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Selfies of Sickness: The Use of Video Diaries with Chronically Ill Children

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Abstract. This paper describes the use of video diaries as a tool for understanding children's patient experience and as a potential method for directly gathering patient experience information from children. It was hypothesized that this method would uncover otherwise hidden knowledge about children ages 10–16 years with chronic illnesses. The aim of this paper is to assess the potential applicability of this method as a standalone tool for the public healthcare sector to capture and better understand the patient experiences as a basis for continuous service development. Therefore, this paper does not describe the results on children's patient experiences. The video diaries proved to offer rich data, but certain shortcomings were also identified. Motivating teens, especially boys, was found to be difficult. Needed changes are addressed, and suggestions for future work are presented.

Keywords. probes, video diaries, patient experience, feedback, children, teenagers, chronic illness

1. Introduction

Globally, patients continue to set higher demands for healthcare services, and in response, healthcare providers increasingly use the patient experience as a measurement of performance [1]. In Finland, the healthcare sector's interest in better understanding user participation and patient experience has risen during the New Children's Hospital 2017 project. In this national-level project, both public and private sector actors, industrial partners and private donors collaborated to fund, design, and complete it. The Lapsus research project at Aalto University is exploring the perspectives of children and their families on the children's hospital visits, treatment and care, and everyday life with illness. The aim of the project is to help build the world's best children's hospital for both the children and their caregivers.

Earlier during the project, pediatric patients and their families were observed and interviewed, and workshops were held. The initial aim was to focus on the use of design probes, especially video diaries as a tool for understanding children's patient experiences. The hypothesis was that use of this new medium would motivate the participating children and teens to reveal otherwise hidden aspects of their lives with chronic and sometimes terminal illnesses. The participants were children ages 10–16 years with chronic illnesses (e.g., rheumatism, diabetes, gastrointestinal disease). They were given a probe package consisting of a tablet, a binder with tasks and instructions, 3 story cubes, and a marker pen. They were asked to complete the given daily tasks and

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record video clips or diaries on the given themes at their homes over the next 9 or 10 days. The tasks were constructed based on the McCarthy and Wright's categorization of experience as sensual, emotional, compositional, or spatio-temporal [2]. As well, some tasks dealt with the social aspects or encouraged the participants to directly influence their healthcare practices. The tasks prompted the participants to complete the daily activities and reveal their feelings toward their chronic illnesses through drawing, making, and storytelling. One to 2 weeks after the participants returned the probe packages, the children were interviewed to better understand their responses.

During the project, it became clear that the children's hospital lacked a practical tool for gathering information about the patient experiences of children, who stated that they would appreciate such a feedback channel. The focus of this paper is to evaluate the potential applicability of video diaries as a standalone method for the public healthcare sector to collect data on and understand the patient experience as a basis for continuous service development. In the field study, children's patient experiences were mapped out, but these results fall outside the scope of this paper.

2. Method

The researchers experienced with diverse ethnographies and cultural and design probes, wanted to find a modern-day equivalent to the most classic of all self-reporting methods—the diary. Probes are intended to inspire respondents and elicit their reflections on their experiences through making and crafting [3]. Thanks to YouTube, Big Brother, and the ubiquitous penetration of smartphones, children today are highly competent at both consuming and producing video clips and self-reporting their views in blog posts. Studies even suggest that the data gathered from children's video diaries are deeper and more truthful and personal level than the data gathered in interviews [4].

Video diaries were chosen because they can provide information not available through any other method [5, 6]. Probes that offer opportunities to respond verbally and visually through action make it easier for participants to express their feelings [7, 8]. Selecting a potentially playful probe was expected to enhance and sustain the motivation of the participating children [9].

A research aim was to find out what children say about their patient experiences in their own words and how they express themselves. Additionally, this new method for directly gathering patient experience information from children was tested. As well, the children's hospital wanted to improve its feedback system, and an aim of this work was to evaluate the applicability of video diaries in this context.

2.1 Implementation

The participants were recruited through the hospital, where nurses made the initial contact with potential outpatients. If the patients were interested in the study, a doctor called their parents and informed them about the study. Next, the researchers inquired the parents' whether their child was willing to participate the study resulting the delivery of the probe package. Some probe packages were delivered via mail.

The study was carried out January–May 2016. Fourteen children participated by creating video diaries, while 2 children declined to record videos but were willing to complete and discuss the tasks in interviews. The considerably high rejection rate of 59% is addressed later. In total, 20 of 34 contacts declined to participate. The

participants' delivered multiple daily video clips, mostly 2–5 minutes, long but ranging from 3 seconds to 17.5 minutes in length.

2.2 Analysis

The daily tasks in the probe package were first read and summarized as a baseline for the value added and knowledge gained from the video diaries. In the subsequent interviews, possible ambiguities and shortcomings were clarified, and supplementary questions were asked. The qualitative data were analyzed with Atlas.ti using an analysis framework with 16 top-level codings based on the themes drawn from McCarthy and Wright [2].

