Patient voices

Dear doctor, please know that you do not know until I have told you

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True patient involvement in treatment decision-making starts with clinicians who tolerate not having ready-made answers, encourage patients to open up and are interested in how living with the diagnosis is for this person.

I have spent 15 years investigating to what extent doctors and patients make treatment decisions together. It has always been important to me as a researcher to be as objective as possible. I now realise that this attempt led me to disregard my personal experiences. I was 13 when I was diagnosed with psoriatic arthritis and have now over 30 years of experience with the disease and the role of chronic patient. Being a patient has become a separate and lonely part of my identity. Separate, because as a person with the disease, I am me and also a patient. Lonely, because I do not know how to genuinely share this experience with others. I know what it can be like not to tell everything, not to loved ones or not to doctors—because it seems unimportant, because it is too personal or because I do not expect others to understand.

As a patient, I am dependent on the doctor's knowledge and the doctor's access to treatments. The doctor also largely determines my view of which policy is possible and desirable. The doctor may—consciously or unconsciously—formulate information slightly differently, give slightly different information or not give information at all because it does not seem relevant enough to share with me. I also know what it is like to face a treatment choice, like when my symptoms were increasing and my rheumatologist proposed another medication. It meant that I had to stop my then-current treatment, which intervenes on both conditions. The brochure on the proposed medication was said to be about psoriatic arthritis, but the text dealt exclusively with the arthritis, not psoriasis. How could I make a proper assessment? The dermatologist was adamant: the skin is subordinate to the joints, because the disease can cause permanent damage to joints and not to the skin. I have already suffered permanent joint damage and would like to avoid further damage, but I have also been covered in psoriasis patches. What about my self-image? And the effects on my daily life—the itching, the time it takes to rub the ointment in or not knowing what to wear. Moreover, yes, the psoriasis disappears but its treatment can cause damage to organs, all this I know from experience. I thought all sorts of things about it, but the doctors did not ask and I felt left out.

I would be very happy if the doctor could say with certainty: 'This works, this is what you can expect, this is what is best for you now'. The truth is that the best policy often is uncertain. This uncertainty can be twofold: there is insufficient medical knowledge and/or there is sufficient medical knowledge, but how I assess the advantages and disadvantages of options can be very different from how the next patient does. When there is uncertainty in at least one of these ways, medical knowledge alone does not provide sufficient basis for treatment advice and this is when shared decision-making comes in. This is jargon for the most appropriate decision model when the informed patient's opinion is needed to determine the best course of action. In practice, it is easier said than done. How many times did I not come up with the right question at the right time? How many times have I genuinely participated in the decision-making or just thought I had?

Shared decision-making is not always easy, there may be little time, it may be hard to understand the information, it may be overwhelming, or it may be difficult to determine what is most important. Nevertheless, if there is uncertainty, it is essential that doctors really try to find out what matters to patients in order to choose the policy that fits best into the patient's life at that moment. It therefore affects me, both professionally and personally, when I get the impression that doctors (too easily) argue that shared decision-making does not work and that patients do not understand or want it and doubt whether it is necessary at all. It affects me when assumptions are made about relevant considerations for patients, without testing those assumptions. The reason is that not only the medical perspective is necessary but also incomplete: it is not about me, the person who has to adapt her life over and over again to the disease, its treatment and its consequences.

How to encourage shared decision-making? Taking my personal experiences into account, I find myself wondering whether our efforts to understand and foster shared decision-making are on the right track. The easiest thing to do is focus on what can be measured reasonably well—which options and information do doctors provide and which options do patients prefer, and take this as input to develop decision support. All of it seems necessary, but is it essential? Should we rather aim for a fundamental change in attitude on the part of doctors and medical students? I believe that involving a patient starts with wanting to understand what the situation is like for the patient, combined with being open to *not* having answers and to *not* showing the way. What if doctors were more curious? What if they concerned themselves with what is important to *this* patient? What if they were to connect with patients as individuals, in ways that patients feel able to share what the disease and treatment is doing to them, even if patients feel thresholds to open up. What if doctors were to regularly ask themselves whether they truly listened to their patients?

Increasingly often, I think shared decision-making is about this: curiosity to understand the patient's situation, connection to listen and self-reflection to grow. As a doctor, with the best will in the world, you do not know what matters to me if you do not ask me. Letting me really contribute to shaping my care is respectful, humble and humane. Besides, you could have been me and I could have been you. Would I have known what matters to you?

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