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Published in:
Building Continents of Knowledge in Oceans of Data

DOI:
[10.3233/978-1-61499-852-5-935](https://doi.org/10.3233/978-1-61499-852-5-935)

Published: 01/01/2018

Document Version
Publisher's PDF, also known as Version of record

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Please cite the original version:
Karisalmi, N., Kaipio, J., & Lahdenne, P. (2018). Improving patient experience in a children's hospital: New digital services for children and their families. In *Building Continents of Knowledge in Oceans of Data: The Future of Co-Created eHealth - Proceedings of MIE 2018* (pp. 935-939). (Studies in Health Technology and Informatics; Vol. 247). IOS Press. <https://doi.org/10.3233/978-1-61499-852-5-935>

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Improving Patient Experience in a Children's Hospital: New Digital Services for Children and Their Families

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Abstract. Digital services are increasingly being developed for the healthcare sector. In Finland, the five university hospitals in 2016 launched a virtual hospital platform, Healthvillage.fi that includes several portals. The aim of this study is to explore the needs of children and their families related to digital services in the context of a children's hospital in Finland. Two methods were used to examine the needs and expectations of children and their families: a web-based survey for parents and video diaries for children. We identified nine categories of needs and noticed they were related to better communication between families, healthcare professionals, and peers. These observations were used to further analyze possible novel digital services for child patients' families to support and to complement the recently launched Healthvillage.fi platform.

Keywords. Child patient, children's hospital, digital services, parents, patient experience, peer support

1. Introduction

New digital services aim to activate patients toward maintaining their own state of health and to provide a better patient experience (PX). In Finland, the five university hospitals in collaboration in 2016 launched a virtual hospital platform, Healthvillage.fi (Terveyskylä in Finnish) [1]. This platform includes several portals or digital health hubs for a variety of diagnoses or disease groups where patients can anonymously access reliable information about diseases and health and services. In addition, information is provided in the forms of current news, stories, self-care instructions and queries, as well as gamified quizzes. Two of these portals, relevant for this article, provide services for children and their families (Lastentalo.fi) and for peer support (Vertaistalo.fi)

Peer support services can be seen as a novel approach to complement traditional healthcare services, but digital solutions for peer support are still in early development. As part of the Healthvillage platform, the Vertaistalo.fi portal provides support for finding peer groups and reliable information about the topic. What characterizes peer support is that peers can understand each other in a way that the surrounding people of

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each person's social network are not capable of [2]. Peer support can be provided in different ways, from personal or group meetings to online support [3].

From the perspective of parents of child patients, digital services for peer support offer new and interesting possibilities to complement traditional services provided by healthcare organizations [3], since they can be used regardless of time and place. Social media has brought new dimensions to the ability to reach people in a similar life situation. Often, peer support is studied from the perspective of a particular group [e.g. 4-5]. However, the needs and services of families with children in terms of peer support have scarcely been studied.

Furthermore, although considerable research has been devoted to digital healthcare (or eHealth) services, less attention has been paid to understanding how patients experience these new services. It has been suggested that PX is comprised of more than patient satisfaction alone and that PX contains the following aspects: a continuum of care, a focus on expectations, individualized care, and alignment with patient-centered care principles [6-7]. From the viewpoint of PX, child patients and their families have special characteristics as patients; PX and care do not solely revolve around an individual patient but a child together with their parents and other members of their family or supporting network. Some studies have investigated the needs of child patients concerning the quality of care and conditions inside the hospital [8-11]. One study suggested that it is important to involve children and their families in designing the care in order to improve quality [12]. However, research on the needs and expectations of child patients and their families toward new digital healthcare services is lacking.

The aim of this study is to support the development of digital healthcare services targeted at families with child patients in the context of a children's hospital. We approach the topic from two perspectives: *What kinds of needs and expectations for new digital services to support peer support arise from the experiences of parents with child patients? What kinds of needs and expectations for new digital services targeted at child patients arise from the everyday experiences of child patients?* Our hypothesis is that by providing alternative digital services in addition to traditional face-to-face services, the PX can be enhanced. If we understand the needs and expectations of child patients and their families, digital healthcare services can be designed to directly address those needs. The study is part of the Lapsus research project [13], which has received permission from the ethical committee.

