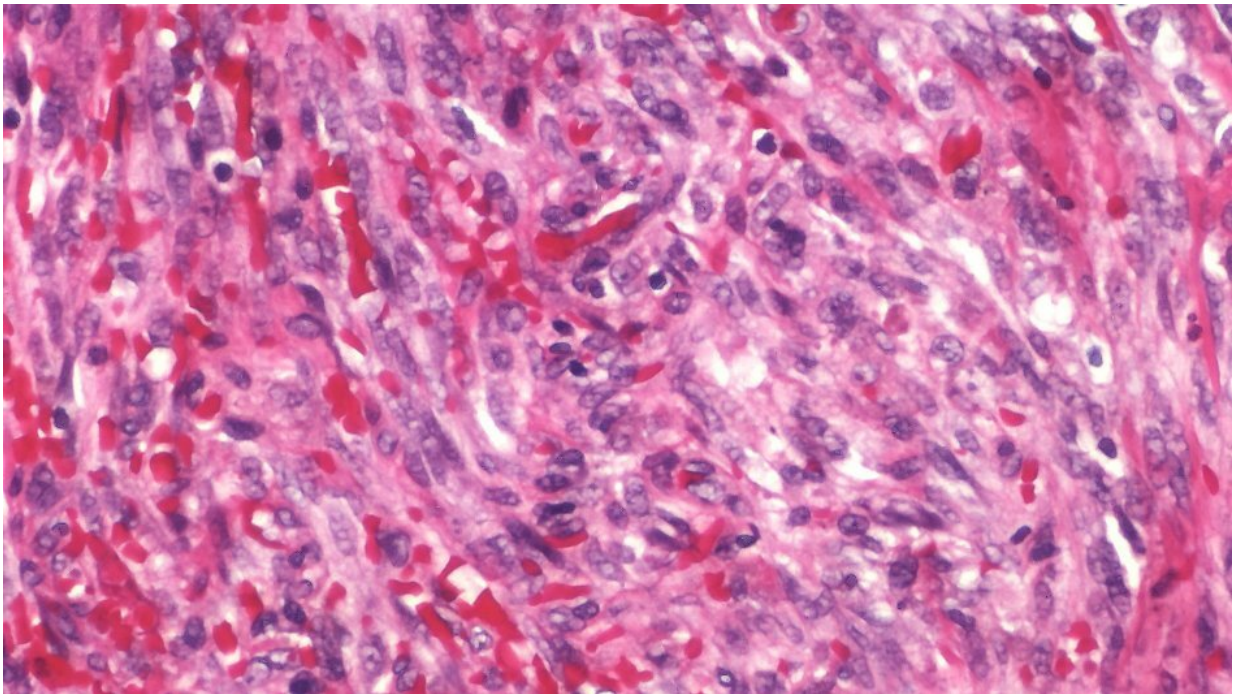


I think therefore I am – how perception influences sarcoma survivors' journeys

September 29 2020, by Joanne Duffy



Kaposi sarcoma (cropped image). Credit: [Yale Rosen](#), [CC BY-SA 2.0](#)

Sarcoma is a rare cancer, the main type of which typically affects tissues like bone or muscle. Sarcomas develop in our connective tissues—the kind of tissue which supports other tissue in the body and has a structural role, making them quite different from other cancers, and they make up about 1.4% of cancers diagnosed in the UK.

The symptoms of sarcoma are varied and vague. It can start with anything from a small lump to bone pain. Many people who present with these symptoms will be diagnosed with something else in the first instance, since a GP is unlikely to consider cancer immediately.

Occam's razor says when you hear hoofbeats, think horses, not zebras. And so it makes sense that a patient with bone pain or another similar complaint will be treated with pain medicine, physiotherapy or other common treatments first before cancer is a consideration.

A waiting game

All of this means that sarcoma patients often experience long waiting times to [diagnosis](#). The disease is missed and grows in the background. For the purposes of research studies, this period is divided in two.

