


Retroperitoneal Liposarcoma: A Patient's Experience

Journal of Patient Experience
Volume 9: 1-3
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DOI: 10.1177/23743735221143951
journals.sagepub.com/home/jpx


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About a year ago, in September 2021, my GP broke the news to me:

“There is a name for your disease. It’s called *Retroperitoneal Liposarcoma*”.

“Is it cancer?” I asked.

“Yes,” she said.

Different patients may react differently to this news. But what I would like to share is not how I felt and what my reactions were at that time. Instead, I’d like to reflect my journey afterward, comprising 3 phases: preoperative, surgery, and recuperation.

Preoperative

Liposarcoma is a rare type of cancer that begins in the fat cells. It is a malignant tumor that primarily develops in the retroperitoneum, and hence Retroperitoneal Liposarcoma (RLS). Surgery is considered the gold standard for treating RLS. Three things were important for me before the surgery: exercise, nutrition, and spirituality.

I decided to do light exercises every day before the surgery. Since my tummy is a bit big and heavy, exercises in the form of easy walking and dancing using a YouTube video as instruction were suitable for me. I did a 10 to 15-minute session a day. This kind of exercise reduced the symptoms I experienced. I felt better in general. Exercises, although only simple movements, whenever possible, should be included in the preoperative checklist for cancer patients. Idorn and Thor Straten (1) believed that exercise is healthy for cancer patients and may also be therapeutic.

Another aspect that might be important to cancer patients is the role of nutrition in preparation for surgery. Like many cancer patients, I was not sure what to eat and what not to eat. I didn’t know to what extent my diet would affect cancer treatment. Rather than relying on information from the Internet, I should perhaps seek professional advice from dietitians to improve my nutritional status before the surgery.

There were 6 weeks before the surgery. I needed to take various medical examinations, such as CT scans (abdomen, pelvis, chest), MRI, PET scan, kidney function, ECG, and a biopsy. These tests were not for the faint-hearted. They can shake your confidence. As a practicing Christian, prayers have become dominant in my life. Through prayers, I felt an inner strength and peace that I could not explain. My spiritual life grew strongly during this period. It gave me tremendous strength day after day to face these challenges.

Another important aspect worth mentioning is the communication with my surgical oncologist. His explanations were systematic and thorough. He explained what he would do in the surgery and where was the best to do it, which is in a specialist sarcoma center. He spelled out the risks one by one, stating which ones were unlikely to happen and which ones were likely to happen. He also mentioned the type of my disease and asked for further tests. Preoperative diagnosis is a critical step to allowing optimal treatment planning, according to Gyorki et al (2). The most important comment he made during the initial consultation was perhaps when he mentioned that the surgery was for a cure intent. This assurance was very important to me, even though he also said that recurrence is common for liposarcoma. But Gyorki et al (2) also outlined that the best chance to minimize recurrence risk is at the time of initial diagnosis, and that’s why I needed to go through many medical examinations before the surgery.

When my wife and I left his office after the first appointment, I was convinced I would be in good hands. That wasn’t the only appointment before surgery. It is common that patients may not fully comprehend everything the surgeon says. So, in my case, we had subsequent appointments, as well as meetings with the head nurses and the anesthetist

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from the hospital. The team seemed to have a process in place to ensure that the patients were fully aware and understood what to expect after the operation. As also mentioned in Ha and Longnecker (3), I believe that good patient-doctor communications are very important, not only the medical care.

Surgery

RLS should be treated in a specialist sarcoma center and by a multidisciplinary team. I was lucky that my surgery was performed at a high-volume sarcoma center. The surgery took 7 to 8 hours to remove a basketball-size tumor from my abdomen—a giant RLS tumor. I don't know how long the tumor has been growing in my body, perhaps for a few years. After the successful surgery, I stayed in the hospital for 10 days.

Three aspects struck me when I was in the hospital. The first one is diet and nutrition consultations by dietitians. If I knew that this kind of health service is available, especially to cancer patients, I would have sought their diet advice before surgery. In their study, Kirov et al (4) found that malnourished patients with RLS experienced more postoperative complications and prolonged hospitalizations. It is clear that the nutritional status of preoperative plays a significant role in reducing complications and hospitalization. I was malnourished, and strangely enough, I wasn't aware of this until after the surgery when the surgeon told me so. I then realized that I was unhealthily skinny. Luckily, I did not experience any complications postoperative.

The second one was physiotherapy. Because I had a big and long surgery, recovery postoperative is very important. I needed to learn even how to walk with the aid of a frame after 3 days of staying in bed. Walking was a challenging task for me. The role of physiotherapy was just phenomenal.

The last one was spiritual care. For cancer patients, spiritual care is just as important as medical care (5). I personally believe that spirituality plays a prominent role in confronting this disease. In the hospital, multifaith, multireligion spiritual care was provided. Although not specific to a particular denomination, I felt that my spiritual needs were fulfilled. The spiritual caregiver shared Bible verses, played a hymn on his mobile phone, and offered a prayer; simple but meaningful.