3. Applicability as a Standalone Tool for Capturing Patient Experience

3.1 Finding Patients and Losing Them

The recruitment process was initially quite complicated and time consuming due to complexities surrounding data protection, which delayed the study. Hospital personnel were very enthusiastic and eager to help but had to handle recruitment alongside their normal duties. Having several people—nurses, doctors, and researchers—contact the potential participants was unnecessarily cumbersome, and the process was streamlined to include only a single contact with the patients or their guardians.

The rejection rate was very high. Most of those who declined to participate were teenage boys, who expressed the most difficulties talking to a camera. The most commonly given reason was a lack of time due to school, hobbies, and/or friends. Another frequently stated reason was the patients' current situation: either the present medical condition made participation unpleasant or impractical, or the patients felt that additional reflection on their illness at that moment was undesirable. In most cases, refusal to participate was not directly linked to the chosen research method.

3.2 Motivation

Most participants were motivated to take part in the study and explicitly preferred the video diary/probe over interviews and questionnaires as a research method. A few teenagers did not seem to be as enthusiastic about the study as their parents and likely participated only because their parents wished it. The data gathered from these participants were poorer in quality, and some tasks were not completed or done with very little detail and effort. In these cases, the patients' recorded diary entries were also often very short.

Most of the children were genuinely interested and put real effort into their responses. Of course, there were still some shortcomings, such as forgetting to complete a task or properly explain the choices made. Overall, the received data were very rich both visually and verbally. The method also received some critiques. It was described as "strange," too time consuming, laborious, and stressful. Some participants said that talking directly to a camera was "too weird" or even "frightening." Some

children's personalities affected their participation; they were shy or had difficulties telling about personal matters or their feelings.

Over half of the participants stated that they would not alter any tasks. They appreciated the opportunity to complete the study at home and to take as much time as they felt necessary. They also experienced the tasks and video diary as more motivating than interviews and thought that they would likely obtain richer data than questionnaires. A few participants deemed the method too laborious because it required them to commit to completing tasks for 9 or 10 consecutive days.

3.3 Technical Difficulties

A few problems occurred in the use of tablet computers. Many participants chose to record videos at night in bed with the lights turned on low while talking quietly to avoid disturbing siblings or for the sake of privacy. Also, moving the tablet to show the various assignments caused the microphone to pick up incidental background noises. More unfortunately, three participants accidentally deleted all or part of their videos. This was caused by their unfamiliarity with Android devices (and the failure to follow the instructions to not delete any recordings). Luckily, most files could be salvaged from the memory cards.

3.4 Analyzability

A researcher with a background in user-centered design reviewed the tasks in the binders, watched the videos, and conducted the interviews. The binders and the videos provided good background information about the participants and their patient experiences which could be clarified, elaborated, and extended. The aim of the interviews in this study was to get a deeper understanding of the participants, in addition to validating existing preconceptions because confirming facts is criticized as an objective in probing studies [10]. In a separate phase of the research, a 2-hour in-depth interview covering the same topics as the probe study was conducted. Therefore, it can be confidently stated that the data gathered using the probe and the video diaries were much more accessible for persons not trained in qualitative analysis. The binders and the video diaries could be analyzed by a nurse, whereas the longer interviews demanded research skills, both to conduct them and to analyze the results, which hospital personnel do not necessarily have.

4. Adjustments

4.1 Integration into the Hospital Process

One major weakness of this method was recruitment. To succeed, the continuous study of the patient experience using probes and video diaries has to be integrated into the normal nursing routine so that no extra steps are needed to recruit, deliver, or collect the probes. Also, the analysis of the received feedback must be an ongoing, adequately resourced process within each ward or unit.

4.2 One Size Does Not Fit All

Participation has to be motivating and fun. Attention was paid to make the probe interesting and playful, but it will need even more variations to fit the heterogeneous user group. Customized solutions could include gender- and age-specific variants (e.g., 6–10, 11–14, and 15–17 years old [11]). While the tasks can be similar, the execution should differ: for instance, younger participants can paste stickers and draw pictures, whereas teens are more able and willing to express themselves verbally. That said, some of the older participants explicitly stated that they liked the stickers and overall playfulness, and all the boys enjoyed designing and constructing their own medical devices.

As well, it is advisable that the tasks can be executed in different ways because children are individuals and prefer different things. For instance, the designed imaginary medical device could be drawn, built from Legos or other objects found at home, or described in a story telling how it heals people. The tasks and instructions should be clear and unambiguous. Instructions that are too long should be avoided, the essential parts must be clearly highlighted, and examples should be included to provide inspiration and guidance. The study showed that some children found recording video diaries to be terrifying or strange. Some agreed to participate only if they could film the binders or tasks instead of themselves, and we recommend allowing this possibility.

5. Discussion and Future Work

It takes time to build a working probe package, and motivating teenagers to participate can certainly be challenging. However, this method has been shown to produce very rich, detailed pictures of pediatric patients' daily routines, emotions, and experiences. The video diaries used were well liked by the patients, and after this method is integrated into the partner hospital's medical practices, it should be a valued part of its ongoing quality assurance. Future work includes reviewing the materials with appropriate hospital staff to validate that the initial claims concerning analyzability are correct. The use of other emerging communication channels, such as Snapchat and WhatsApp, should also be investigated.

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