

TRANSCRIPTION

cpsi Canadian Patient Safety Institute
iscp Institut canadien pour la sécurité des patients
Kapka Petrov
Patients for Patient Safety Canada

[0:00:10] I was 33 years old five years ago, and I woke up one bright April morning with severe upper right quadrant abdominal pain that I have never experienced before in my life. The pain was so intense that I had trouble walking. We knocked at the door of our neighbours who told us that our trouble is just starting. They showed us the way to the nearest hospital and they offered to take care of our daughter. And we didn't understand why the comment was about the trouble.

[0:00:47] The doctor came after nine and a half hours of waiting and told us that he is going to give me an ultrasound to rule out gallbladder stones. The ultrasound was done. He didn't show any stones, so he advised to stay on a plain diet and to not eat pork and not drink wine, because these would be things that are probably inflaming the pancreas.

[0:01:10] I kept insisting that the pain is on the right upper quadrant side and the pancreas is situated on the left side of the body and I didn't have any pain there. We went home. Sure enough, two days later, I was uncontrollably vomiting green and the pain was escalating to very unbearable levels. We went back to the emergency room. This time they kept me. They proceeded with an emergency surgery on 15th of April to pull out the gallbladder laparoscopically. And I paid attention that when I came out from the surgery, the other patients that were with me in the room for recovery were able to stand up, to walk around, to move, and to eventually go home with the help of their family members.

[0:01:56] I could not move. Something was very heavy and pulling in whatever the surgery was on the right upper abdominal side. The operating surgeon was connected to the nursing station on a call and he identified that actually the gallbladder was full of stones. It was open on one side and it was stuck to the liver. The stones were spreading all over the abdomen.

[0:02:26] My husband begged and advocated for me to stay in hospital so that I can recuperate instead of being sent home immediately the same evening. The operating surgeon indicated that that's not necessary, that he has done the best he could and that complications are not expected, so I will just go home and be discharged on the same day.

[0:02:45] So the surgeon called early next morning and he wanted to know how I was doing. My husband told him that I'm not doing well. I did not get any sleep because of the

severe right upper quadrant pain and that he doesn't know what to do. The surgeon disclosed to him over the phone that actually, when he was pulling the gallbladder, the gallbladder was so inflamed that he caused a minor hemorrhage of the liver, but everything should be fine. And he also explained to him that probably that was the reason that I was in so much pain. He prescribed me some pain medication when he was doing the surgery so he encouraged my husband that I should take my pain medication and stay home. For four consecutive days, he was calling, and my husband told him on the fourth day that something is actually majorly wrong and we're planning to go back to the hospital to look for help despite that he was assuring us that we should not go to the hospital and I should continue taking my pain medication.

[0:03:48] Upon our return to the hospital, I was admitted after one day of observation in the emergency unit, and I saw another general surgeon who stated that she is working under the same team with the surgeon who operated on me and that she is going to do everything to prevent any lawsuit. At this point, I was wondering, what is it all about, that lawsuit? I'm not planning to sue and that's not my intention. I need to get help.

[0:04:22] She indicated that she's going to perform an emergency liver surgery to open the duct and see whether any remaining stones from the gallbladder are probably causing the trouble. And she mentioned that she will be performing ERCP and she will be performing cinterectomy [ph] which are two procedures to help release any stones that might be caught between the liver and between the cystic duct and the gallbladder.

[0:04:48] Shortly after, I was discharged from the hospital with a jar of morphine. I was not able to walk and my husband had to hold me. And we asked whether I can have any sort of assistive device to help me walking and standing on my feet because I was not able to do so. We did not get an answer.

[0:05:10] Quickly enough, after a couple of weeks, I resumed again the green vomit and the severe pain was escalating to unbearable levels. The morphine was not helping. We saw the gastroenterologist in August. My husband mentioned to him that after 15 years of marriage, he has never seen me in such a weak state. Two days later, the family doctor called my husband and asked him to immediately go to her office. She mentioned to my husband that she just received the report and she gave him a copy of it. The report was stating that he has seen me in his office. I'm much better and improved and he does not need to see me any longer. Meanwhile, we called on a few occasions the initial surgeon and we wanted to get in contact with him and see whether he can provide any help. He stated that I do not have a surgical issue, I shouldn't bother calling him any longer and that he cannot be of help.

[0:06:05] And this is when we felt betrayed, confused, and very bitter because we did not know where to go for help.

[0:06:16] We went to another hospital, and this time, it was a downtown university reputable hospital where we had the impression and the family doctor had the impression that they are topnotch, as she mentioned, for research and for taking care of patients. They switched me to cancer medication for vomiting patients that I was supposed to take every second or third hour or every time I was vomiting. And they also told me to take much more morphine every time, as much as I needed, so that it helps with the pain. They mentioned that a surgeon is not going to be called because they don't think that I have a surgical issue, but a pain management issue.

[0:06:57] We went back to the hospital and we told them that we just talked to the Telehealth Ontario and nurses told us that we shouldn't move out from the hospital. They admitted me. They kept me for seven days in which I generously vomited green. I went through all the testing again. It was repeated, and of course the MRI showed, as per the previous MRI, that everything seems to be fine.

[0:07:17] My condition deteriorated to a point that I was not able to take a shower, I was not able to dress. I was not able to take care of my family. My husband has almost lost his job at that point from not being able to go to physically work and contribute. My parents from Bulgaria kept calling and saying, "Please come home. We feel you are dying." Our daughter kept holding onto me and saying, "But I need you, Mommy. Please promise me that you will fight." I could not believe that at the age of 12, our daughter had to mature to a point of advocating for me.

[0:07:55] My husband bought the tickets to go back to Bulgaria, and the night that he bought the tickets, I wrote my eulogy. And I wrote in my eulogy that I appreciate having my family and my friends in my life and that I would like to ask my husband to take care of our daughter and that I very much appreciated the gift of being a mother to my daughter.

[0:08:23] January 2010, we flew back to Bulgaria, and I was kept in the hospital for a very long time from end of January, January 31st until March 19th. Many doctors, all levels of specialists and all kinds of specialists were brainstorming every day of what they can do. They rushed me on 19th of March 2010, almost a year later, to the surgery. After the surgery, I woke up in the ICU and the first words that I heard through the many tubes that I had attached to me were of my father. I just remember his face coming to me and saying, "You make it. They saved you. They discovered horrible things, but you make it. You are alive and you'll keep living."

[0:09:15] The main causation for the pain and all the turbulence in vomiting and all this saga for one year was that there was a metal clip deep inside, not visible through standard testing, because the standard testing was done in a lying position versus me leaning so that the clip could be seen. The clip was clipping the artery. The clip was clipping the main nerve of the liver, and it was clipping the extra-long cystic ductus [ph]. And the cystic ductus got wrapped with more peripheral nerves from the abdomen, which were the cause of all this horrible pain and vomiting.

[0:09:52] We felt relieved. We felt validated. At the same time, we felt very puzzled how nobody would even think that something so simple can cause so much trouble and such a deteriorating state of existence where I would be just outsourced to go home and to live on morphine until I make it.

[0:10:13] The message that I would like to give to health care providers across the country is, patients do not come to health care providers just for the sake of chatting with them for no reason. We come with our real pain that is not in our head, but triggered through something physical most of the time. And it's obvious mistakes happen in the medical community. My expectation as a patient is that you don't run away, that as a doctor, you come back and you help me to get better, because my life matters most of everything else and the quality of my life is extremely important to me.

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