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How to Motivate Children with Severe Disabilities to Adhere to Their Therapy?

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Abstract. Rehabilitation therapies after a serious accident or disease are usually repetitive and lengthy, requiring high motivation and adherence of the patients to achieve therapy goals. Moreover, the exercises are often painful leading to a decrease in motivation. Keeping motivation and adherence on a high level is even more challenging when the patient is a child or youth. In this paper, we address the question how to motivate this patient group to continuously attend therapy sessions and repeat the painful exercises. To address this issue, we developed the mobile application PAPP with integrated motivation concept that stimulates intrinsic and extrinsic motivation by corresponding features within the app. The intrinsic motivation is considered by means of gamification. An ice bear called "Teddy" and his journey to Spitzbergen is introduced and accompanies the patient journey. The extrinsic motivation is implemented by introducing the virtual currency "Papp-Taler" with integrated rewarding system. The usability test results show promising results. The app still requires extensions such as an external data storage to enable therapists and parents to monitor the progress. In future, it will be possible to use the app in a study to investigate whether it can motivate young patients to adhere to their therapy and whether that has a positive influence on the therapeutic outcome.

Keywords. rehabilitation, motivation, mHealth, engagement, gamification

1. Introduction

Rehabilitation therapies after a serious accident or disease are usually repetitive and lengthy, requiring high motivation and adherence of the patients to achieve therapy goals. Moreover, the exercises are often painful leading to a decrease in motivation [1]. Factors that motivate patients have been well studied for different areas in adult medicine. Wissink et al. examined the correlation between the motivation for physiotherapy and the outcome of therapy in geriatric stroke patients (n=84). The study showed that a more positive therapy outcome results from partner training and increased motivation [2]. In the meta-study by Meyns et al., 15 studies on the influence of motivation in paediatric motor rehabilitation were examined. The analysis provided evidence that children with higher motivation achieve better rehabilitation results [3]. Additional studies indicate that a mobile application (app) can have a motivating effect, be it in motivating for a healthy diet [4,5] or motivating primary school students to write creatively [6].

In the last years, serious games have been tested in healthcare applications. A serious game in healthcare is designed for achieving a health goal rather than for pure entertainment. For example, virtual reality (VR) games have been tested in movement

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rehabilitation, but they have not yet been tested comprehensively with children [7]. Nevertheless there is still limited knowledge available whether apps or serious games can influence motivation of young patients and which factors are important to improve the success of therapy. We believe in a co-creation design process for successful app development. Thus, we developed and implemented a concept for a mobile application in strong collaboration with physicians and therapists of a rehabilitation centre to address the question how to motivate children and youth to continuously attend therapy sessions and repeat the painful exercises.

The project was conducted in cooperation with the rehabilitation center in Affoltern am Albis (RZA) which belongs to the University Children's Hospital of Zurich. The aim of a stay at the rehabilitation centre is to foster as much independence as possible in the affected children and young people and in this way, improving the quality of life for the whole family. Currently, the pediatric rehabilitation takes place at RZA in an interdisciplinary approach. The rehabilitation team closely works together with the parents of the children and integrate them as essential part of the care, motivation and treatment [9]. Patients at the RZA have to complete several therapy units daily. The active participation in the therapy units is influenced by the motivation of the young patients. Since the young patients live in the RZA during their rehabilitation, their adherence to therapy is accordingly high. However, motivation for a therapy is more than just being present and following the instructions of the therapists. It means to take an active role in the therapeutic session and to achieve the goal of the therapy. To increase the motivation, the RZA already developed strategies based on the experiences of the rehabilitation team. The existing methods include variations in therapy units (to avoid that things are getting boring) or give stickers as gratification.

The question underlying this work is whether the therapy adherence and motivation of children with severe disabilities can be effectively supported by an app. Therefore we developed an app called „PAPP“ (Patient-App) for iOS and Android using elements of rewarding and gamification. The aim of the PAPP is to enable a clinical study in a follow-up project which allows to answer the formulated question.

2. Related work

Promising elements which can influence the motivation of young patients can be derived from game theory. Two types of motivation should be considered: intrinsic and extrinsic motivation. Extrinsic motivation occurs when we are motivated to perform a behaviour or engage in an activity to earn a reward. Intrinsic motivation is a behaviour that comes from within the individual because it is naturally satisfying without a reward [8]. This distinction of extrinsic and intrinsic motivation indicates that there are different sources of motivation. Gamification is the application of playful elements in a non-playful context (e.g. context rehabilitation). The Octalysis Framework is a human-centric gamification design framework that lays the eight core drives for motivating humans [10]. This is based on the premise that almost all games appeal to certain core drives (see Table 1) within us and motivate us towards a variety of decisions and activities. A core drive is for example development and accomplishment which requires perceiving a challenge. Another core drive is Epic meaning and calling which creates the belief that the user is contributing to some greater mission such as protecting or supporting someone.