2. Methods and Data Collection

Two methodological approaches were applied: a web-based survey for parents and video diaries for children. The survey method was selected to reach a large number of potential respondents and inquiry about their needs on a general level. The video diary method was chosen since the aim was to gain more profound, qualitative information from children regarding their experiences as expressed by themselves [14]. In addition, video diaries can provide latent information not available through any other method, for example, information about feelings or dreams [14-15].

Web-based survey about peer support for parents: The target population of the survey were parents of children with special needs who have a long-term illness or disability. The survey was available from January to February in 2014. Participants were searched for through the mailing list and the Facebook site of a Finnish national association for peer support for special needs children. The survey consisted of 12 open-

ended questions related to the following themes: participating in peer support groups, communication within the group, methods of peer support and future views. The data were gathered anonymously. The data included 73 responses from parents who had children with special needs. Almost half (41%) described the diagnosis of their child; altogether, 22 diagnoses were mentioned. The age range of the children was wide, though most of the children were in primary school or younger.

Video diary for child patients: The participants were children aged 10–16 years with a chronic disease who were followed up regularly at the juvenile rheumatoid arthritis, diabetes, or gastroenterological outpatient clinics of the Children's Hospital, Helsinki University Hospital. The study was carried out from January to May in 2016. The method included providing the child with a probe package, which consisted of a tablet, a binder with tasks and instructions. The children were instructed to complete the given tasks and record daily video clips or diaries on the given themes at their homes for 10 days. The tasks were related to the following themes: the illnesses and their check-ups as well as their spatio-temporal dimensions, feelings and the social aspect of being ill. After the study period, face-to-face interviews with the children were conducted in order to gain a deeper understanding of the data. Fourteen children participated in the study. Of the 14 participants 11 were female, and 6/14 had rheumatoid arthritis, 5/14 diabetes and 3/14 had an inflammatory bowel disease. The data consisted of the filled binder with the completed tasks; the video clips, each averaging 2–5 minutes in length; and the interviews, each averaging 55 minutes in length.

Analysis of the data: For the purposes of this study, the observations were grouped into meaningful categories representing the needs for the new digital services. The process followed the principles of the content analysis method [16]. The first author (NK) was responsible for the analysis. The qualitative data were analyzed using Atlas.ti software, and special attention was paid to retain traceability between the methods and observations.

3. Results and Analysis

We identified nine categories of needs of children and their families that new digital services could target. All categories were related to better communication with both healthcare personnel and peers (see Table 1).

Table 1. Categories of needs relating to better communication with healthcare personnel and peers.

Description of the need	Source of the data (% of respondents)
A. Need for communication and to receive information and tips	Survey, video diaries
B. Need to share experiences, reflect on feelings, and process issues	Survey (ca. 56%), video diaries
C. Participation in peer support to be easy and affordable	Survey (ca. 20%)
D. Children specifically need peer support	Survey (ca. 67%)
E. Peer support that is not diagnosis-specific is needed	Survey
F. Fathers should be taken better into account in peer support	Survey
G. Siblings should be taken better into account in peer support	Survey (ca 20%)
H. Information about peer support is needed from healthcare personnel	Survey (ca. 14%)
I. Peer support should be better coordinated, there should be an explicit party that is responsible, and the hospital should have an operations model	Survey

These categories of needs were utilized as a starting point for further analysis to identify the possibilities of novel digital services for child patients' families to support and to complement the recently launched Healthvillage.fi platform, particularly relating to the portals for families with children and for peer support. Figure 1 illustrates the connections between the identified needs (marked in red), novel digital channels and services (marked in purple and green), and how they could be linked together with the existing portals.

