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15.02.2019

Tags: France, Patients, AFLAR, Rheumatism, Association

Françoise Alliot-Launois, VP of the French League Against Rheumatism (AFLAR), discusses the issues around bone and joint infections in France, AFLAR's work to help patients suffering from these diseases, and the broader role of patient associations within the French healthcare ecosystem.

Bone and joint infections are a major public health issue in France. Could you describe the situation?

In France, 20 million people are suffering from bone and joint infections, almost a third of the population. The major ones are osteoarthritis, with 10 million people afflicted, and osteoporosis, with 5 million. Then there are more than 200 rare bone and joint diseases including fibromyalgia, inflammatory rheumatisms and ankylosing spondylitis.

There is hence a very large array of bone and joint diseases.

Bone and joint diseases are chronic conditions that start insidiously, usually around midlife. As a result, people afflicted have to spend the second half of their lives dealing with the condition.

On the one hand, in the case of rarer autoimmune diseases that affect bones and joints, such as rheumatoid arthritis and ankylosing spondylitis, there have been remarkable therapeutic advancements over the last ten years with the development of biologics and biosimilars such as

TNF inhibitors. However, it should be said that these treatments are not benign. Even though they cancel the symptoms of the disease, they can have side effects and have to be taken by patients for the rest of their lives. Thus, patients undergoing these therapies need to be closely supported by healthcare professionals and patient associations.

On the other hand, for degenerative joint conditions such as osteoarthritis and osteoporosis, there have not been such breakthrough treatments and patients must live with and manage chronic pain for the rest of their lives. Moreover, these conditions can lead to functional handicaps. This affects their professional, social, family and even sexual life. It can also have detrimental effects on their mental health. Not to mention the financial burden that it can represent. In the case of osteoporosis, our biggest concern is that it is under-diagnosed and under-treated. The reason is osteoporosis is an insidious disease that only manifests itself after a bone fracture.

However, after patients leave the emergency room, only a small percentage are hospitalized to check for complications. To make matters worse, there is no coordination between hospitals and family doctors. As a result, a lot of patients are not diagnosed and do not receive treatment. Patients are thus at risk of re-fracturing their bones. Among other types of fractures, vertebral fractures are even less diagnosed because medical practitioners do not measure their patients or even brush off height loss as something that goes along with ageing.

However, losing more than three centimetres in height is usually the result of vertebral fractures. This dire situation is unacceptable as it can lead to the death of patients. If patients become immobilized because of multiple fractures, blood clots can form and migrate. Fractures of lower limb bones, especially the neck of the femur, are the most dangerous as they can directly cause death: fractures of the neck of the femur have a 30 percent mortality rate. To make matters worse, as patients grow old, co-morbidities will add to these problems.

How does AFLAR help patients get access to better care and improve their quality of life?

Our goal is to answer the actual preoccupations of all the stakeholders, not only patients but also their family, friends, physicians and nursing assistants.

In order to improve the quality of life of patients, pain management is a critical factor. We also collaborate with the French Society for the Study and Treatment of Pain (*Société Française d’Etude et de Traitement de la Douleur*) in order to study the quality of life of patients and propose the most adapted solutions.

AFLAR also organizes a lot of actions in order to increase awareness of the great challenges of bone and joint diseases for society. We collaborate with medical schools and all the relevant institutions at the governmental, regional and local level. Regarding institutions, the *Haute Autorité de Santé* (HAS) invited us to participate in health commissions, such as the commission on biosimilars. Moreover, we have also been collaborating on lombalgia with the Social Security and the HAS. At the regional level, we work with regional social security funds and health agencies (*Agences Régionales de Santé*). In each region, together with these institutions and healthcare providers, we think and experiment about the best healthcare provision pathways.

In France, there are all types of patient associations. Some are very structured, other less so. How would you characterize the associative landscape in this country?

The French associative landscape is too fragmented: there are over 15,000 patient associations. Most of them are very small. Moreover, 30 percent of them are specialized in specific rare diseases. In my opinion, some of these associations should merge together in order to have more impact.

Of course, associations can only have an impact because of the remarkable work of volunteers. At AFLAR, volunteers are usually suffering from bone and joint diseases themselves or are family members and friends of the sick. Some are young people suffering from these conditions. Most are retirees who dedicate some of their time for the benefit of the association and patients. They are a precious help, especially when they possess skills useful for the association such as nursing, physiotherapy or even law and accounting

I would like to say a word about the new so-called sanitary democracy law that was introduced in 2002. This new law mandates user and patient representatives in healthcare institutions such as hospitals, clinics, retirement homes and governmental institutions. But in my opinion, this law, although a welcomed initiative, did not go far enough. More often than not, user representatives only have a consultative voice, but no voting or vetoing rights. Moreover, they are heavily supervised by healthcare professionals, making them less independent. They should have a more proactive role and be able to make and apply recommendations in order to improve the operation of healthcare centres. This would increase the trust of patients in the healthcare provision system, which studies show is low.

AFLAR has developed several partnerships with the pharmaceutical industry. Why are such partnerships important?

Our collaboration with pharmaceutical companies was born out of our members’ awareness of the fact that research and innovation are driven by the industry. If there were no pharma companies, there would not be any therapeutic advancements. At the same time, research needs close ties to patients in order to move forward.

We have helplines in our 10 locations where volunteers listen to the preoccupations of patients and answer their questions. Many of these questions are about the latest research and innovation. Some patients are asked to participate in clinical trials for a new medication and want to know if it is a good idea or not. Patients have a strong desire to be a part of the research effort. In order to help the industry, we provide them with information through patient surveys, focus groups and interviews. Moreover, because patients live with their condition for decades, they are in need of information about anything that might help. Our role as an association is to guide them towards the best choices for them. Some might be tempted to try alternative treatments such as homoeopathy and natural therapies. We do not think it would be wise to prevent them from following these treatments if they want to and risking alienating them from the standard path of care. However, we do want them to have all the information about the best standard therapies.

All this said we realize that medicine is not the holy grail. Any drug administration needs to be complemented with a strong support system, which engages healthcare providers, family and friends, institutions, associations and companies.

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