The Development of Digital Health Intervention for Reducing Psychological Problems in Chronically Ill Children

Abstract
Chronic illnesses predispose children for higher risk in developing mental disorders. Furthermore, mental disorders themselves can have long-term health consequences and interfere with the treatment process of underlying chronic disease. The risks associated with chronic illness to mental health are related to both somatic and psychosomatic changes taking place during illness period. Current study aims to develop an intervention that can at least partially buffer the negative psychological changes associated with chronic illness through an innovative mobile health platform. The intervention, called Triumf, is a mobile health platform that uses game environment to provide psychological support and foster constructive behavioral change. Initial testing with children has indicated feasibility of implementation and acceptability of intervention content.

Author Keywords
Digital health; mental health; chronic illness; gamification; serious games; health IT; mobile health.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous
Introduction

Global prevalence estimates of children with noncommunicable diseases (NCDs) are rapidly increasing, affecting currently approximately 25% of children [1]. The main types of NCDs are cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes [2]. Recent study found that 58% of children with various NCDs experience at least one mental health condition [3]. Moreover, these estimates were consistent across different NCDs showing that psychological issues are almost universal regardless of the type of chronic disease [3]. Mental health problems that accompany NCDs have a huge effect on the quality of life - in combination, they account for the greatest burden of disease.

In addition to the distress following the diagnosis and during treatment, long-term well-being and quality of life of the child may also be influenced. Estimating the long-term effects reaching to adult life is difficult as psychological problems are also common in general population. In spite of that, it has been found that childhood and adult cancer patients have a higher risk for depression, post-traumatic stress disorder, and anxiety for possible cancer recurrence [4]. Greater distress during cancer treatment contributes to a higher risk of negative long-term psychological effects while more support available reduces it [4].

It is difficult to estimate whether emotional problems contribute to the development of chronic disease or vice versa. For example, two meta-analyses focusing on the links between diabetes and depression (based on both self-reports and diagnoses) found that a chronic condition increases the risk of developing depression [5] and also that depression increases the risk of developing a chronic condition [6].

There are several factors that may increase the risk for a child to develop emotional problems after chronic disease diagnosis, such as the age on diagnosing, personality traits, social and emotional problems before diagnosis, problem solving skills and coping mechanisms, close relationships, family functioning and relations within the family (before and after diagnosis), and parent’s mental health [7, 8, 9].

Psychological intervention for chronically ill children is especially important because treatment delivery is partly dependent on the motivation of patients to follow the prescribed regimen. This can be severely affected by psychological issues that lower self-regulatory behaviour capacity [10] and can therefore cause serious treatment compliance problems if left unattended. In current mainframe practice, psychological interventions are usually initiated only reactively (in response to manifestation of mental health problem).

The number of children with NCDs is growing rapidly and psychological help has to become more accessible to accommodate their needs. Providing kids with digital psychological support while undergoing treatment may help to decrease the impact of NCD on their current and long-term mental health outcomes. We are developing a mHealth platform Triumf to offer psychological support via game environment.

Triumf Mobile Health Intervention

Triumf platform helps children with chronic diseases cope with their diagnosis, its treatment and offers psychological support. It is achieved via specifically designed mobile game environment. The solution enables improvement in treatment monitoring and enhances communication between patients, their families and medical personnel.

It makes psychological support engaging for children. Using Triumf solution, children play a fun game, find out more about their illness, get psychological support from a virtual friend and get rewarded from changing their habits. The game is co-designed with ill children and research based content and machine learning is used to monitor and support their mental well-being.
Methodology
Online therapeutic interventions have been effectively used for over two decades by now [11] with its advantages and disadvantages detected [12].

A serious game could be defined as follows: “a mental contest, played with a computer in accordance with specific rules that uses entertainment to further government or corporate training, education, health, public policy, and strategic communication objectives”. If a game consists of three main components - story, art and software -, a serious game adds up pedagogy, which embodies communicating the knowledge or skill. Pedagogy has to be incorporated to the game in a way that the storyline of the game and the entertaining part comes first. [13]

According to the Player Experience of Need Satisfaction model, engaging a player to a game happens through satisfying three intrinsic needs: competence, autonomy, and relatedness [14]. According to Self-Determination Theory, when these components are satisfied, it results in increase in self-motivation and mental health [15].

