

WHEN SURGERY GOES WRONG: THE IMPORTANCE OF THE PATIENT'S VOICE

Author:

Kapka Petrov lives in Toronto, Ontario, with her husband and daughter. She spoke about her personal surgical and post-surgical experiences, with the theme "Perioperative Nurses: The Need for Strong Advocates in Patient Safety," at the 2015 ORNAC National Conference in Edmonton, AB. She has become vocal advocate for patient safety through the Canadian Patient Safety Institute (CPSI) and was featured in a National Post article entitled "Toxic gas, accidental burns and surgeries gone wrong: A look at medical mistakes in Canada" (September 20, 2015). Her story is also the focus of a CPSI video that can be found at <http://www.patientsafetyinstitute.ca/en/toolsresources/member-videos-and-stories/pages/kapka-petrov.aspx>. Kapka can be contacted with questions at kapkapetrov@gmail.com.

In 2009, at the age of 33 and in previously excellent health, I woke up with severe right upper abdominal pain on an April night. I ended up in a local hospital, after waiting in the ER for over 9 hours, I was seen by a doctor who dismissed my symptoms and sent me home. A few days later I was feeling very sick and was vomiting and, once again,

struggling with excruciating right abdominal pain. I returned to the same hospital. On this visit I was hospitalized due to pancreatitis and for five days I was on IV fluids and narcotic painkillers before having my gallbladder removed laparoscopically. After the surgery I was sent home approximately 6 hours later. I was unable to move, eat, stand, sit or take care of myself and my family.

The surgeon telephoned my home regularly over the next 4 days and stated that he was very concerned about me. He informed me that there had been some liver hemorrhaging during the surgery but that I should be fine and not need to return to the hospital as it would resolve itself on its own. When I had not improved, after 2 weeks, I returned to the hospital. A colleague of the surgeon, who indicated that she was from the same surgical team, informed me they would do everything possible to prevent a lawsuit.

This surgeon then proceeded with an endoscopic Retrograde Cholangio-Pancreatography (ERCP) and shincterotomy of the biliary tract. I was discharged the next day with a jar of morphine and provided with no further follow up.



Photo courtesy K.Petrov

Kapka and her family in early 2009 just a few months before her first surgery and the start of her ordeals as a surgical patient.

Photo courtesy K.Petrov



Kapka with her daughter in a Toronto Hospital, April 2009, for the initial surgery.

Over the next 9 months I was hospitalized eight times without any cause or solution being found. Eventually I was finally discharged in January 2010 and was given no hope for improvement. I was unable to hold down food or liquids. As a result I became very weak and had to use a walker for support. I also became very dehydrated and my skin turned

grey-ish and became quite wrinkled at times. I had severe upper right quadrant abdominal pain and felt like something was pulling deep inside me.

The gastroenterology team at a university hospital refused to arrange for me to see a surgeon for a second opinion and assured us that it was too late for any surgery, that there was no medical reason they could find for my symptoms, and I had best get used to taking my prescriptions. I was on 8 mgs of Zofran 8 mgs, 10 mgs of Stemetil every four hours, 600 mgs of Gabapentin (later reduced to 300 mgs), 5-10 mgs or morphine, orally, every 2 hours and 3mgs of hydromorphone every 4 hours. Despite all this medication there was no change in my symptoms, the vomiting continued despite the strong cocktail of Zofran and Stemetil (as noted in the clinical notes from the nurses) and the pain remained intense and severe. During one of the ER stays a doctor

informed us that “whatever happened had happened” and “a lawsuit will not help.” He advised us that we should stop “bothering” the hospital with our visits and I should just stay home and take my medication. He even offered to prescribe a higher dosage of painkillers and the anti-vomit medication. We were wondering why so many of the health professionals we saw were so concerned about the presumable lawsuit rather than the fact that my health was quickly deteriorating for no obvious reason (according to their reports). Our daughter was met by a social worker, sent by the school, who gave her worksheets to fill out explaining how to deal with the death of a loved one. She kept holding me tightly and saying “Please mommy fight for your life. Don’t leave me.”

