The patient is the only person who experiences the complete course of a healthcare problem, from first symptom to contacts with the healthcare system to examination, treatment and follow-up activities. Only the patient experiences all the difficulties that the healthcare problem may cause, from practical issues in the home to social and psychological challenges. This thesis explores how caregivers together with patients can draw on these experiences in healthcare service development. Researchers and three healthcare units have collaborated to develop a model for co-creation with patients in healthcare service development, through patient diaries. A total of 53 patients from the different care processes have contributed ideas and experiences using paper and pen, blogs, or by calling an answering machine.

The model includes three ways for learning from patient diaries. First, ideas from diaries can be used as input for healthcare service development. Second, a larger sample of diaries can be compiled to create a report of patient experiences, in which problem areas in the care process can be identified, and combined with other statistics. Third, individual patients’ stories can be highlighted and used as a basis for discussion in the organization to shift the focus to patient experiences, serving as a motivator for change within the organization.

This thesis shows that patients are an untapped resource of creativity and that patients are able to share ideas and experiences regarding a range of topics, often concerning areas in the patient’s care process that are normally inaccessible to the caregiver. Acquiring knowledge regarding parts of the patient’s care process that are invisible to the caregiver is key to improving care and supporting the patients’ own efforts.
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