#Strongertogether – patients and radiologists working together for better communication and good care!

I was involved in an ECR2021 session “eHealth – How to enhance radiologist-patient communication through IT”. We were four experts in this session. Three radiologists and myself as a patient expert. We talked about patient platforms and use of tools to team up with them, to have better information and empower patients. Another question was about communication and discussion with patients. The other panelists were Prof. Elmar Kotter and Prof. Peter Mildenberger both from Germany, as well as Prof. Christoph Becker from Switzerland.

Christoph Becker opened the session and brought up a remarkable thought during his talk: “The radiologist is a member of the team of the patient” and I couldn’t agree more. As a Person living with MS, I am not just a patient. I am a human being, a person with needs and a life, in more detail I am a woman living with MS and have an almost normal life. I want to keep my quality of life and live as I want to live. My MS is not the boss, I am, and to keep that status I need this “team”. A team of doctors, experts, my physiotherapist, coaches etc., digital health solutions and of course last but not least: the radiologist.

When I go for an MRI, I don’t want to wait for a letter full with technical jargon followed by a consultation with my neurologist explaining to me just some pieces of the letter weeks later. I want to know the changes in my brain now, like new lesions or the status of my brain atrophy. It doesn’t need to be very detailed, but I want to be informed. I want to have that discussion, because the radiologist can show me the changes on the picture, we can have a look in my personal “photo album” of my brain and all this additional information I can have is great.

To be clear, I don’t expect a recommendation for my next medication etc. from the radiologist. It is very clear for me, radiologists are not neurologists, but they know something about my MS and to know this is important. I expect additional information from the radiologist that my expert doctor wouldn’t share with me because they think that’s not interesting for me, even though I would like to hear it. Here is a dilemma, because time is
very limited, we don’t have the chance to have a conversation which allows my neurologist to get to know me better. So how can this expert doctor know what I want to know?

For me, sometimes there are these little details helping a person living with a chronic disease and help make a difference in decision making. I want to feel that I have all my questions heard and to feel comfortable having this team taking good care of me. It is a question of trust, as Professor Kotter mentioned and all the panelists agreed. It is trust in the doctors of course, but also in the system, the feeling that the patients receive the best care. It is this feeling to be able and empowered to take the next steps, to have an open discussion about how my MS progresses and to know if I have changed from Relapsing Remitting MS to Secondary Progressive MS, which would be the next level of this disease which nobody wants, but it can happen and to know this as early as possible can also make a difference in care. Mood: Do something before the situation becomes totally dramatic.

To have a team for me means to hear everyone in Team Birgit, so that means the radiologist too. It is an important voice.

During the discussion a question also came up about payment. We all know healthcare is subject to conditions, rules and policies. Especially in statutory healthcare systems where budgets and time for appointments are very often limited. These conditions are not always fair for doctors in some countries.

We agreed in our discussion that both patients and doctors see the need to have a valuable conversation. It is necessary for patients to be seen as a person, not just as patient. It is time for a change, as a patient advocate and expert I have been talking for a very long time about this and the need of good conversation.

This is why patients and doctors have to come together. There is a change necessary in the systems and also in conversations with patients. This needs to be heard. From systems themselves and also from governments. The need is very clear: more time and therefore better reimbursement for doctors. The other perspective is, we need more digitalization. These tools, like patient portals to inform and prepare the patient in advance, apps for smartphones and artificial intelligence can help to design more efficient processes and save time to have the mentioned conversations. To have the information exchange to inform the patient and to empower and enable the person to make the best decision for their own healthcare and disease management. We need these conversation and patients and doctors want to do this. It is a necessity, not a nice to have. This is an important need.

This is what I have learned in this session. My personal take away message.

The thing is: nobody can do this alone. Both voices, Patients and Doctors are strong, but it is not very effective to stay in your own silo and just do our own thing. We should join together, strengthen voices, have a discussion and an information exchange. It is important to know the different perspectives to be able to find ideas, solutions and suggestions. To create clear messages and address them to the systems. We need to be heard. Maybe we can’t change everything, but we can mention the needs, problems and questions. We can ask for answers, better solutions and can improve results. I guess you will agree, that’s the goal of good healthcare. Also, to empower patients and to enable them to make the right decision at the right time to have a good quality of life.
Or to use the well-known saying of patients: Nothing about us without us. In this special case I would suggest not just patients. It’s a common thing, so: Patients and Radiologists. Because two strong voices can reach more, can be better heard when it comes to asking for changes for people living with diseases and also for radiologists and other doctors.

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