Streptococcal Toxic Shock Syndrome: A Physician Tells the Story of Her Survival

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It’s a rare disease, this Streptococcal Toxic Shock Syndrome, and caused by what the press likes to refer to as the “killer bacteria” (Group A Streptococcus Type M). And yet in the summer of 1998 I got this disease. Out of the blue. At age 47, in perfect health. And thus began my saga of physician as patient, a story of great suffering and great blessings. I am a better physician because of it, and I have developed deeper, more loving connections with the people closest to me.

My story is not told from memory. From the onset of the first symptoms until my awakening in an intensive care unit 14 days later I have total memory loss. I have slowly pieced together as much of these 2 weeks as possible. I have spoken with doctors and nurses, with family and friends. I have copies of all of my medical records. Yet there is an emotional gap, which I can’t bridge. The powerful drama of those days is lost to me. This loss is a mercy and a sorrow. The memory loss has proved to be almost as dramatic and powerful as the illness and recovery.

Streptococcal Toxic Shock Syndrome (STSS)

On 1998 June 20, I took a bad fall backwards on stone steps, slamming into my hips and, more lightly, the back of my head. No blackout, no neurological symptoms, no signs of fracture; simply an enormous painful black bruise over my hips. I ignored it and got on with my life in Stockholm; it did not bother me.

Nine days later, on June 29, a Monday, I noticed that I had some new pain in my hips where the bruise was. I remember wondering why this might be but was not concerned. The following day, Tuesday, I woke up with what I thought must be flu symptoms: deep body ache and fever. I called the hospital and told them I would not be coming in to work. This phone call is the last memory I have until 14 days later.

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My symptoms worsened through Wednesday. My 11-year-old daughter, who was home alone with me during those days, remembers that on Thursday (July 2) I became desperate because I could not urinate and I had developed very severe pain over the symphysis.

I know now that I was delirious and in the beginning stages of kidney failure. I even tried to catheterize myself after persuading the local health clinic to send over a catheter. Finally, I sought help at the clinic. When I arrived there, after my daughter had put me in a cab, I collapsed in the waiting room, screaming with pain. The doctor immediately called an ambulance and took some blood to test.

At the hospital emergency room, I was seen by surgeons and gynecologists. I was examined with ultrasound, x-rays, and a computed tomography (CT) scan. No one knew what was causing my apparent sepsis and pain. Finally, because I was failing, they sent me to the intensive care unit (ICU), where samples were taken for culture and I was given imipenem. My C-reactive protein at this time was 488 mg/L (SI system; reference level, <10); white blood cell count, 1.9 x 10^9/L (reference level, 9.1-9.4), platelet count, 149 x 10^9/L (reference level, 150-400), creatinine, 166 umol/L (reference level, <120), fibrin D-dimer, 6.26 mg/L (reference level, <0.25), aspartate aminotransferase and alanine aminotransferase high. My blood pressure was 80/60 mm Hg.

On Friday (July 3) my condition continued to deteriorate and I still had severe low abdominal pain. An explorative laparotomy was performed on suspicion of intra-abdominal sepsis, during which I suffered cardiac arrest and was revived. No cause of my condition was found, although a huge retroperitoneal hematoma from my fall was seen, unfortunately not accessible for puncture. There was also some ascites, from which samples were taken for testing. I now had acute heart failure, acute respiratory distress syndrome, disseminated intravascular coagulation, and multiple organ failure. I was put on a respirator and returned to the ICU.

Immediately after the laparotomy, my infectious diseases specialist made the diagnosis of STSS. She had suspected it earlier but waited for the results of the operation, to be certain. She added clindamycin and gamma globulin to my medications. Two hours after the operation the blood culture results came in: β-hemolytic streptococcus group A type M.

The next day my blood values began to turn around, but I was still critically ill and was on the respirator for 6 more days. There were to be frightening moments: cellulitis in the groin,
respiratory distress, worsening infection parameters. I never developed necrotizing fasciitis, although a surgeon was standing by.

What was the port of entry for the bacteria? My specialist believes that either the hematoma was the portal or that it became the feeding ground for bacteria that entered via some other unknown portal. (Gynecological tract? Throat? Small sore? There was no evidence that one of these sites was involved.)

The respirator was finally removed. But I did not wake up as expected, not for many days. CT and lumbar puncture scans were performed. There were no signs of infection but there was edema in the frontal, temporal, and occipital lobes of the brain: was this contracoup from the fall plus sepsis? Finally I began to communicate, but at first I was hallucinating continually. Whether these hallucinations were a result of the brain edema or the heavy drugs or both, we'll never know. My first real memory is from my 13th day in the ICU, the day I was released to the infectious diseases ward. Six weeks later, after intensive rehabilitation, I went home.

