# mHealth Applications for Childhood Cancer Support and Self-management: Persuasive Systems Design features

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Abstract. The wide accessibility of mobile devices and the potential for self-management and informational support through mHealth applications provides an opportunity to address unmet informational needs, achieve patient self-management, and provide long-term care for young cancer patients and their parents/caregivers. The aim of this paper is to examine the functionalities and features offered by mHealth applications for the support and self-management of childhood and adolescent cancer patients. In order to evaluate the influence of these apps on the user's motivation for behaviour change, an extensive review was conducted and the features of the selected applications are further analysed using the Persuasive Systems Design. The review provided in this paper found a number of mobile health applications fulfilling a variety of functions and needs for childhood and young adult cancer patients and their families. Most of the analysed applications provide one or few features from the Persuasive Systems Design primary task support, dialogue, or social support category.

**Keywords:** mHealth, Cancer Patients, Self-management, Persuasive Systems Design.

#### 1 Introduction

mHealth is defined by the Global Observatory for eHealth (GOe) as medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices [1]. Common application areas for mHealth include improving data collection, raising awareness and education, remote telemonitoring in real-time, or delivering healthcare services more effectively [2,3].

In 2018, over 10590 children were expected to be diagnosed with cancer in the United States, along with 1180 estimated deaths, which makes it the second-largest cause of death for children aged 0-14 years [4]. Leukaemia, brain and nervous system tumours, and lymphoma are the most common types in children and adolescents; while the overall survival rate has been increasing over the decades, the incidence rate has not declined [5]. Cancer and its treatments have significant impacts on the quality of life of the patients, causing side effects and symptoms such as intense pain, nausea, weight

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loss, and infertility. In addition, children and adolescents can suffer psychosocial side effects such as post-traumatic stress, anxiety and depression, learning disabilities, relationship or sexual dysfunction, and employment and education discrimination [6]. These disruptions affect their self-esteem, social and family life, and future life plans, requiring a life-long survivorship plan [6,7].

Despite these recognised needs, many cancer survivors still report having unmet information needs regarding clinical areas such as cancer recurrence and fertility concerns, and in areas such as healthy lifestyle behaviours, interaction with others at their age, and financial impacts [8]. These areas of unmet needs also apply to parent/caregivers, and both the patient and their family as a result experience distress, highlighting a need for providing centred care for young cancer patients [8].

The wide accessibility of mobile devices and the potential for self-management and informational support through mHealth applications provides an opportunity to address unmet informational needs, achieve patient self-management, and provide long-term care for young cancer patients and their parents/caregivers. The aim of this paper is to examine the functionalities and features offered by mHealth applications for the support and self-management of childhood and adolescent cancer patients. In order to evaluate the influence of these apps on the user's motivation for behaviour change, the features of the selected applications will be further analysed using the Persuasive Systems Design (PSD).

# 2 Background

Self-management empowers the patients to make decisions and engage in behaviours that affect their health. It can be a good strategy for treatment allowing patients to identify challenges associated with their condition [9,10]. Self-managing includes learning about the condition, participating in making health decisions, understanding and knowing how to deal with specific health emergencies.

The pervasiveness of information and communication technologies in everyday life provides great opportunities for managing health conditions. Fogg [11] identified that computers can play roles as a tool, media, and social actor. However, in order to have full effect digital tools need to be based on reliable and tailored information that will allow patients to better understand the content and adopt changes in their every-day routines. From this perspective technology-assisted health behaviour change support systems would need to provide goal setting and behaviour change techniques such as self-monitoring, feedback, reinforcement, and social support. Furthermore, Michie et al. [12] introduced a behaviour change taxonomy with 93 behaviour change techniques clustered into 16 groups including feedback and monitoring, goals and planning, social support, shaping knowledge and regulation. In this context, Persuasive Technology (PT) are interactive systems effective at promoting various health and wellness related behaviour by shaping and reinforcing behaviour and/or attitude [13].

Oinas-Kukkonen and Harjumaa [14] developed a Persuasive Systems Design (PSD) model presenting behaviour change support features divided into four categories: Pri-

mary Task Support, Dialogue Support, Credibility Support, and Social Support features. PSD features influence behaviour change by assisting the user in achieving the primary task (goal); supporting human-computer interactions with feedback prompts, suggestions or reminders; indicating system's credibility; and motivating users by leveraging social influence.

The PSD model can assist in designing and evaluating systems that influence attitudes or behaviours. Multiple studies have used the PSD for the validations of different systems [15-18]. According to Win et al. [18], besides the behavioural influence of individual PSD features, the categories of features can also contribute to positive outcomes enhancing health behavioural changes.

To be effective in patients' healthcare management, the applications need to consider appropriate software design features that will guide the user towards the desired attitude or behaviour change. By implementing Persuasive Systems Design features, the applications can be seen as an effective self-management tool that elicits users' motivation for undertaking activities that are important for successful management of their health condition.

## 3 Methodology

For the purpose of the paper, a search of two databases SCOPUS and PubMed (that include a large number of health journals) was conducted. The search terms were combinations of ["teen", "adolescent", "child-hood", "child", "young", "youth", "paediatric"] AND ["mHealth", "mobile", "eHealth", "mobile health", "mobile application", "smartphone", "mobile device", "mobile app"] AND ["cancer", "oncology", "oncologist", "tumour", "chemotherapy", "malignant", "carcinoma", "melanoma", "blastoma", "sarcoma", "leukemia", and "lymphoma"].

The query returned 531 results from SCOPUS and 1218 results from PubMed. Of the 1749 results, 40 articles were selected for full-text review.