When I was in the hospital, I was being looked after by a network of medical teams, from dietitians, and physiotherapists, to the pain management team of doctors and others behind the scene. If patients like me before being admitted to the hospital knew that it wouldn't be just the surgeon and nurses but a whole network of medical teams, it would undoubtedly give them the extra strength they needed to face extensive surgery. The preoperative appointments with head nurses and an anesthetist helped, but knowing the full extent of the support I would get during the hospitalization would indeed give me a lot of courage, knowing that everything would be just fine.

Recuperation

After being discharged from the hospital, it took me more than 2 months to recuperate. The progress day by day seems to be very slow. I needed to start moving, a challenging task in the beginning. Luckily, while in the hospital, the trainee physiotherapist who looked after me mentioned community-based physio care for patients like me. She then enrolled me in the program. It is basically government-funded physiotherapy support for suitable patients after being discharged from the hospital. It involves a physiotherapist coming to the patient's residence once a week for 4 weeks. These physiotherapy sessions were incredibly valuable to me. It gave me the confidence to start doing light exercises, such as a 5-minute walk, 2 or 3 times a day, which increased gradually every week. This contributed significantly to my recovery.

Because RLS is often found at an advanced stage, the size of the tumor might be big. Surgery on RLS often needs to remove other affected organs, and in my case, the right kidney. Living a normal life with 1 kidney is possible, but it has to be carefully managed. Therefore, regular monitoring of renal function becomes a necessity. Working together with my GP has become more routine than ever before. Apart from the renal function, other parts of physiology, such as liver function and blood pressure, cannot be neglected, as they interact with each other. I, therefore, adopted a lifestyle approach to medicine or simply lifestyle medicine through nutrition, exercise, and stress management.

Lessons Learned

Let me summarize what I have learned from the 3 stages of my journey. At the preoperative stage, exercises, nutrition, prayers, and extensive communication with the medical team were very important in preparing me for the surgery. While at the hospital, working with dietitians and physiotherapists and having conversations with the spiritual caregiver made me physically and spiritually stronger. And during my recuperation at home, continuous physio exercises made me recover faster. Adopting a healthy lifestyle is no longer something nice to have but is now a must.

This cancer experience has changed me. Cancer makes me humble. It reminds me that life is not always guaranteed. It can be taken away at a moment's notice. There is not a single day that goes by where I am not thankful to be alive and healthy, and I pray it stays that way for many years to come. Every day, I am reminded of this Bible psalm: *Teach us to number of days that we may gain a heart of wisdom* (Psalm 90:12). Isn't it true that we need to be grateful every day? Being grateful is a universal belief beyond any religions or faith.

Finally, as someone who has experienced cancer, having a positive mindset in life is everything—an ingredient for strength and survival. Raque-Bogdan et al (6), who studied positive psychology, also found that hope influenced the

quality of life of cancer survivors and caregivers. For me, whatever prognosis sarcoma experts said in the scientific literature (like Tseng et al (7)), I have to remain positive, and I can only achieve this through prayers¹ and daily devotions.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article

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Note

1. *Pray without ceasing* (1 Thessalonians 5:17, NKJV).

References

1. Idorn M, Thor Straten P. Exercise and cancer: from “healthy” to “therapeutic”? *Cancer Immunol Immunother*. 2017;66(5):667-71. doi:10.1007/s00262-017-1985-z
2. Gyorki DE, Choong PFM, Slavin J, Henderson MA. Importance of preoperative diagnosis for management of patients with suspected retroperitoneal sarcoma. *ANZ J Surg*. 2018;88(4):274-7. doi:10.1111/ans.14125
3. Ha JF, Longnecker N. Doctor-patient communication: a review. *Ochsner J*. 2010;10(1):38-43.
4. Kirov KM, Xu HP, Crenn P, et al. Role of nutritional status in the early postoperative prognosis of patients operated for retroperitoneal liposarcoma (RLS): a single center experience. *Eur J Surg Oncol*. 2019;45(2):261-7. doi:10.1016/j.ejso.2018.07.001
5. Jim HS, Pustejovsky JE, Park CL, et al. Religion, spirituality, and physical health in cancer patients: a meta-analysis. *Cancer*. 2015;121(21):3760-8. doi:10.1002/cncr.29353
6. Raque-Bogdan TL, Ash-Lee S, Mitchell J, et al. A group positive psychology intervention for cancer survivors and caregivers: a pilot study of activating happiness©. *J Psychosoc Oncol*. 2020;38(6):649-69. doi:10.1080/07347332.2020.1801943
7. Tseng WW, Pollock RE, Grignol VP. Disease biology is “king” in retroperitoneal liposarcoma. *Ann Surg Oncol*. 2021;28(Suppl 3):832-4. doi:10.1245/s10434-021-10472-6