We sent my medical reports worldwide and sought help from any source. My medical insurance provider informed me that, based on the information received from the specialist (and contrary to what my GP was reporting) they believed my condition was improving (this was back in September when I was running out of short term disability coverage and was fighting to get Long Term Disability (LTD). The specialist had falsely documented that I was improving and that he did not need to see me any longer) and so I was deemed to be not eligible for long term disability. I was forced to return to work, part-time, which involved stopping sessions (as a vocational



Kapka in a Bulgarian hospital shortly before her March 2010 surgery.

Photo courtesy K.Petrov

rehabilitation counselor) to vomit, holding the walls of my office to walk, and holding my abdomen in pain all day. Later, once my manager at work advised me to look for a better hospital and to contact a lawyer, and she called the LTD provider to inform them that they better review my file again since I was a liability at work, I was approved for LTD. Shortly after the approval, my husband received a letter, for no apparent reason, from the insurance reminding him that he is beneficiary on my life insurance policy. I think it made him entirely numb. He, very mechanically, picked up the phone and booked flights back to Bulgaria (where I am from and lived until I immigrated to Canada in 2001).

The night before we left Canada we discussed custody and finances and I wrote my eulogy. There were no tears left and I was too exhausted to feel anything emotionally. He got me a

wheelchair, took our daughter from school in the middle of her grade 7 year, and we flew back to my home. My friends collected donations to pay my arrears health insurance contributions (a requirement to re-activate my national health insurance) for the many years I had not been living in Bulgaria. Doctors in Bulgaria were very concerned with the state of my health. I had lost 30 lbs and gone from a size 12 to a size 6. I had extreme fatigue, low blood cell count, decreased platelets, red blood cells and white blood cells, and anemia. I had taken to passing out with no warning. And of course I was also emotionally traumatized. The persistent right upper quadrant abdominal pain and pulling in the area, along with the vomiting, were an ongoing part of my daily existence.

They began looking for a solution. I was in the hospital for most of

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PROVINCIAL & REGIONAL CONFERENCES /
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25th ORNAC National Conference	Niagara Falls, ON	Apr 30 - May 4, 2017
25th PRNABC Conference	Kelowna, BC	June 24 - 27, 2016
ORNAA Provincial Conference	Red Deer, AB	Sept 21-24, 2016
SORNG Education Day	Regina, SK	Oct 1, 2016
ORNAO Provincial Conference	Toronto, ON	Apr 28 - May 1, 2016
CIISOQ/CORNQ 36th Conference	TBA, Quebec	Oct 13 - 15, 2016
NBORN Provincial Conference	Oromocto, NB	May 6-7, 2016
Atlantic OR Nurses Conference	Halifax, NS	Sept 22 - 24, 2016

OTHER CONFERENCES / AUTRES CONFÉRENCES

AORN (www.aorn.org)	Anaheim, CA	Apr 2 - 7, 2016
ASIORNA (www.asiorna.org)	Hong Kong	Oct 8 - 10, 2016
ACORN (www.acorn.org.au)	Hobart, Australia	May 25 - 28, 2016
CORL (www.operatingroomleaders.com)	Toronto, ON	Nov 13 - 15, 2016
CNA (www.cna-aiic.ca)	Saint John, NB	June 20 - 22, 2016

Additional conferences can be found at www.ornac.ca.
Jetez un coup d'œil aux conférences additionnelles à www.aiisoc.ca.



Photo courtesy K.Petrov

Kapka with her husband and daughter, in 2011 – after the surgery in Bulgaria but still dealing with the weight loss, lack of sensitivity to hunger, and compromised immune system.

February and part of March 2010. Our daughter was enrolled in Bulgarian school and had to learn to read and write in Bulgarian. This was a lesson, for us all, in resilience, courage and tenacity and we understood that, as her parents, we were setting an example for her to never give up... no matter how difficult life may be.

On March 19, 2010, Professor Dr. Gaydarski, the former Minister of Health for Bulgaria, operated on me and videotaped portions of the surgery. It was an open exploratory laparotomy of the upper abdomen. It revealed that the cystic duct (contrary to the surgical reports which indicate it had been removed) was left (3.5 cm). Metal clips were also found deep in the abdomen. They were holding the duct and cystic artery. The clips were removed along with the remainder of the duct, some parasympathetic fibers, and a semilunar ganglion.

