
ESSAY/PERSONAL REFLECTIONS

It takes two: How shared experiences can influence postoperative recovery and adaptation

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“If I have to go through this again, I will not do it” Ms. Richardson commented while lying in her hospital bed one month after undergoing a total pelvic exenteration. “I was not expecting to be here for so long” she added. I’m sitting next to her, listening to all her frustrations related to her postoperative recovery. I replied to her “Remember, you had major surgery. These are the outcomes we expected. We just had to take one day at a time.” She looked at me in disbelief, just wanting for all of this to be over.

“So what went wrong?” I asked myself. I counseled her and her family ad nauseam about the procedure and complications. In preparation for her surgery, she talked to patients that underwent the same procedure to learn about their experiences. She met with the ostomy nurse and social worker to discuss issues related to the postoperative period. I tried my best to counsel her. It’s not every day that a patient undergoes a total pelvic exenteration. Total pelvic exenteration is associated with a high risk of post-operative complications. The operative mortality rate is approximately 3–5 percent, the major perioperative complication rate is around 30–44 percent, and the overall 5-year survival rate in patients who successfully undergo the procedure is about 20–50 percent. The main objective of this surgery is to achieve cure. Still, the recurrence rate could be as high as 50 percent. This procedure is a life changing experience. Patients may have up to two colostomy bags impacting their body image. They have to go through the process of adapting and learning how to deal with these new appliances. In young patients, the surgery can adversely affect their sexuality. All of this information cannot be conveyed in just one clinic visit.

After several meetings, she and her family decided to proceed with surgery. The procedure was otherwise uneventful. She remained in the hospital for 16 days prior to be transferred to an inpatient rehabilitation unit, where she remained for approximately one month. She was transferred back to the hospital secondary to complications. She remained in the hospital for an additional 11 days. During that time, she has to endure a fascial dehiscence, malnutrition, and infection. She was maintained on total parenteral nutrition. Her major obstacle was the absence of her family during that critical time period. Her family was very supportive, but since they lived quite a distance away, it was extremely difficult for them to be there with her all the time.

It just so happened that one week after Ms. Richardson presented to my office for initial consultation, Ms. Carter was evaluated for the same procedure. Ms. Carter went through the same process of preparation like Ms. Richardson. Even though her postoperative course was difficult, she did better than Ms. Richardson. She had the advantage of being younger and healthier. She stayed in the hospital for 17 days after her surgery. She was readmitted twice. One admission lasted 2 days and the second, 7 days. She has to endure complications like infection, pulmonary embolism, malnutrition (also requiring parenteral support), and acute renal failure. Upon one of my discussions with Ms. Carter, she commented “I could not imagine that I was going to have so many issues, but if I had to do it again, I will not think about it twice. I want to be with my loved ones. If this is my only chance, then I will go for it.”

Coincidentally, both women were in the hospital at the same time during their last readmission. During morning rounds, they both looked at me in disbelief when I mentioned to them that they were doing fine. I noticed that Ms. Richardson was getting depressed as days passed. Nothing that I tried medically could make her better. “What else can be

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done? I wish I can get them together so they can realize that they are not alone. So, why not get them together? This will help them both while coping with the obstacles from their surgery." After presenting the idea to both patients and asking for their permission, we decided for Ms. Carter to visit Ms. Richardson as she was the strongest. After a brief introduction, both women talked for about an hour. They compared their experiences and realized that they were not alone as they originally thought. While they were in the hospital, they spent an hour daily enjoying each other's company. I noticed that Ms. Richardson mood improved significantly. Meeting Ms. Carter gave her something to look forward, instead of spending time focusing on the negative aspects of her recovery. When Ms. Carter was discharged from the hospital, both women decided to keep in contact with each other on a weekly basis. Ms. Carter called Ms. Richardson each day until she was discharged to check on her progress. Their relationship evolved more than just weekly phone calls. They have met each other at their respective homes, introducing each other to their family members.

Almost two years has passed since that first encounter. Both women are still alive and still keep in contact with each other in a weekly basis. When one follows up in my clinic, she provides me feedback about the other's progress. They experience similar complaints and, in turn, console each other. For example, Ms. Carter came to one of her routine visits and mentioned that she was having some vaginal discharge. The exam did not reveal any abnormality. At the end of our meeting she said: "Ms. Richardson will be expecting my call to see what you have to say as she is having the same issue." I just chuckle to

myself. A year after Ms. Richardson's surgery, she was noted to have a recurrence. When we discussed options including surgery, I noticed that she was a stronger person than the one that I met at the beginning of this journey. I know that some of her strengths come from the unconditional support and friendship that she received from Ms. Carter. She opted to have surgery and recovered well. Ms. Carter was there for her during that time.

During one of our encounters, both women acknowledged that talking to patients that had the procedure and were already recovered helped them on having some sort of an idea of what to expect. However, the biggest impact on their recovery came from having each other and sharing their experiences. This experienced has taught me that human relationships could be very powerful in patient healing. We work so hard on keeping the privacy of each patient for understandable reasons. Our hospitals are full of individuals that are isolated in their rooms recovering from surgery, adjusting to their new diagnoses and/or undergoing treatments. They are trying to adjust to their new reality with or without support. Even though family support could play an important role on the road to recovery, certain aspects like sharing experiences seems to play an important role as well. Creating the ambience in the hospital to promote this type of interaction could be positive for some patients. Of course, we have to take into consideration that the opposite could occur as well. The best gift that I could ever have as a physician was to witness the initiation of this relationship and the great impact that it had on the parties involved.

Names have been changed to protect the identity of both patients.