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Abstract

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Connecting Parents to a Pediatric Emergency Department: Designing a Mobile App Based on Patient Centred Care Principles

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Abstract. Introduction: Patient centred care fosters a holistic approach of care switching the focus from a disease perspective to a patient’s experience perspective. Patient centred care is of particular importance in the context of paediatric emergency medicine. Indeed, parents entering a paediatric emergency department (PED) are usually under stress caused by their children’s illness, the unfamiliar setting of the PED and delays of care. All these factors can deteriorate their experience as well as the relationships between healthcare providers, the patients and their parents. Methods We explore potential areas to improve the patient experience during his journey into PED. The dimensions of the picker’s patient centred care are used to guide observations, conduct interviews and focus groups. The areas of improvement are then operationalized through their translation into app functionalities. Results Our novel application allows supporting users on 7 of the 8 dimensions of picker’s patient centred care model. The app supports parents in their decision-making to consult a PED, it provides relevant medical information to avoid unrealistic expectations and accompany the family after discharge thanks to tailored information sheets about diagnostics. Conclusion: Our mobile app allows to make a big step toward the improvement of the patient-caregiver relationship. The direct benefits will be shared by patients and caregivers, as well as the institution.

Keywords. Patient Centred Care, mHealth, Emergency Medical Services

1. Introduction

Patient centred care is defined by the Institute of Medicine as a care that is responsive to individual patient needs and values and that guides treatment decisions [1]. This concept is targeted on a holistic approach that does not focus only on the patient disease but encompasses also the illness experience, understanding the whole person, the search of a common ground, incorporating prevention and health promotion, enhancing the patient-physician relationship, and being realistic. Although there is no clear consensus about the exact dimensions that must appear under this umbrella

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concepts, one of the most popular model (picker’s) delineates 8 dimensions, including: 1) respect for the patient’s preferences 2) information and education; 3) access to care; 4) emotional support; 5) involvement of family and friends; 6) continuity and transition; 7) physical comfort; and 8) coordination of care [2]. Recent research has shown that there are many benefits to patient centred care, broadly categorized as care experience, clinical and operational benefits. Studies show that when healthcare administrators, providers, patients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and patient satisfaction increases [3].

In the context of visits to the paediatric emergency department (PED), patient centred care is of particular importance [4]. Parents often arrive with a high level of stress and expectations due to the perceived emergency of their children’s illness. When in contact with the PED unfamiliar setting, they endure delays of care in case of crowding and have to deal with caregivers’ diagnosis. This may lead to a poor experience and deteriorate their relationships with healthcare providers.

Thanks to their unique features, mobile apps have the potential to improve experience of parents going to PED with their children. We present in this paper the identification of potential areas to improve the patient experience during his journey into PED. These areas for improvement are then operationalized through app functionalities.

2. Methods

In order to build an app following the picker’s patient centred care principles, we explored each principles with stakeholders and translated our findings into functionalities of an app.

![Figure 1 Eight dimensions of Picker's Patient centred Care](image)

The areas of improvement were identified through semi-structured interviews of 15 parents visiting the PED to understand their needs. Additionally, observations were performed at the PED to generate a map of their journey [5]. Finally key stakeholders were interviewed and guided by the patient centred thematic. Based on our findings we conducted several focus groups involving psychologists, clinicians and computer scientists to translate the collected needs into functionalities of a novel mobile app. Finally, an app called “InfoKids” was implemented with the requested functionalities.
3. Results

3.1. Identified areas for improvement

**Respect for the patient’s preferences:** During the semi-structured interview of parents in the PED, most of them revealed their difficulty to evaluate the condition of their children. Indeed, the perceived severity of the illness is often difficult to evaluate leading to many non-urgent visits. This reveals the necessity to support parents in their decision to visit or not the PED [6,7]. Providing support for decision making has the potential to both reduce stress and to diminish the unnecessary visits to the PED.

**Information and education:** Our interviews also revealed a great demand for information before arrival and after discharge. Before arriving at the PED parents usually do not know what will happen during their journey. As a consequence, they tend to frequently interrupt caregivers to ask information about the care process and may develop frustration due to their misunderstanding [8]. These interruptions also disturb caregivers, obliging them to repeat over and over the same explanations.

**Access to care:** Access to the location of hospitals is not always simple. In case of stress nobody want to have to struggle to find the entrance of the emergency, or to identify the closest way to the hospital.

**Emotional support:** Disappointment is the experience of sadness involving unfulfilled hopes or expectation. Parents have limited information about the occupation in the PED and thus can have inappropriate expectations about their waiting time. Expectations of appropriate waiting times in the PED may vary considerably. While some expected to be seen by a physician within 1 hour, others expected a 3- to 6-hour wait. Moreover, non-users seem to expect faster service than users.

