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# Patient-Centred Design of Healthcare Services: Meaningful Events as Basis for Patient Experiences of Families

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Abstract. Patient experience has become a crucial part of the quality of any healthcare service. Experiences and their structures are not however trivial phenomena that are easy to describe and model. Instead, subjective and dynamic experiences seem to escape definitions and measurements. In order to map the dimensions and dynamics of patient experiences of families, i.e. experiences in families where one or more children are or have been seriously ill, we conducted in depth interviews with 17 parents. Both the interview structure and analysis were based on the technology as experience framework, which states that products and services are not just used but lived with. The results of our study describe patient experiences that are rich and complex yet structurally similar in their manifestations and development. Event-based and situational patient experience evolve through meaningful events relating to the patient's reflections on past events and in the framing of the current situation. The presented situational patient experience model can be utilized to evaluate and design healthcare services.

Keywords. Patient experience, experience-based design, interview

#### 1. Introduction

Patient-centred design of healthcare services emphasizes the understanding of patient characteristics and needs as the basis of the design [1]. This approach of focusing on the users and customers is in general known as human-centred design [2]. Recently the product and service design research and practice have evolved towards experiences as design drivers and the potential of this experience-based design has been noticed also in healthcare service design [1]. While human-centred design is quite well established and methods and frameworks exist on understanding and modeling the user characteristics and needs, experience-based design still lacks generally accepted concepts and definitions [3]. The major gaps in user experience research which also are important in the context of healthcare services are: 1) understanding of context of experience, 2) characterizing experience over time, and 3) multidimensionality of experience [4].

The New Children's Hospital project<sup>2</sup> in the capital area of Finland aims to utilize the idea of patient and family-centredness as well as patient and family experiences in

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design and implementation of the hospital processes. In order to succeed in this the hospital has started collaboration with major Finnish universities as well as service design agencies. This paper describes the initial results of a large research project aiming to support the development of the New Children's Hospital on experience-based design. The paper contributes to the patient experience literature by developing and describing an event-based patient experience model, which can be used to understand the patient experiences from the perspectives of the patients. The goal of the study was to map the dimensions and dynamics of patient experiences of families with children. The focus was on parents and their experiences of the illness of their children. The research questions were:

- How do patient experiences emerge in families with children?
- What are the main dimensions of patient experiences of families with children?
- What are the recurring structures of patient experiences of families with children?

## 2. Research design

The technology as experience framework of McCarthy and Wright [5] was utilized as the main theoretical basis for the study. According to McCarthy and Wright products and services play a central role in how we live our lives and therefore user or service experiences should not be separated from other life experiences or isolated into mere separate interaction events. Instead, a holistic approach is needed to truly understand and appreciate people's experiences. Although, the technology as experience framework does not provide a general description of the dimensions of experience or even encourage towards such classifications, it provides a basis for analyzing experiences through the concept of experience threads. The experience threads are not elements of experience but ideas to help to think more clearly about product and service experiences. McCarthy and Wright name four main threads of experience:

- The sensual thread, i.e. the experiencer's sensory engagement with a situation
- The emotional thread, i.e. how the experiencer's perceiving, thinking and reasoning is affected by her values, needs, desires and goals
- The compositional thread, i.e. what kind of relationships exists between the parts and the whole of an experience
- The spatio-temporal thread, i.e. what kind of roles do space and time have in product or service interactions

The technology as experience framework was selected as the starting point for the study since it acknowledges the fuzzy boundaries (or boundlessness) of experiences and manages to provide analytical guidelines and tools for studying experiences without predefined and static ideas of what the experiences are or can be. These both aspects are extremely relevant with patient experiences, since being a patient or ill is not usually a single isolated task or event, but affects the whole life of the patient and her family. In addition, many health-related experiences such as a feeling of pain are very difficult to define in comparable ways.

## 2.1. Data gathering

Interview was selected as the research method, since observations of child patients and their families would have been impractical to arrange and would have proposed some ethical challenges. The research plan was approved by the ethical review committee of our partner hospital. The participating 17 families were selected in collaboration with our partner hospital so that the interviews could be organized during or adjoining a preplanned hospital visit of the family. The interviews lasted one to two hours and they were conducted during the winter 2015-2016 at home of the interviewees or in the premises of the partner hospital or our university. In three cases both of the parents participated in the interview. The participating families belonged to two patient groups: 1) families with a small child with a congenital disorder (9 families), and 2) families with a teenage child with recently diagnosed chronic illness (8 families). Small children, less than two years old, are both resource-wise and by head count the largest patient group at the hospital. The teenagers were selected as the second group in order to enable comparisons between the experiences of the parents and the children in the further phases of the research project. The interview structure was based on the critical incident approach [6] and more precisely the critical decision-making method [7]. Our version of the critical decision-making method, critical experience interview [8], consisted of four steps:

- 1. Letting the interviewee describe the incident (illness of the child) in her own words
- 2. Constructing a timeline for the incident in collaboration with the interviewee
- 3. Identifying the experiences and emotions relating to the incident and events
- 4. Identifying the used communication tools and partners as well as information sources

## 2.2. Analysis

The data analysis was guided by the technology as experience framework [5]. The transcribed audio recordings of the interviews were coded by two researchers. The code book included codes based on the technology as experience framework (sense, emotion, value, desire, need, overall story, medical operation, phase, time, time period, and place) as well as codes based on the service design approach (actor, service interaction, communication media, and critical information). After the coding, both common themes and differences between the interviews were identified.

