

Child patients value warm medical encounters

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Aalto University researchers and the HUCH Children's Hospital carried out collaborative research into the views of child patients and their families on hospital visits, the care received and life with long-term illness. The research project included developing a patient experience

survey for the parents of patients at the Children's Hospital, and investigating the children's own experience for designing future digital services.

Video diaries was one method used to collect research material. To this extent, the observation can be divided into the children's and parents' encounters, the ease and sense of care as well as the physical framework.

'Children and young people value individual and warm encounters for example, continuity of care as well as check-up visits and ease of care of the illness as well as functional and pleasant premises. In the future, digital services could be seen as one central way of better supporting the [patient experience](#) of children and [young people](#)', is how computer science researchers Johanna Kaipio and Nina Karisalmi describe the project.

Fear and pain play an important role

In depth interviews were carried out with over 20 families with children who are [patients](#) to examine the families' patient [experiences](#) and the central issues related to them. The most important factors that came to the fore were the success of care, how care was organised, issues related to care staff, attitude towards the illness as well as support and day to day arrangements.

'The workload imposed by the illness relates to the day to day life and the quality of life of the patient and his or her family, so for example help or support from peer support groups or from friends and the wider family can have an impact on a child patient's parents' ability for cope with day to day life,' adds Professor Marko Nieminen from Aalto University.

The parent's fears and feeling of disbelief about the child's illness play

an important role, according to the research, not to mention taking the child's own fear and experience of pain into consideration, and the help from staff in the middle of all these experiences. These experiences are also reflected against earlier expectations.

Some of the factors, such as the feelings about the illness as well as support and day to day arrangements, are not directly within the scope of influence of the [hospital](#), but they still have to be taken into consideration as part of the overall patient experience.

'The new Children's Hospital will be commissioned next year and the objective is to build a hospital where Finnish children will receive the best care in the world. We consider patient and family experiences as valuable sources to develop an overall better hospital service', enthuses Pekka Lahdenne from the HUCH Children's Hospital.

'The patient experience stems from the user and service experience as well as from research into service pathways and user-oriented planning. On the basis of the research, it seems that a completely new way of examining customer satisfaction is emerging,' added Professor Nieminen finally.

The research perspective is thus built up from the patient and not from the hospital's production organisation, by examining the whole life situation of the patient and his or her family. The research indicates that traditional, organisation-oriented [customer satisfaction](#) surveys are too narrow.

The next stage of the [research project](#) is to examine in more detail children's emotional experiences, as well as carrying out electronic surveys on the most important experiential statements found in the different stages of the patient pathway. In addition to Aalto University and HUCH, the Children's Hospitals of Turku University Hospital and

Oulu University Hospital as well as the Tampere University of Technology are involved in the research project.

Provided by Aalto University

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