

Joseph

Expertise and trust

Joseph is an avid runner. He used to play soccer, until he tore his meniscus. He stopped playing, although he continued to visit his club on the weekends to watch the game and maybe drink a beer or two. Not surprisingly, he gained a lot of weight in a short time, until he decided that he had to do something. He bought a smart running wristwatch and started, very cautiously, to implement a running regime, gradually increasing the running distance (but never by more than 10% every week).

That was eight years ago. He has been running marathons for three years. He's had quite a few injuries in the meantime, but never the meniscus. There is a nerve in his right foot that's blocked (Morton's neuroma), he has some lumps in the deep tissue of his feet (which appears to be early stage Morbus-Ledderhose), and his hips lack flexibility (CAM impingement), which sometimes leads to annoying pain in the upper legs.

Joseph lives in a country where it is increasingly difficult to get an appointment for specialists. Rather than waiting for an appointment he and his partner, Samir, research his symptoms online to find the diagnoses that seem to fit his troubles. At the same time, he is a keen member of a running portal, where he can upload and share data of his smartwatch with other members of the online community. With the help of the other community members, he found ways to deal with the injuries. Sometimes, he however was also really annoyed by some of the comments made by some members, who really push homeopathic remedies and misinformation about the pharmaceutical industry. He was always skeptical but realized other members seem to buy the claims made by these members. For the other problems, he decided that he should see a physician, as he thought he might need adapted soles and physiotherapy respectively. He went to see a physician on separate occasions to get a referral. Joseph thought these meetings went very well – although the orthopedic surgeon who examined his hips wanted to make some X-rays, before giving Joseph the referral that he needed.

Discussion: Expertise and trust

In the digital age, individuals with health concerns can be significantly less passive and more actively engaged than ever before. They are increasingly able to do research on the internet to form their own opinion on their condition. At the same time, the increase of online peer-to-peer support groups and communities can offer collective and collaborative ways of finding solutions for health problems, especially in underfunded healthcare systems, where it sometimes takes month to get a referral to a specialist and physicians have limited time for an individual consultation with their patients.

Having the possibility to get more information about one's health condition and at best connect with others that share one's issues, can be experienced as "empowering" and one can feel less lonely or powerless. This can enable people to cope better and to participate in some form of shared decision making. But there are costs as well. While Jacob and Samir might be able to differentiate between credible sources for health information, for others this could be more difficult. While there are a lot of great online resources, and many can also access literature on platforms such PubMed and get a basic understanding of their health issues, others have more problems and might fall for non-credible information online. As it is not always immediately clear to everyone, what an evidence based and peer-reviewed study looks like.

And while the interaction between Joseph and the specialist went smoothly, this is not always the case. Physicians study for years to become specialists in their field, and might be less open about the google findings of their patients and dismiss the results of their online search as "Dr. Google." And it is very difficult to really assess if a person not trained in medicine, can get a full understanding of their health condition, without the help of a physician. In the case of Joseph, he may think that everything went well,

but he may well have missed out on treatment because he thought that he knew what ailed and helped him. Is his problem really related to hips lack flexibility, or is there something else going on? More fundamentally, what happens when patients start treating physicians as a mere hurdle to get the referral that they think they need?

Such questions are not new or unique to the emergence of mobile health, ever since the emergence of the internet, there have been weary voices expressing concern about what this development means for health care professionals, who are now encountering more opinionated but often also misinformed patients. At the same time, it should be noted that physicians too are only human, and often quite specialized in their expertise. As such, it is not uncommon that, for example, some people with chronic disease might become more knowledgeable about various aspects of their condition than many of the health care professionals they encounter as they are the ones living with this health condition every day. In many ways, it is a welcomed shift that the traditional paternalist culture of “doctor knows best” is gradually changing and the doctor-patient relationship is becoming less unequal. The question is whether this will lead to more self-responsibility of individuals with health issues? Not everyone has the time and energy to do this much research on their health condition as Josph, and some just don’t have the resources to acquire the knowledge they would need to, and they might fall into the trap of misinformation. The topic of patient and experiential knowledge, and the relationship between patient and physician is an ongoing interest in ethics and is now heightened with the emergence of mHealth.

LITERATURE

- Hardey, M. (1999), Doctor in the house: the Internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health & Illness*, 21: 820-835.
- Hendl, T., & Shukla, A. (2024). Can digital health democratize health care? *Bioethics*, 1-12.
- Jansky Bianca. Digitized patients: elaborative tinkering and knowledge practices in the open-source type 1 diabetes “looper community”. *Science, Technology, and Human Values* 2024;49(1):53-77.
- Samuel G, Lucassen AM. The environmental impact of data-driven precision medicine initiatives. *Cambridge Prisms: Precision Medicine*. 2023;1:e1.