Towards patient centred care - information technology supporting patient narratives

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The poster presents two ongoing research projects aiming to develop design implications for information technology (IT) use to support the emergence of patient centred care. Taking a patient perspective the research concerns clinical work as well as emergent forms of Internet use in the patient-provider relationship.

The first study focuses on hospitalized patients with chronic heart failure (HF) and aims to improve clinical decision making by involving the patient’s subjective experiences of health and illness (patient narratives). The overall hypothesis is that patients will have better quality of life, better acceptance of their disease, and shorter length of stay if the caregivers and patients share clinical decision making. A central component of modern healthcare delivery is relevant IT use. An important part of the project therefore explores how IT can support the capturing and integration of the patient narrative into the planning and delivery of healthcare. An etnomethodological approach is applied for data collection involving observations of the particular care context and the collection and use of patient narratives. The empirical data is further complemented by semi-structured interviews with healthcare professionals. Tentative results from the initial stages of the research are presented. The work is conducted in a multidisciplinary research project at the Sahlgrenska Academy at the University of Gothenburg, (Institute of health and care sciences), in Sweden.

The second study aims to contribute to the development of Internet use in healthcare to support the patient-provider relationship. The research concerns the use of patient narratives (longer stories) as medical information on the Internet and explores how public as well as private actors publish patient narratives online. In particular the study concerns the role of this form of technology use for patients, for healthcare, and for further development of IT use. Applying the research approach as presented above data is collected by online observations and interviews with publishers and patients. The poster presents some early results from the research and a literature review mapping out previous experiences of using patients’ narratives to support others in online settings. Also, the review identifies areas for future work to support the development of this form of IT use. The presented work is conducted at the Center for Medical Informatics at the IT University, Göteborg, Sweden.

The studies presented in the poster are related by the aim to understand the patient narrative (e.g. its components and how it is created in different settings) and by the idea to explore how increased knowledge about the patient view can inform the design of information technology use.

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