Abstract at halfway review

Title
At the fringes of autonomy – when, how and what information should be given to enable patient decision-making in healthcare

Background
In Swedish healthcare, treatment may not be given without informed consent from the patient, unless explicitly permitted by statute. This harmonizes with the central principle of self-determination in medical ethics. Informed consent requires among other things that the patient has sufficient capacity to understand, process and deliberate information – a potentially complex task when it comes to treatment decisions. It is important to consider factors such as when, how and what to inform about, since they might constitute important determinants of patient decision-making.

Aims and method
This project aims to explore less studied aspects of self-determination and decision-making in healthcare. Through an analytical philosophical method with a normative ethical approach, it seeks to provide a deepened understanding of the application of the principle of autonomy on treatment decisions in which patients can and should participate.

Preliminary results
The first publication addresses the question to what extent "temporising" – postponing the presentation to patients of treatment decisions that are to be made - has implications for patient self-determination. The main conclusion is that temporising may threaten self-determination, either by raising the probability that the patient loses decision-making capacity or by making it more probable that the decision ultimately made is a different decision from the one initially faced.

A review of the literature has shown that despite the vast amount of literature on informed consent, there is limited consensus regarding what information the patient ideally should be given. Among considerations guiding what treatments are offered or even recommended to patients, the second study focuses on considerations not directly related to the interests of the patients themselves (non-patient-oriented) and analyze which of these, if any, should be disclosed to the patient, and why.

Importance
This project has practical implications for healthcare, since it explores until now poorly developed questions concerning patient autonomy in medical decision-making. Increased awareness of factors that influence patient self-determination could be of importance both for legal development and future informational guidelines for healthcare.

Published papers