Lin et al. developed an app called “Fish'n'Steps” to increase the physical activity of the users) [11]. The app measures the number of daily steps taken by a user and links this

to the growth and emotional state of a fish avatar. In 14 of 19 study participants, physical activity changed in a positive way. This was shown by an increase in the number of daily steps (n = 4), a change in attitude towards physical activity (n = 3) or a combination of both (n = 7) [11]. A virtual avatar Avafeed is the central element of an app developed by Hswen et al. [12]. The aim of this app is to teach children to distinguish between healthy and unhealthy food. The children decide what Avafeed gets to eat. Depending on their choice, the physical condition of the avatar changes which gives responsibility to the children. Within the "Octalysis" framework [10], this kind of motivation is called "Epic meaning and calling" aiming at giving the children a task and thus a responsibility. Proven successful, we have chosen to base our motivation concept within PAPP upon the Octalysis framework [10]. Based on Octalysis, both extrinsic and intrinsic reward approaches were designed.

3. Methods

In cooperation with therapists and physicians at the RZA, we collected requirements for a mobile application that aims at increasing the motivation of the young patients in actively participating in their therapy units. One of the requirements was that the app had to support the two operating systems iOS and Android, because the app should run on the patients' personal mobile phones. For this reason, the open-source cross-platform framework Flutter from Google (https://flutter.dev) had been chosen for developing our mobile application PAPP. Kanban, an agile methodology for software development, was used in the software development process.

The usability of PAPP was studied in a qualitative usability test with patients recruited from the RZA. The usability test consisted of the following three parts: a pre-interview, a scenario-based test and a post-interview. The purpose of the pre-interview was to clarify the technical competence and experience of the test subjects regarding the use of mobile phones and apps. This information helps to judge the results of the test persons. During the scenario-based test, the test person had to address three use cases comprising several tasks. The use cases were: navigate through the onboarding pages, create an appointment, and read the QR code with the app to collect coins. After solving each task, the user had to answer questions that could only by answered when the tasks were completed successfully. For example, after reading the QR-code to collect coins the participants were asked how many points they earned. The follow-up interview was conducted as semi-structured interview where the test subjects were asked to express their opinions on the app. For the solved tasks, it was noted in a Rainbow sheet whether the tasks could be solved or not. The Rainbow Sheet gives a visual representation of which parts of the user interfaces need to be revised to improve usability.

4. Results

The collected requirements showed that PAPP is expected to be used by young patients at the RZA during their stay. It has to be equipped with a motivation system and it should give patients an overview of their appointments with therapists. In the following, the concept of PAPP and its implementation are described as well as the results from the usability test.

4.1. PAPP-App

We developed a motivation concept that stimulates intrinsic and extrinsic motivation by corresponding features within the app. Table 1 shows the 8 core drives as defined in the Octalysis framework and their implementation in PAPP. The intrinsic motivation is considered by means of gamification. An ice bear called "Teddy" and his journey to Spitzbergen is introduced and accompanies the patient journey at the RZA.

Table 1. Octalysis core drives and their implementation in PAPP

Octalysis core drive	Implementation in Papp
Epic Meaning and Calling	Avatar Teddy and his journey to Spitzbergen. Users collect experience points through their therapies to help Teddy in managing his journey.
Development and Accomplishment	Therapy goals will be made available in the app, also listing goals that have been achieved already to demonstrate the development of the patient on his patient journey.
Empowerment of Creativity and Feedback	The user can collect items to equip Teddy on his journey (see below). However, there are different options available. The user has to decide for an equipment that well supports Teddy. Feedback is given depending on the selected equipment.
Ownership and Possession	Papp-Taler (virtual coins). Additional equipment such as hiking shoes are gained through leveling up. This equipment supports Teddy on his journey.
Social influence and relatedness	Build a group with other patients at the RZA and discover secure places on Teddy's journey (not yet implemented)
Scarcity and Impatience	Not considered
Unpredictability and Curiosity	The QR code distributed by the therapist does only reveal the value of collected points after scanning it. So, it is unpredictable for the patient what he gained before scanning the code.
Loss and Avoidance	Not considered

