

# Decreased Memory Bias via a Mobile Application: A Symptom Tracker to Monitor Children's Periodic Fever

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**Abstract.** Memory bias, the tendency to rely on certain events over others, can become an issue in chronic illnesses, especially when symptoms are reported retrospectively. This paper examines a case where continuous symptom registration can be facilitated, memory supported, and memory bias reduced by introducing a mobile application. The aim of the paper is to report on the design of an app for collecting subjective data over an extended period to continuously follow children with periodic fever. The research approach is qualitative, building on interview data. The design method is co-design, a collaborative and participatory approach involving researchers, physicians and other key stakeholders, with focus on the views of the parents. We argue that collecting data continuously through an app moves the discussion from memory to the specific data points, which is illustrated through trends shown in the visualizations of the data. Moreover, we highlight the importance of systematically collecting data over an extended period through a data-driven approach to both forward clinical practice and research on complex, often chronic topics such as periodic fever, which is genuinely under-researched to date.

**Keywords.** Memory bias, healthcare, co-design, children, mobile apps

## 1. Introduction

Memory bias is a notion that has been widely debated as one of the major biases when it comes to cognitive biases in general [1]. A cognitive bias refers to a systematic error and a simplification in the thinking process that occurs in the brain as people are attempting to interpret the information at hand [2]. More specifically, memory bias refers to the tendency to intentionally or unintentionally rely on recalling certain events and autobiographical memories and favoring those memories over others [3]. This recall process often relates to significant events, including traumatic, unconventional events, or even to systematically selecting the most recent events in a series of events [4]. Memory bias and the tendency to rely on most recent events are especially visible when dealing with a prolonged period such as a chronic condition of any type [5]. Memory

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bias can become an obstacle to giving an adequate description of symptoms, which is crucial in most diagnostic processes as well as follow-up of chronic conditions. It applies particularly to disorders where no specific diagnostic test or marker is available. Periodic Fever, Aphthous Stomatitis, Pharyngitis, and Cervical Adenitis, PFAPA, is an autoinflammatory disorder characterized by regularly recurring fever episodes accompanied by one or more of the features in the acronym. It is generally seen as the most common autoinflammatory disorder among children in many parts of the world. The diagnosis is mainly based on the patient's medical history and symptoms, but there is no specific test to confirm or exclude the condition. Instead, it is necessary to follow the course of the disease over time [6,7]. A symptom tracker is a valuable tool for tracking the disease progression, characterizing the fever episodes, and getting an overview of their regularity. However, it can be challenging for the parents to document and report symptoms in a structured manner. This paper examines a case where memory bias can be reduced drastically by introducing a mobile application (an app) for the system tracker. The app has three primary functions: i) to be readily available for the parents to register symptoms regularly; ii) to visualize data over time to reduce memory bias and; iii) to feed data to the pediatricians treating the children. This type of continuous data collection could improve how children with periodic fever can be cared for, clinically assessed, and how the condition can be researched. The paper report on the co-design of an app to support memory, facilitate continuous data collection, and reduce memory bias for children with periodic fever. We focus on the parents as valuable stakeholders in the co-design process.

## **2. Related Research**

PFAPA syndrome typically has an onset under the age of 5 and is a common and important differential diagnosis among preschool children with recurrent fevers [6, 7]. The fever episodes usually last 3-6 days and typically recur regularly with an interval of 3-6 weeks [6]. Between the fever episodes, the patient usually is symptom-free with normalized inflammatory variables and grows normally. Awareness and recognition of PFAPA are vital for providing adequate treatment and avoiding misdiagnosis [6, 7]. While mHealth apps have benefits such as accessibility, cost reduction, improved patient quality of life, alongside more precise and personalized disease management, to fulfill the positive outcomes, they need to be linked to clinical practice and adapted to both patients and healthcare [8]. A symptom tracker can be used as a way to gather patient-generated health data (PGHD), which can help patients organize details and activities of the illness, increase engagement, and promote patient empowerment while enhancing adherence to treatment [9, 10]. Factors, such as differences in parental approach to fever management and methods of diagnosis may also influence the design of the tracker and whether memory bias is decreased [11]. It is important to involve relevant stakeholders in the design process to reach a fruitful design. The fundamentals of co-design entail that the relevant stakeholders have a voice in the design processes that will ultimately affect their lives [12, 13]. Including tertiary stakeholders, such as parents, in co-design can lead to digital technology that will both be relevant and useful [14, 15]. In co-design, all stakeholders that partake in the co-design process are regarded as intelligent, active partners who actively contribute to the design process through their insights into their expertise (in this case their expertise from taking care of their children with PFAPA), an expertise that will be shaped by the technology that is being designed significantly.

### 3. Methods

In this paper, we report on an ongoing project and the combined experiences of 100 parents that have contributed to our co-design process. In this phase, we wanted a broader perspective and therefore did not limit participants only to parents to children with periodic fever. The app will be used in Sweden to support parents of children with PFAPA systematically and continuously digitally log and track symptoms. The multidisciplinary research team consists of researchers and designers with pediatrics and health informatics expertise. The research approach is qualitative, and the data collection for this phase was conducted through semi-structured interviews with parents. All interviews were read several times, collaboratively coded, and analyzed through content analysis [16], and validated with pediatricians. As mentioned above, the design approach is co-design, and the project considers all stakeholders involved in the co-design process. In contrast, this paper focuses on the views of the parents (based on the interview data) and implications when co-designing for continuous monitoring of children.

