

BELIEFS OF PEOPLE WITH A RARE DISEASE ABOUT HOW ACTIVE A ROLE THEY CAN PLAY WHEN CONSULTING A SPECIALIST

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Summary

- While health literacy has been studied for decades, the aim has nearly always been to prove the existence of a direct link between health literacy and how the patient's condition develops. Only a few researchers have tried to understand the role patients' health literacy plays in their interaction with doctors. In the context of rare diseases, patients and care-givers voice tremendous 'information hunger'. But often they are left starving, metaphorically speaking, as so few sources are available, and those that exist are so inappropriate to patients' needs. As gathering information is a way of coping with symptoms, complaints and eventually diagnosis, patients develop strategies to close the information gap by any means available. How effectively they do this varies considerably.
- This study examines the process of obtaining information, communicating and playing an active role. We want to learn more about the strategies of patients who have access to digital information and of those who don't, and how this impacts their health literacy and participation in healthcare. We want to see what effect the digital health revolution has for people with limited resources, and how that group of patients copes with the situation.

Method

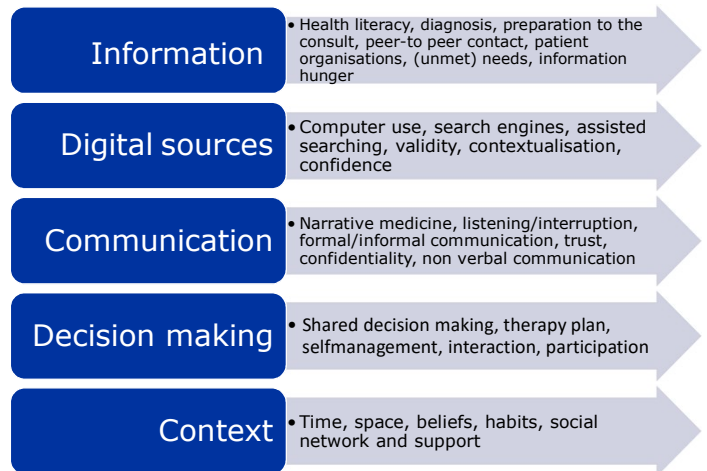
- In-depth semi-structured interviews are conducted with patients suffering from a rare disease. The interviews are analyzed and coded using the constructivist grounded theory method¹. Patients are recruited through patients' organizations or via rare disease coordinators working in Flemish university hospitals.

"If my doctor talks about my perspectives and my health evolution, I will look it up afterwards. Then I probably will ask for more information in the patient group"

(female patient with rare cancer)

• During interviewing patients, a topics list makes shore that different aspects that could influence the process of participation are taken into account.

Topics list for interviewing patients



- After initial (analytic) coding of the interviews, the 5 categories helped defining threads for analysis and enabled comparing data through a process of focused coding.

PRELIMINARY FINDINGS

- Searching for information is a way of coping with a rare disease. In addition to medical information, patients look for stories from other patients. Even though they realize that diseases not always develop in the same way, it still directs thoughts and concerns of where life is heading. It provides a sense of coherence.
- Before they are diagnosed, patients mainly use search engines and search terms based on symptoms or complaints. This search leads to information on blogs or sponsored sites that do not necessarily improve health literacy.
- After diagnosis, the process of focused searching and informing can start. If patients are very interested in the disease and its origin at the outset, their approach changes over time to research based on phenotype.
- Some patients find difficulties in using computers, sometimes because of (physical) disabilities or because the hardware available functions less well than it might. They may also have trouble finding relevant information because of language barriers or pay walls.
- People can become metaphorically 'cachectic' owing to lack of information, in a similar way to patients suffering from physical symptoms as a disease progresses. The damage caused by this cachexia or state of deprivation adversely affects mental and physical well-being.
- Patient organizations and communities for rare diseases are crucial to fulfil the need to share knowledge and experience of treatments and to enable patients to gain some understanding of the future outlook. They have an impact both online and offline.

¹ Charmaz, Kathy. *Constructing grounded theory*. 2nd edition. Introducing qualitative methods. London ; Thousand Oaks, Calif: Sage, 2014.