

Title.

Patientcockpit: My wishes when I get ill

Name

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3 messages

- Asymmetry in information constitutes a difficult patient situation
- The patient of the future insists in being involved - actually in charge
- I wish a cockpit to navigate in and understanding informations

The details

It's difficult to be a patient - not only in Denmark. The illness, the roles and the expectations as a patient contributes to the difficulty.

Foucault describes also the actions of discipline that's imposed on the patient. The clothing, the hospital rythm, the humiliating procedures and the clinicians "one step up" adds to the disciplinary culture of the health system.

Also the surveillance technology of the health system imposes a self corrective state of the patient and a dependent, submissive state.

The asymmetry of information aggravates the situation. The patient is in the centre, not as a subjective person but as an object of observation. Not as a user but to be used. (this logic is a consequence of reading Foucault, so beware).

Furthermore the patient is presented to differing logics of doctors, nurses, market, management, politics etc. The different logics subscribe to information in both open and concealed versions.

The patient's medical record is not owned by the patient, but owns the patient - the patient of the record. The medical record acts as a panopticon - the instrument to observe and discipline the patient.

Access to information paves the road to positions of power and lack of information demounts the person being in control of the disease and the everyday living. Use of technology further enhances this asymmetry of power. When knowledge in understanding the information is added the asymmetry is even further enhanced.

Topol suggests by the title of his book, that a shift of paradigm is emerging. Pushed by the very accessibility of information by mobile technologies, the diminishing costs and social spread. Information can be made understandable by technologies that support interpretation and advice. There is an emerging possibility that the patient can comprehend the disease on a level as most clinicians.

This submission is a call to discuss how to create tools for the patient to collect and structure clinical information and use technologies for understanding the information and get advices that puts the patient in charge of his/her life and have access to reliable advices.

The road to this end is

- collection of data (as in personalised medicine),
- a comfortable security structure (who uses my data, how is my data used),
- ways to show data (the cockpit),
- the use of "intelligent" technologies (the understand engines),
- the overview of "contracts" with health agents (health systems and health professionals).

There is also a need to educate health professionals to interact with the emancipated patient in a level playing field.

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