Abstract

Changes in society and changes in the appreciation of the knowledge of patients have led to more active participation of patients in research and more attention being paid to their perspectives. The involvement of patients in research can happen in many ways and may have many advantages. Some drawbacks and doubts about patient participation and the investigation of their perspectives have also been mentioned. This thesis aims to clarify the additional value of the involvement of patients and the investigation and development of their knowledge and perspectives in research. It aims to answer the question whether attention to the perspectives of patients and participation of patients in research have complementary value and, if so, how this can be realized in practice. It describes how patients can be involved in research without overburdening them and without excluding vulnerable patient groups. We demonstrate how the subjective individual experiences of each separate patient can be developed into shared objective knowledge, also known as the patients’ perspective. We show, by describing several research project with patients with renal diseases or Acquired Brain Injury, how patients can be involved in order to foster such a process and in order to explore the patients’ perspectives which can be seen as complementary to the professionals’ perspectives.