The extrinsic motivation was implemented by introducing a virtual currency with integrated rewarding system: Young patients collect Papp-Taler (coins) and experience points in their daily therapies by scanning a QR code that is provided by the therapists. The therapist decides depending on the commitment of the patient in the therapy session, how many Papp-Taler are earned. In this way, a patient receives one, two or three Papp-Taler and ten, twenty or thirty experience points for actively being involved in a therapy session (see Figure 1). When a predefined number of Papp-Taler has been achieved, a reward such as a visit to Zurich Zoo is offered by the parents of the patient (Figure 2). This reward can be chosen in the app so that it is present all the time to the patient and can motivate in collecting Papp-Taler. The collected experience points increase the level of their virtual avatar Teddy on his journey to Spitzbergen (Figure 1). Teddy is far away from home and wants to walk home, but he is not yet fit enough for his long and challenging journey. The task of the patient is to level Teddy up by collecting experience points in his or her therapies. In this way, patients have the responsibility on Teddy which is an important role that might increase their personal motivation and engagement in the therapy.

In addition to the motivation system PAPP provides an overview of their appointments (Figure 4). Currently, the patients' appointments are managed with the planning system at the RZA and these appointments are printed and distributed as printout to the patients on a weekly base. It contains the appointments for a week, listing appointments from for one day per page. For each appointment, the type of therapy, time, location and the name of the therapist is listed. PAPP supports entering those

appointments manually by the patient. A completion aid minimizes the data entry effort. After entering the first few letters, the system suggests suitable therapy types (physiotherapy, occupational therapy, etc.) to the patient (Figure 3) from a list of possible therapies. The RZA offers a total of 24 different types of therapies.

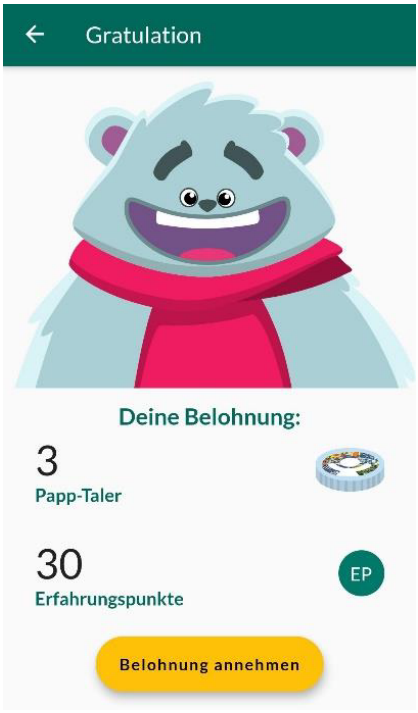

Figure 1. The patient scans the QR Code and receives three Papp-Taler and thirty experience points for Teddy.

Figure 2. The patient chose a visit to Zurich Zoo as a reward. He already collected fifteen Papp-Taler. 50 are necessary for visiting the zoo.

4.2. Data storage

PAPP stores two types of data: 1) Progress data, i.e. information that reflects the progress of a patient (e.g. number of Papp-Taler and experience points collected), 2) Appointment data, i.e. information on upcoming appointments. As the requirement collection showed, a future involvement of therapists or parents as passive listeners of the patient's status or active motivators is desired. This requires the storage of data on an external data platform that allows data sharing. Because the therapy appointments contain personal medical data, such data platform has to fulfill the requirements of data protection. In this work, we focused on the implementation of a motivation system and resisted on realizing the data platform. In accordance with the RZA we decided that the data should be stored locally. But the modular software architecture of the PAPP allows a later change to an external data storage without much effort.

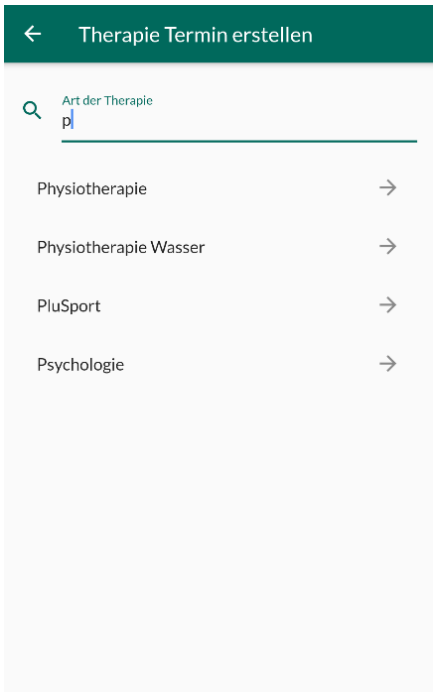

Figure 3. The PAPP completion aid suggests suitable therapy types to the patient after typing three letters.

