

Empowerment and chronic disease management: Sara Riggare's inspiring story

74- 19/04/2024 Sara Riggare managed to personalize her treatment through self-tracking and precision medicine... a promising approach to improving the management of chronic diseases.

Sara Riggare is both a patient and a health informatics researcher at Uppsala University (Sweden). Diagnosed with early-onset Parkinson's disease, she decided to practice self-tracking: using a free application downloaded to her mobile phone, she measured finger agility with a tapping test. These tests, lasting a minimum of 20 seconds, were performed at least 10 times a day with each hand over a 5-day study period. Simultaneously, medication intake times were manually recorded. This way, Sara Riggare could measure variations in her motor function throughout the day and noted a decline in function around lunchtime. Based on these self-tracking results, Sara Riggare sought to regulate her symptoms. She collaborated with her neurologist to adjust the timing and/or dosage of medications. This enabled her to better self-manage her chronic illness, a learning process she described in scientific literature (1).

"With my engineering background, I simply thought it made sense to try to understand the input and output parameters of the dynamic bioreactor that I am. But where to start? Which of the billions of symptoms or charming and attractive side effects of Parkinson's disease should I try to track first? Well, that's the million-dollar question, isn't it? And since PD is a very individual disease, the answer may be different for each of us. Similarly, our individual situations are

probably very different. I'm sensitive to a certain molecule, so I take a very low dose and still get a good effect. With self-tracking, it's about finding the best way to manage one's situation, condition, etc..." – Sara Riggare
<https://www.riggare.se/saras-self-tracking/>

Decrypting

Sara Riggare has “scientified” the patient’s perspective and perception. She created her own health resources and data. She better understood the origin of individual variations in symptoms. In doing so, she gained skills and knowledge about the disease and its treatment.

She demonstrated that it was possible to improve treatments by personalizing them through self-tracking and precision medicine. She found that sharing data from self-tracking has the dual advantage of potentially contributing to both patient and clinician learning.

Sara Riggare still requires active support from her neurologist and other healthcare professionals. Their exchanges take place in the context of a balanced clinical meeting, where the patient’s viewpoint is respected, and the questions they deem important are better addressed. Acquiring this mastery, the efforts made to achieve it, and the exchanges with the teams also allowed her to better understand the healthcare system and the possible improvements that self-tracking can bring.

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(1) Riggare, S., & Hägglund, M. (2018). Precision medicine in Parkinson’s disease—exploring patient-initiated self-tracking. *Journal of Parkinson’s Disease*, 8(3), 441-446.

<https://content.iospress.com/articles/journal-of-parkinsons-di>

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