The "patient interval" refers to the length of time from a patient first noticing symptoms to the first time they seek care from a doctor. The "diagnostic interval" is the length of time it takes for a patient to get from their first doctor's visit to a diagnosis of cancer.

This can take a very long time for some patients, and it can be very upsetting for a patient to realize they have been living with a growing cancer for, in some cases, months to years, before they have a confirmed diagnosis and get a treatment plan.

In a recent study examining the length of time taken to diagnosis for sarcoma patients and the impact this has on health-related quality of life, results showed that the important factor was how patients feel, rather than the actual length of time it took to get a diagnosis. If patients felt negatively about how long it took them to be diagnosed, they typically had a lower health-related quality of life later on.

Building the skills to cope

Dr. Justin Grayer, a Psychologist at The Royal Marsden who works closely with cancer patients, explained a bit about the complexities of working with people who have cancer, and why support is so important:

"Cancer and its treatment can be hugely challenging for people and their families—there are so many situations to navigate. Most people find that they experience a whole range of thoughts and emotions—much like the weather, they can be unpredictable and feel outside of our control; however, they are all natural. If it's stormy weather outside we know how to keep ourselves dry and warm; if it's too hot we find ways of keeping cool. Cancer can seem very different to other challenges people have experienced before and so some people feel that they don't know how to take care of themselves or cope. However, their usual ways of coping will probably help them cope with cancer as well, for example talking to friends, listening to music or spending time in the garden or park. Being kind to yourself is also really helpful, although sometimes difficult to do. When treatment finishes, people often expect themselves to feel elated and to get back to their old lives, but it can be a psychologically challenging time. Where possible, it helps if people can give themselves time to both physically and psychologically heal."

This study was a cross-sectional examination of long-term survivors of sarcoma, which means the subjects were asked to reflect on a time that had already passed—essentially they were asked to look back on their diagnosis rather than being asked in real time. The study looked at 1,099 long-term survivors of sarcoma, with just over half of the patients responding to the questionnaires they were given.

Dr. Olga Husson, staff scientist in the Division of Clinical Studies at the Institute of Cancer Research, who led on the study, said:

"This study shows that we need to make sure that patients are adequately supported at the time of diagnosis. This means helping patients develop healthy coping strategies and framing their diagnosis in such a way that we can maximize their health-related quality of life over the long term."

The patient point of view

Bill Russell was diagnosed with sarcoma in 2016 and spoke to us about his experience with getting a diagnosis, and how tough it can be.

"Like many patients with sarcoma, I experienced a delay in diagnosis and, even when I had one, the sarcoma center wanted to see the slides of my cells for themselves. I had a further complication in that I had a further delay before surgery due to the need for other wounds to heal. Luckily I was one of the people who had good health literacy as I worked in healthcare and a very supportive wife who is a retired GP. This gave me a good supportive coping strategy but I quite understand that many other sarcoma patients would not have that knowledge or support, and that would certainly make things more difficult. Emotional support is so important after any life changing diagnosis, and this should be part of the training of healthcare professionals. This study is a really valuable piece of work, and it's great to see high quality research with patients at its center."

So what will this work mean for the future? Well Dr. Husson and her team have more work in the pipeline on this topic, and they're hoping that it will make a real impact.

"This study answered a lot of questions we had, but also had its limitations," she explained.

"The results here are useful and interesting, but they only capture a small part of the picture as we only looked at long-term survivors of [sarcoma](#)."

We have another study in the works which is a longitudinal study—this follows patients from the [time](#) of diagnosis until two years later. It's running in the Netherlands and the UK, which is really useful because it allows us to compare the countries' healthcare systems too, which are quite different. This will allow us to answer all of our research questions, and to include not just long-term survivors, but also those with aggressive disease, and also assess the impact of diagnostic timelines and objective outcomes like survival."

Long-term outcomes for survivors are complex and varied, and further research in this area will allow researchers to understand the problems and find solutions that can improve health-related quality of life of patients as they live with and beyond [cancer](#).

Provided by Institute of Cancer Research

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