Physician as Patient

I have worked as a physician in the palliative care section of a geriatrics ward, both before and after my illness. I considered myself an empathetic doctor before I contracted STSS, but when I went back to work I found that I understood on a much deeper level what my patients were experiencing. As a young woman dying of a brain tumor asks William Hurt in the film The Doctor, “Have you ever seen a CAT scan from the inside?”

There is not room here to discuss the many aspects of being a critically ill, debilitated patient, such as shock, terror, pain, dependency, exposure, eternal waiting. Let me focus on some aspects that have particular relevance for us as physicians.

One of the most dramatic and distressing things that happened to me in the hospital was that I fell out of bed one night. I was too weak to reach a call button or call for help and was found on the floor in the morning. This was a deeply terrifying experience and the fear of falling again remained with me throughout my hospital stay and long into recovery at home. We ought never to underestimate the fear of falling felt by many patients and many elderly people.

Another powerful event occurred when I had regained consciousness. I was still very ill and helpless, and when I developed new symptoms I was taken to radiology. I was in pain and was feverish. I survived the wait in the cold cubicle in the hall, I survived being moved onto the table and placed in position. What was intolerable was returning to the hall cubicle and waiting for the radiologist to approve the films. I was so uncomfortable and scared that I panicked, and I had to be returned to the ward. My weakness and pain, fever and fear, did not allow me to endure this experience. I will never forget this when I send a patient for an x-ray.

Sometimes patients hallucinate, for various reasons. My hallucinations are very, very strong memories. Unlike dreams, which tend to fade rapidly, my hallucinations remain vivid. They are an important part of my memory bank. My most terrifying hallucination was that a specialist had informed me and my husband that I was suffering from late-onset Down’s syndrome (!). It took many conversations before I could understand that this was not the case. I know now that, when my patients relate a hallucination, for them it is an entirely real experience.

Constipation: we joke among ourselves about our patients’ constipation. What I learned as a patient was that constipation is scary. It filled my whole existence. I was so weak that I felt I could never make the effort to go to the bathroom. I no longer take constipation so lightly.

And I remember clearly the kind of total weakness that meant just listening to someone talk took more energy than I had. Twice I had to send my daughter home, because just having her sitting quietly in my room was too much for me. Eating was a dreaded ordeal. I could not take one bite of food without breaking out into a feverish sweat. And then learning to sit: sitting for only a few seconds made me want to pass out, and I nearly did, from breathlessness, pain, and dizziness. I dreaded the times when I had to practice sitting under the watchful eyes of the physical therapist, but I had to learn again to sit and then, far in the future, to walk. I realize now how little I have understood this about my patients’ energy: that just listening, just eating, just making the smallest movement, exacts a large price.

Then there were the feelings of humiliation from exposing my most intimate self, dysphasia, and total dependency. I was catheterized innumerable times, my teeth had to be brushed for me, I had to be washed. My diarrhea had to be cleaned up. I had to have help with every movement. I could not speak clearly. How precious, how precious were the kind words spoken by nurses as they helped me through all of these things. My love and respect for the nursing profession has deepened incalculably.

Many patients have a great need to talk about their experiences, especially with doctors. It is often so hard to find the time to be attentive to these needs! But now I know that we must find the time, if humanly possible. My amnesia evoked powerful feelings and an overwhelming need to find out what had happened to me during those lost days. And there was a deep need to somehow make sense of what had happened; talking through things with doctors is of vital importance, even long after the crisis. Many months later I visited the ICU, the primary care clinic, and spoke with the infectious diseases specialist. These contacts were worth gold to me. Part of the healing process is this talking, as the pieces...
of a puzzle come together.

These are some of the things I experienced as a critically ill patient the summer of ’98. I am now fully recovered. Yes, I am a better physician now, and many wondrous things have happened as a result of my illness. The bond between me and my sister, who sat with me during the first 3 weeks, has a depth I have never experienced before in any relationship. Since I almost died, my father and I have a deeper and more loving relationship. My bonds to other people around me are stronger, and I know in a much more tangible way how interconnected we all are.

And of course there are the things that have happened to me during the past year that never would have happened had I not survived. Six months after I got STSS, my son performed the Tchaikovsky violin concerto in Stockholm, with six of my American relatives present. For this, and for many other things, I am grateful.

On July 2, 1999, the first anniversary of my hospitalization, I invited two close friends to dinner. After dinner I lit candles and related my entire experience of STSS. When my story was done, we went into the front yard and lit sparklers—a celebration of life.