Following the surgery the pain and vomiting stopped. I was happy to be alive... but now had no sensitivity to hunger and compromised immune system. I have to remember to eat because my body does not experience hunger. I fight, every day, to rebuild my failing immune system – nearly a year with a clenched artery and cystic

ductus has kept me in survival mode and had long term impacts on my health. But we thought the worst was over and that we needed to just forgive, forget, collect the broken pieces of our shattered lives, and move on.

In October 2012 I learned that I required a hysterectomy. I (reluctantly) trusted another surgeon who presented as superior in his skills. Following the surgery I was told that a colostomy bag would be attached in near future whenever I was “ethically ready.” We did not understand the question and our response was “if you want to attach a colostomy bag on me then apparently there is a need for it. How, as a patient, would I know when I would be ready for such a radical life altering measurement? The answer was that he did not know why bad things kept happening to me. We never received any clarification and had never been told about any incidents, during the surgery, that would have resulted in such a radical measure. There was a mention in the surgical report that another surgeon was called in, due to ablation of the sigmoid colon, and that he would record in my file what had taken place. My family doctor later requested information from the hospital and their letter stated there was no record of a surgical note or incident report.

Little did I know that, in the months to come, I would experience a slow paralysis of the lower left side of my body, excruciating and ongoing pelvic pain in the coccyx and sacrum, loss of mobility, and general daily suffering. When mentioned to the surgeon my concerns were dismissed and I was told that he did not know why bad things happened to me all the time and that he just forgot what exactly happened.

Continued crippling pelvic pain, for which I refused the band aid of pain management including a recommendation of a morphine catheter in my spine, progressive immobility, and deterioration of my elimination abilities, urged us to seek help once again in Bulgaria. In June 2013 I was operated on by doctors who were puzzled as to why I would be left suffering in this way. They discovered that my sigmoid colon had been burned, during the hysterectomy, to the point where there was no tissue left. The laser resection, during the hysterectomy, had resulted in the sigmoid colon, peritoneum, and left ovary growing together (and forming adhesions). The Bulgarian team of surgeons was able to separate them. But the numbness, tingling and excruciating pelvic and rectal pain persist to this day (3 years later).

As a result I live with severely impaired mobility and elimination abilities. My overall physical abilities mean that the simplest tasks require a paramount effort.

As a patient, I am advocating for an open dialogue with physicians when things go wrong. I am hopeful that the global pillars of safe health care become the credo of health care providers and allow us to create effective two way communication. My experience in Bulgaria was not different because of the medical

expertise of the team – it was different because they listened to my concerns, took my suffering seriously, and did not have to be concerned with hiding past errors. They also were very much concerned with figuring out the reason for my pain and finding a treatment, right away, rather than continuing to medicate me with painkillers while ignoring the main cause.

I also believe, based on my experiences, that patient satisfaction is a much needed measure in every doctor's annual objectives and that growth and improvement happen through taking ownership when things go wrong. We have to acknowledge that mistakes happen and address them - this is essential to save lives and improve the quality of the lives of all patients on a national and global level.

Closing ranks, or trying to make 'problem patients' go away does a disservice to everyone involved – the patient and the entire healthcare team – and does not instill confidence in our healthcare. My experience made me feel like the individuals involved were more concerned with a lawsuit, or their reputation, than they were with providing care to me when things had gone wrong. A different approach could have reduced my suffering and created a much more positive result for the healthcare providers. No patient should suffer needlessly – and no one's suffering should be dismissed or treated as inconvenient.

When a patient is adversely impacted by a surgical intervention the entire healthcare team is impacted and its ability to provide quality care can suffer. Timely disclosure, objective report writing and taking measurements to improve the adverse event are necessary to revolutionize the standards in health care. At the end of the day, we are all patients at some point in our lives and we need to be able to put our faith in the hands of the experts. To do this we need to know that they will do their best for us – both when things go right and when they go wrong.

Photo courtesy D. van Nieuwkerk



Kapka presenting "Perioperative Nurses: The Need for Strong Advocates in Patient Safety" at the 2015 ORNAC National Conference in Edmonton, AB.