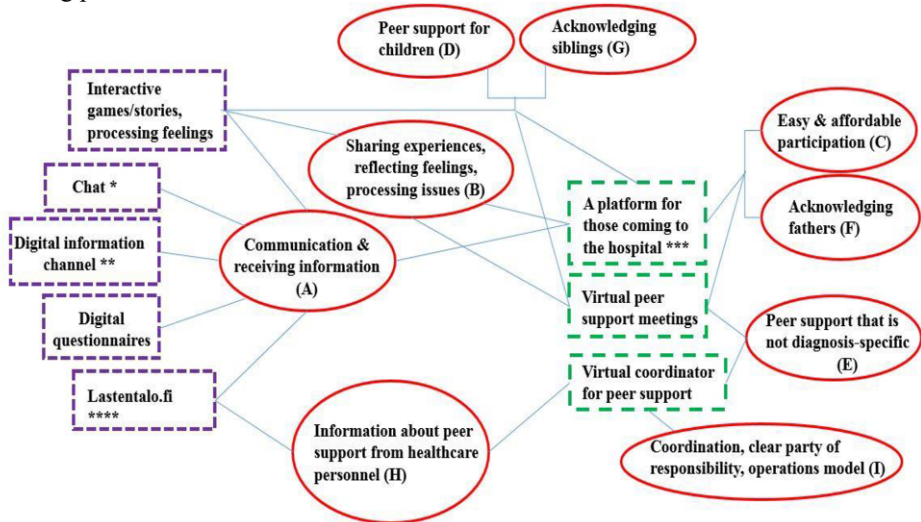


Figure 1. Connections between the identified needs (marked in red), novel digital channels and services, and existing portals for families with children (Lastentalo, marked in purple) and peer support (Vertaistalo, marked in green). * with the nurse/doctor; ** between doctors and parents; *** where patients sign themselves in; **** includes hospital ground plans, 3D models, information about novel treatments, links to research, information about illnesses, care and associations, and short informative video clips

4. Discussion

Our study aimed to identify the possibilities of digital health services to meet the needs and to enhance PX of children and their families in the context of hospital care. We noticed that these needs were related to better communication with both healthcare personnel and peers. Previous studies have also identified the children's needs related to communication [8-11] and peer support for siblings [5]. However, these studies have not considered digital health services or related children's needs.

Development of digital services and platforms to support traditional services is a timely topic in Finland. The recently launched health portals by the Finnish university hospitals for families and peer support will eventually include interactive digital services (e.g. an interactive game for processing feelings) and communication channels (e.g. chat and video meetings), although at the moment, these portals focus on providing reliable information to citizens and patients. In the future, new digital healthcare services are expected to activate children and young ones to self-care.

We identified nine categories of needs related to better communication between families and healthcare professionals and peers. Further analysis focused on supporting these needs and link these to already existing digital platforms and portals provided by hospitals. The proposed new services and channels include e.g. digital questionnaires

and virtual peer support meetings. The ideas of new digital services introduced in this article can be utilized not only in children's hospitals across Finland but also in similar hospitals around the globe. When digital services are developed and become more common, they can have a positive impact on the PX of children and their families.

The survey showed that parents believe children need peer support as has been noted in earlier studies [8]. However, while clarifying this topic with children through the video diaries, it became evident that not all of the children perceived it as necessary. The children usually discuss their illness with their closest friends and family members, and some of the participants even had a relative with the same disease. This may have led to some children not feeling the need for peer support as strongly as others. More importantly, the video diaries indicated that the children want to live just like other children of the same age and that their life was defined by their everyday goings-on and not their illness. This observation clearly demonstrates the importance of seeking experiences expressed by the children themselves and not solely by their parents. One focal challenge of our study was the sensitivity of this topic. It was difficult to find participants for the video diaries [17]. What is more, ethical perspectives needed to be taken carefully into account. The knowledge gained through this study helps clarify how information about PX can be obtained from children, as well as what kind of issues they and their families believe are important and valuable.

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