gently and reminded him how he lost 3 kilograms of body weight during a 3-hour water deprivation test. After this short education, it didn’t seem necessary to continue—he now understood the mechanism of his disease.

We both learned something during that visit. Hassan came to realize the potential danger of his disease. I learned never to underestimate the power of pausing to assess my patients’ understanding of their own illness and to avoid jargon when explaining disease processes. A rather simple disease for us as doctors may seem incomprehensible to our patients. It’s a unique artistic element of medicine to be able to translate the complexity of disease into understandable terms. Taking time to explore your patients’ self-perception by letting them explain their disease using their own words adds a valuable perspective and ensures a common understanding for the communication to follow.

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doi: 10.1053/j.ajkd.2022.04.015

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