**Involvement of family and friends:** Managing children health is not always simple from an administrative point of view. When parents have to perform a PED administrative entry it is often a source of burden for them and for the administrative clerks. Beside the discomfort that administrative entry can represent in emergency situation, the accuracy of this information is critical in emergency care. Correctly and fully matching patient names and unique identifiers, with relevant clinical information, is of prime importance. Misidentification of a patient can lead to hazardous errors [9].

**Continuity and transition:** Once their children have received cares, the parents should receive discharge information by the physician. The short period of time devoted to this transmission, the confusing medical jargon used, the lack of careful listening by the parents and many other external factors may lead to misunderstanding of the aftercare instructions. Some studies demonstrated as many as 78% of persons discharged from an emergency department do not clearly understand their aftercare instructions, yet only 20% are aware of their lack of comprehension [10].

**Coordination of care:** A good care coordination is strongly dependant of a good organization. In emergency department, it is difficult to forecast crowding and thus to liberate the associated care resources that would be required to deal with it [10]. Emergency caregivers could better organize their work if they have a better forecast of
the emergency occupation. The ability to accurately forecast affluence in emergency departments has also considerable implications for hospitals to improve resources allocation and strategic planning.

3.2. Proposed functionalities

**Respect for the patient’s preferences:** In order to support the decision of the parents to depart or not the emergency, the app integrates a list of symptoms linked to advices on immediate measures and explaining when to consults. The advices have been elaborated based on those contained in a textbook on paediatric diseases from two paediatrician, the Prof. Gervaix and Prof. Galetto. In order to facilitate the information retrieval, these symptoms are organized in a hierarchy elaborated using card sorting technique [11].

**Information and education:** The app contains educational videos explaining the care process aiming at responding the most common interrogations of the parents visiting the PED. For instance, these videos present the whole process of emergency care helping the parents to clearly understand the different stages he will go through. Moreover, hot topics such as the classification of the patients into the different emergency levels depending on the severity of the situation are explained in specific videos.

**Access to care:** The application provide a map locating the PED and the closest parking spot in order to facilitate their arrival. Additionally this map provides the shortest way from the user location to the emergency.

**Emotional support:** To avoid unrealistic expectations, the application provides a real time view on the waiting room occupation and a forecast of daily occupation. This current occupation is displayed through the 5 lanes representing the different level of emergency. Each patient is presented by an avatar allowing everyone to understand the number of people waiting. The other view provides statistic on the daily occupation based on the average occupation computed on the 5 last days.

**Involvement of family and friends:** Administrative entry is facilitated by the automatic transmission of pre-entered administrative information by the user to the institution. A software, at the administrative clerk’s disposal, displays this information allowing him to compare it with the one already in the clinical system. The differences are automatically highlighted in order to facilitate corrections of inaccurate data.

**Continuity and transition:** In order to offer a continuity of care after discharge the application provides automatically a medical information sheet about the diagnosis to the user. This information sheet is based on a paediatric textbook providing advices related to paediatric diseases. To select the most adapted information sheet, the diagnostic entered by the clinician in charge of the patient is automatically mapped into one of the sheets explaining the diagnosis.

**Coordination of care:** Although the app can function standalone, it has the capability to be connected to a software accessible to the caregivers allowing a bi-directional communication between the user and the care institution. Through this
channel the user can announce its arrival at the PED and the reasons for the visit. Thanks to this system, the caregiver is able to forecast the affluence and future occupation of the PED by visualizing the list of incoming patients. This offers the possibility to take adequate measures to limit PED overcrowding.

4. Conclusion

Patient centred care is increasingly recognized as a critical dimension of high-quality health care since the landmark Institute of Medicine report, Crossing the Quality Chasm [12] included it as one of the six quality aims for improving care. Our work with patients and caregivers allowed us to identify 7 areas where an app have the potential to improve patient centred care. The single dimension that we didn’t discuss was the physical comfort since it wasn’t directly impacted, although indirectly the possibility to wait outside the emergency room and to be recalled on due time improves indirectly users’ comfort.

Although, it still need to be validated by a formal evaluation, we expect that the benefits won’t be exclusively for the patients but also for the caregivers and the institution. Indeed, as pointed out previously, there are a lot of non-urgent visits that can be avoided if parents are able to evaluate more accurately the illness of their children. Also the resource will be managed in a more efficient way by knowing in advance what will be the affluence to the PED and expected occupation. Finally, the caregivers will be supported in their communication with the parents.

References