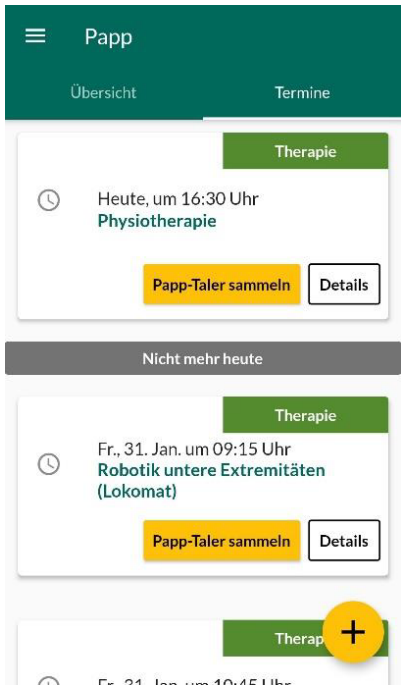

Figure 4. Further information such as the location of the appointment are shown after clicking on "Details".

4.3. Usability Test

The qualitative usability test was conducted with five patients of the RZA. The patients were between 9 and 15 years old. The median was 13 years. Each of the five test persons used his or her own mobile phone (iOS = 2, Android = 3). All five patients use their mobile phone on a daily base. Four of the patients were familiar with the concept of QR-Codes; two of them already used a QR-Code before. The results of the scenario-based test revealed a serious usability problem in creating an appointment. 4 out of 5 users were unable to identify the different types of appointments (therapy, private appointment, exercise) and thus, were not able to create a private appointment. Another problem was to distinguish optional from required data entry fields within the appointment creation screens because the children did not know the meaning of the term "optional". These usability issues were already addressed afterwards.

The post interviews demonstrated the concept underlying the app was not completely understood by several participants. It did not became clear to the users that they can get a reward by collecting Papp-Taler and the role of experience points for Teddy was unclear. In contrast the general concept to gain coins through therapies was understood by all five participants. The feedback regarding design and understandability of the interactions was diverse. Some participants claimed that they were not sure where to click next while interacting with the app; others confirmed that the app was easy to use. However, all participants liked the idea of collecting coins to get a reward and some confirmed they would like to help Teddy on his journey.

5. Discussion

In this paper, we introduced the mobile app PAPP for children and young people to be used in an inpatient rehabilitation setting. PAPP aims at enhancing the motivation of the young patients to adhere to their therapy and to stay active within the therapies. Studies suggest that motivated children have better rehabilitation outcomes. However, there are still few studies that assessed motivation in paediatric rehabilitation within a theoretical framework [3]. We based our motivation concept for PAPP on the Octalysis framework [10] and implemented features to address 6 out of the 8 Octalysis core drives for motivation. In this work, we were not yet able to assess the efficacy of these motivational core drives in our app. Instead, we focused on identifying usability issues which could already be resolved.

With the focus on a qualitative usability test and limited participants (n=5) a broader usability test with meaningful indicators is necessary as a next step. Based on these results, the app can be finalised for a first clinical trial to investigate whether PAPP can motivate young patients to adhere to their therapy and whether that has a positive influence on the therapeutic outcome. Studies showed that so called "serious games" are effective to assess specific strengths and weaknesses in young children with attention-deficit/hyperactivity disorder (ADHD) [13]. A review showed promising results regarding anxiety reduction, stress regulation, emotion recognition, and rehabilitation. However, there is still a lack of clinical evidence that children with neurodevelopmental disorders can benefit from the application of serious games [14].

Cugelman states that there are 7 persuasive strategies in gamification: Goal setting, capacity to overcome challenges, providing feedback, reinforcement, compare progress, social connectivity and fun [15]. PAPP already covers some of these strategies: The goal is defined by Teddy and his journey. Feedback is given by the therapists and the digital currency. The reinforcement is covered by the collection of Papp-Taler to finally be able to visit an attraction chosen by the young patient. Social connectivity is not yet covered in our app. This concept is difficulty to be implemented in the rehabilitation setting: The patients have different medical conditions, the progress is varying and does not only depend on the motivation, but also on the physical condition of the patient. An extension could be to involve the parents. Fun is realized by some animations of the bear. However, this aspect still can be improved.