## 3. Results

Overall, the experiences of the families followed a similar general structure. The starting point was either regular child healthcare related checkup during which some anomaly was discovered, or long enough lasted symptoms that alerted the parents to contact the doctors. After the initial awakening, a period of diagnosis followed. In some cases, the diagnosis turned out to be extremely difficult and it overlapped with the treatment period. Lastly, after the treatment period and possibly some recovering a follow-up checkup was organized. Experience-wise, the end of the illness was much vaguer than its starting point. Usually, the parents felt that the patient experience ended

when the family was able to return to their normal routines and everyday life. With chronic illnesses, this fell on the time of finding the correct medicine and treatments and learning to live with them. In case of curable illnesses, the ending fell on the time period when the child had recovered enough to be able to participate in most of the everyday activities of the family. Noticeably, neither of these endings matched the potential healthcare service contact points such as discharging from the hospital ward, making the diagnosis and treatment decisions, or follow-up checkup.

Although a general structure was visible in all cases, the parents did not seem to experience the illness of their child and the usage of healthcare services by it. The general structure emerged in the interviews, when the parents were asked to describe the illness in its entirety. When enquired further for the experiences, the parents started to describe individual meaningful events. The meaningful events were incidents and time periods during which something changed within the illness, the treatments, or the parents' understanding about them. Usually, the meaningful events were only deemed as such some time after the events. This is quite understandable since life is not a series of separated incidents but a continuous activity and sensemaking takes time. The meaning can also change when people acquire new knowledge or a new perspective. The meaningful events were related to the illness instead of the healthcare services. For example, a discussion with a friend could become an important and meaningful event because it changed the parents' thinking about the illness. Also, not all healthcare service contacts were deemed meaningful and important. Figure 1. depicts the event based nature of patient experiences as well as the main factors impacting on the experience of the individual events and through it on the general patient experience.

Threefold forces affecting the situational and overall experience can be identified. First, expectations have an effect on the experience. In case of patient experience, the expectations were based on the family's earlier experiences of similar events, the predicted impact the event has on family's everyday life and other activities, the values and attitudes of the family, and the predictions given by the healthcare actors during previous events, i.e. the medical treatment plan. Second, the actual event and its success have an impact on the experience. The most important part of the event is the interpreted success of it. In addition, the parents' observations and understanding about the child's symptoms affect on the experience. Also the special arrangements the family needs to make because of the event (e.g. taking leave from work) affect on the experiences. Thirdly, the outcomes of the event impact on the experiences. The outcomes potentially having a large impact on the experiences are changes in the medical treatment plan, new predictions relating to the recovery time and process, and child's long-term reactions to the event.



Figure 1. Event-based patient experience model. The individual meaningful events form the basis for the patient experience. The event itself as well as previous and following events impact on how the event is experienced.

Interestingly, there were also back links between the events. In some cases for example the diagnosis and treatment changed and thus the parents re-evaluated the meaning and value of the previous events. In addition, reflecting on the past events might change their meaning and thus also the experience. A few of the interviewees said that the interview itself was a good "therapy session" and helped them to process some incidents.

#### 4. Conclusion

The experiences of parents when their children are seriously ill seem to emerge through events that the parents consider meaningful. The events are not isolated incidents but interconnected and affect each other. The event-based experiencing of illnesses and healthcare services create some important implications for designing healthcare services of high quality and pleasant customer experience. In addition to ensuring that the service contact points have a good flow and provide friendly, efficient and familycentric interaction, the service also needs to support families in making sense and valuing the service events. The sensemaking and valuing are especially important in contradicting and repeating service events such as changes in diagnosis and/or medical treatment plans, and continuous treatment periods where the recovery of the patient is not visible for the parents or is difficult to recognize.

This study is a first step in a larger research project and thus suffers from some weaknesses. Particularly, our data is purely retrospective. Therefore the event-based patient experience model can lack some situational factors impacting on how a situation is experienced. In addition, retrospective interviews can miss some aspects of changes in how events are experienced since the interviewee only describes them once from their current viewpoint. However, a retrospective account of experience is not without its merits. It is for example the basis of our decisions of returning to certain services or recommend them to our friends. We plan on continuing the research by developing a survey tool for measuring situational patient experiences as well as the factors having impact on them in the context of children's hospital.

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