Putting together the need of increasing psychological support accessibility to children with chronic diseases, the advantages of online therapeutic interventions and speaking the language of nowadays children through mobile games, we propose that a serious mobile game to support children’s mental health is the approach to take.

Overview
We want to study how a serious mobile roleplay game addressing the psychological needs (a digital intervention) of children with chronic diseases influences their mental well-being.

The game is targeted to school-aged children where players are evolving their inner superhero. The journey of becoming a superhero through fighting the disease goes together with an interactive sidekick who has the role of supporting and guiding the player. The player earns points from treatment procedures, time spent in hospital, taking care of general health (e.g. drinking water, being physically active, keeping good sleep hygiene) and also from solving quizzes about the disease and playing disease-related mini-games that are needed to level up. Players can also interact with other players and see how they are doing compared to others.

Through gameplay the child is screened for possible mental health problems using validated psychological instruments and profiled based on that. Throughout the game, the emotional state of the child is being monitored and mental support (cognitive-behavioural, mindfulness and relaxation techniques) is given.

The game has been developed in cooperation with pediatric cancer patients and survivors and their parents, and medical personnel to provide the maximum utility of the intervention as possible. Initial playtesting feedback sessions have been conducted with five pediatric cancer patients and further refinements of the game are done based on that.
Parents and medical personnel are able to monitor the progress of the game and child’s emotional state. The game will also embody a possibility to use an information channel where information will not reach parents or medical personnel to share thoughts that the child doesn’t want to share, for example, with parents and friends. This information channel is directly connected to a psychologist who could either offer more specific help to the child or ask for a psychological intervention to him or her.

**Expected results**

In 2018, a pilot study will be conducted which assesses the impact of the digital intervention among pediatric cancer patients aged 7-14 (sample size approximately 20 children). Children and their parents will be recruited through the associations of parents of children with cancer and through hospital oncology departments in Estonia. Both children ongoing with the treatment and the ones already through treatment will be included. It will be confirmed that the parent evaluates that participating in the study will not cause any extra mental distress for the child. Parents will give an overview of their child’s mental well-being before, during and after the intervention through filling in screening tests.

Before the intervention, children will be screened with Strengths and Difficulties Questionnaire (SDQ). SDQ is a screening tool measuring adjustment and psychopathology in children aged 4-17 and it has been found to be a good measure to use with chronically ill children as well [16, 17]. The SDQ and impact supplement for the parents of 4-17 year olds and SDQ and impact supplement for self-completion by 11-17 year olds versions of the questionnaire will be used in Estonian. This means that for children aged 7-10 parents will fill in the form and for 11-14 year olds the forms will be filled in by both children themselves and their parents.

Additionally, KIDSCREEN (Health-Related Quality of Life Questionnaire for Children and Adolescents) will be administered with parents and children. KIDSCREEN is an instrument to assess children’s and adolescents’ subjective health and well-being by covering health-related quality of life dimensions, such as physical and psychological well-being, autonomy, social support and school environment. The questionnaire is developed for healthy and chronically ill children aged 8-18 [18].

After the initial screening, children will be instructed to use the game for eight weeks. After four weeks, parents or children will fill in SDQ and KIDSCREEN. After the intervention, information from qualitative interviews with the participants and quantitative information from the game (e.g. total time played, time spent in educational component, the number of questions answered, speed of completing games) is gathered and analysed. SDQ follow-up versions and KIDSCREEN will be administered again to evaluate the effect of the game on children’s mental well-being.

**Acknowledgements**

We thank all the volunteer game testers and authors who wrote and provided helpful comments on previous versions of this extended abstract.
References


15. Richard M. Ryan and Edward L. Deci. 2000. Self-Determination Theory and the facilitation of intrinsic motivation, social development, and well-