### 4. Results

Although still in the design phase, we already see that an app for tracking children's fever is essential and that parents are critical stakeholders due to their vast experience of caring for their children. For instance, regarding having margins set in the app with a specific fever level that could indicate when to contact a healthcare professional, one parent said: *"It might be good to have, just to be on the safe side if there are any uncertainties and so on, but I am rarely uncertain."* Another parent corroborated: *"It might be ok, but I do know it so well myself, from years of experience."* Yet another parent thought that others might need it, but not them: *"It might not be so bad to include for inexperienced people but me, I don't need it, I know it."* These quotes clarify that the parents are the experts, know their children, and have instincts that they rely on wholeheartedly. We conclude that parents are essential stakeholders in a co-design process that aims to aid their care for their children. Next, we summarize the findings, focusing on design features in the app that facilitate reflections, increase compliance and reduce memory bias.

**I. Notifications to increase compliance.** Regarding notifications, one parent uttered: *"O, yes. That and just that would help me enormously."* Also, the same parent said: *"It would be an easy way to track the information and to have an overview of the information too. Everything is always there"* Another parent shared a similar opinion: *"App, yes, definitely...I would lose the paper and forget it at home when I would go to the doctor with my child."* A third parent offered the opinion that notifications might even help with the systematics in the registration: *"It is good to have something that helps you remember the important things, and it would help to systematically register the symptoms every day at the same time."* Yet another parent expressed that it could help during stressful times: *"I might forget, when my child is sick I am sometimes going on very little sleep, but if I would get a notification, then I would still register. So, notifications would help me."* The parents would gain from having notifications implemented within the app.

**II. Visualizations as a crucial factor for reflection.** Regarding how the information registered in the app could be presented, one parent suggested: *"Maybe some kind of graph that shows a clear and simple pattern in the information. Perhaps we should try*

to fill in more information than symptoms to see if there is any correlation between external factors and changes in the body. That would be really good," while another parent said: "Just simple. The only thing that matters is that I am able to see a trend for a specific time period. Everything needs to work fast and efficiently. I rarely have time that I can afford to waste when I have a sick child." One parent also offered the view that the visualizations might help with reflection: "If I could see how it is over time, then I could also see when it is better because sometimes it might be better for a longer time as well, but it is difficult to know without seeing it visually." From these quotes, it is apparent that visualizations are a crucial part of an app for monitoring periodic fever.

**III. Asynchronous messages to decrease the risk of forgetting to notify changes.**

Several parents reported that they wanted to communicate directly and securely with their pediatrician within the app. The messages, or chat, would have to be asynchronous, as the parents are aware that they might want to send a message to their pediatrician in the middle of the night. Still, they do not expect their pediatrician to answer them. They do mind that the messages are only delivered in the morning since they want the messages within the app only because they are afraid to forget to send the message if they are unable to do it when they come to think of it, due to extended sleep deprivation. On that note, one parent described: "Sometimes, when my child is sick, I wake up, and it might be days since I got a good night's sleep. Those nights, it would be good to be able to send a message just there and then, not because I want a reply there and then, but because I really don't want to forget to send the pediatrician a message if something has drastically changed." Sending messages in an asynchronous format would be helpful to reduce the risk of the parents forgetting to send them.

**5. Discussion**

In this section, we discuss the design of the app, focusing on the parents' views and how specific app features can help with compliance while reducing memory bias [3-5].



Figure 1. Prototype of the app versus the analog symptom tracker used before

The app (see Figure 1) has three primary goals: i) to be readily available for the parents to register symptoms regularly; ii) to visualize data over time to reduce memory bias and; iii) to feed data to the pediatricians treating the children. The main findings drawn from the co-design process [14,15] comprise features that our app needs, and features which we hereby recommend for others that are designing mHealth apps to aid parents in caring for their children: i) **notifications** to increase compliance, ii) **visualizations** as a crucial factor for reflection, iii) **asynchronous messages** to decrease the risk of forgetting to notify about changes. Combined, these features should certainly contribute to decreased

memory bias and increased compliance. Even if this first part of the design process did not specifically include parents to children with PFAPA, we believe that a user-friendly and co-designed app can be a valuable tool in diagnosing this disorder as well as in assessing the symptoms over time. If used in a wider context, we also believe that the symptom tracker can create awareness and recognition of PFAPA, as the regularity of fever episodes could be more reliably documented [6,7]. We plan to continue by involving parents and pediatricians in the co-design process to develop a useful symptom tracker and connecting the app to the context of the patients and healthcare practice [8].

## 6. Conclusion

This paper suggests that the use of apps may reduce memory bias. Collecting data continuously, through an app, moves the discussion from memory to the specific data points, illustrated through trends shown in the data visualizations. Moreover, the study underlines that parents are essential stakeholders and should be included in the design process. Our findings highlight the importance of systematically collecting data over an extended period through a data-driven approach to forward clinical practice and research on complex, chronic topics such as periodic fever, which is under-researched to date.

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