There are some open issues that will be addressed in future. The close link between two implemented motivation features (Teddy's journey and the experience points) is not yet well established. The visualization of the progress of Teddy on his journey due to the collection of experience points by the patient still needs to be implemented. Once realised, the journey of Teddy and the treatment path of the patient could be broken down to a common denominator. A second aspect of PAPP that needs improvement is managing therapy appointments using the app. At the moment the appointments are manually entered. The manual entry of appointments has the advantage that patients become aware of their appointments. However, there is a risk that entering appointments will cost too much effort and hamper the use of the app. To overcome this limitation, generating a QR-Code that contains the daily appointments was considered. This could be implemented with the existing planning system at the RZA. For patients already using a calendar app, it would be suitable if the appointments entered in PAPP are synchronized with the calendar app in use. Beyond, it is an open issue how to integrate the app into the treatment process. An interviewed physiotherapist claimed that there is a risk of getting

distracted by the mobile phone during the therapy. Therefore patients are sometimes not allowed to bring their mobile phone to the therapy due to avoid distraction.

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References

[1] Calderita LV, Bustos P, Suarez-Mejias C, Ferrer-González B, Bandera A. Rehabilitation for Children while Playing with a Robotic Assistant in a Serious Game. *NEUROTECHNIX*. 2013 Sep;89-96.
[2] Wissink KS, Spruit-van Eijk M, Buijck BI, Koopmans RTCM, Zuidema SU. Stroke rehabilitation in nursing homes: intensity of and motivation for physiotherapy. *Tijdschr Gerontol Geriatr*. 2014 Jun;45(3):144–53.
[3] Meyns P, Roman de Mettelinge T, van der Spank J, Coussens M, Van Waelvelde H. Motivation in pediatric motor rehabilitation: A systematic search of the literature using the self-determination theory as a conceptual framework. *Dev Neurorehabil*. 2018 Aug;21(6):371–90.
[4] Mummah S, Robinson TN, Mathur M, Farzinkhou S, Sutton S, Gardner CD. Effect of a mobile app intervention on vegetable consumption in overweight adults: a randomized controlled trial. *Int J Behav Nutr Phys Act*. 2017 Dec;14(1):125.
[5] West JH, Belvedere LM, Andreasen R, Frandsen C, Hall PC, Crookston BT. Controlling Your «App»etite: How Diet and Nutrition-Related Mobile Apps Lead to Behavior Change. *JMIR Mhealth Uhealth*. 2017 Jul;5(7):e95.
[6] Kanala S, Nousiainen T, Kankaanranta M. Using a mobile application to support children's writing motivation. *Interactive Technology and Smart Education*. 2013 Apr;10(1):4-14.
[7] Lewis GN, Rosie JA. Virtual reality games for movement rehabilitation in neurological conditions: how do we meet the needs and expectations of the users?. *Disability and rehabilitation*. 2012 Apr;34(22):1880-1886
[8] Barbuto JE., Scholl RW. Motivation Sources Inventory: Development and Validation of New Scales to Measure an Integrative Taxonomy of Motivation. *Psychological Reports*. 1998 Jun;82(3):1011–1022.
[9] Rehabilitation Centre Affoltern am Albis - General information, Broschüren A-Z, https://www.kispi.uzh.ch/rza/de/patienten/broschueren/Seiten/default.aspx, last access: 27.1.2020.
[10] Chou Y. *Actionable Gamification: Beyond Points, Badges and Leaderboards*. Octalysis, Milpitas CA, 2015.
[11] Lin JJ, Mamykina L, Lindtner S, Delajoux G, Strub HB. Fish'n'Steps: Encouraging Physical Activity with an Interactive Computer Game. *Proceedings of the 8th International Conference on Ubiquitous Computing*. 2006 Sep;(4206):261-278.
[12] Hswen Y, Murti V, Vormawor AA, Bhattacharjee R, Naslund JA. Virtual avatars, gaming, and social media: Designing a mobile health app to help children choose healthier food options. *Journal of mobile technology in medicine.* 2013 Jan;(2):8-14.
[13] Peijnenborgh JC, Hurks PP, Aldenkamp AP, van der Spek ED, Rauterberg MG, Vles JS, Hendriksen JGA. Study on the Validity of a Computer-Based Game to Assess Cognitive Processes, Reward Mechanisms, and Time Perception in Children Aged 4-8 Years. *JMIR Serious Games*. 2016 Sep;4(2):e15.
[14] Kokol P, Blažun Vošner H, Završnik J, Vermeulen J, Shohieb S, Peinemann F. Serious Game-based Intervention for Children with Developmental Disabilities. *Current Pediatric Reviews*. 2019 Aug;(15):1.
[15] Cugelman B. Gamification: what it is and why it matters to digital health behavior change developers. *JMIR Serious Games*. 2013 Dec;1(1):e3.n