In order for the article to be included in the review it was required: 1) to be focused on a specific mobile application, 2) the testing sample or target demographic to include childhood and/or adolescent cancer patients (0-19 years of age) or the caregivers of these patients, and 3) the application is intended to provide support and/or self-management, including post-treatment care for cancer patients. Articles that were excluded: 1) did not contain the mobile application, 2) study population was not oncology patients, 3) study was not focused on childhood or young adolescent demographic, or 4) the applications were focused outside of ongoing and post-treatment support and self-management of cancer patients (e.g. cancer prevention, public awareness).

The 40 selected articles were reviewed and discussed by all researchers leading to a selection of 14 articles covering 13 unique mobile applications. Of the included articles, two contained patients within and outside the specified age range, while the rest were within the specified range.

### 4 Results

Based on the provided functions and features the applications can be categorised as: (1) Applications that primarily provide broad informative support to the user (such as knowledge banks, contact information, monitoring and management tools, and diaries); (2) Applications with a focus on symptom management (allowing patients to report, assess, receive feedback on, and receive self-management strategies for their disease and treatment symptoms); (3) Pain assessment or patient-reported outcome applications; and (4) Medication management applications.

For most applications, the evaluation is done with a pilot study, ranging the trial period from 10 days to 6 months. The sample size also varies from 4 to 59 users including young and adolescent patients and their parents or caregivers (Table 1). Need to be noted that the evaluation of the Oncology Family App [19], EAT! [20], Dosecast [21] and FitBit & Facebook [22] showed that adherence rates remained high early on but became far less consistent over time.

Five of the reviewed applications provide informative support for users.

The Oncology Family App [19] aims to provide remote support for the parent/care-givers of children with cancer. The application has four modules: a state-wide hospital contacts module sorted by distance to the user, "When to call" module that describes general oncology and bone marrow transplant symptoms, a blood results table that allows the parent/caregiver to record and examine the child's blood test results, and module containing recommended websites, contacts, appointments, and a personal note-taking feature. According to the app evaluation, modules "When to call" and "Blood Results Table" were the most popular. However, the overall review of the app was very positive for both ease of use and usefulness for the families [19].

Mendoza et al. [22] conduct a pilot randomised control study using a Fitbit smartphone application associated with a wearable Fitbit flex wristband for physical activity monitoring. Additionally, the study made use of a Facebook group for peer support. The participants had a goal (number of daily steps), received affective text messages and a Facebook discussion forum with awarding badges for weekly achievements. The study found that passive engagement with the peer group was more common than actively commenting and discussing posts. Also, only 1-hour non-significant daily increase in physical activity was found among users who did engage actively with the group [22].

Care Assistant [23] is an Android smartphone application for supporting parents/caregivers of children with Acute Lymphoblastic Leukaemia (ALL). The application consists of 8 modules: user information (age, education level, child's diagnosis, treatment, and other demographic data); treatment tracking module (multiple relevant treatment data); family care module (information and solutions for common problems and symptoms); financial and social assistance module (financial assistance organisations and suggestions on transitioning children back to normal life); knowledge centre (credible and systematic information related to leukaemia); self-assessment questionnaires (evaluating the parent/caregiver's own well-being); an interactive platform for parent/caregivers (discussion forum supported by healthcare providers); and reminders

module (allowing users to set customised reminders) [23]. The results from the evaluation study showed that the users found the app easy to use and accessible. They also gained knowledge about leukaemia, found confidence in caregiving, received social support, and had reduced stress while using the app [24].

The Tue Aftercare App [25] is an Android application aiming to enhance post-treatment care and raise awareness of follow-up examinations for former patients diagnosed with childhood cancer and their families. The application uses patient information (age, gender, demographic information, disease type, and other relevant data) to provide tailored information about potential late effects of their disease and the need for follow-up appointments. The app also features an optional calendar and appointment reminders. The application was evaluated very positively, noting the impression of the patients' relatives with the ability to manage and coordinate their child's care [25].

The purpose of the Cherry [26] app is to benefit the patient's care by using an electronic diary for recording thoughts and experiences, including information about cancer and its treatment. It also uses social functions to allow sharing with healthcare providers, friends, and parents/caregivers and feedback from healthcare providers. App preliminary evaluations have shown that users have a positive and enthusiastic view of the app and find it easy to use [26].

Four of the reviewed applications provided symptom management reporting and feedback or management strategies for the users of the app.

EAT! (Eating After Transplant) [20] is a mobile app that supports adolescents (patients recovering from Hematopoietic Stem Cell Transplantation - HSCT) with self-management of issues related to eating. The app provides descriptive information and self-management strategies ("what to do") to help patients and caregivers understand and minimize the effects of their eating issues. According to the evaluation results, the users reported high acceptability and moderate usability of the EAT!, however even though the initial usage of the app was high it declined over time [20].

eChIMES (Electronic Children's International Mucositis Evaluation Scale) [27] is an electronic symptom reporting diary for children suffering from oral mucositis (a common effect of chemotherapy and hematopoietic stem cell transplantation). The application consists of a symptom and pain assessment, instructions on use, and a diary for assessment dates. The app was considered easy to use, understandable, and suitable for measuring mucositis [27].

mOST (Mobile Oncology Symptom Tracker) [28] is an eDiary for cancer patients performing an assessment of treatment-related symptoms. Besides symptoms tracking, the app also supports reminders with an audible alert and customizable text and time. The results of the evaluation trial show that patients see the app as easy to use and would recommend it to others [28].

Advanced Symptom Management System for Young people (ASyMS-YG) [29] is an extended version of ASyMS for young people. By using mobile phones, ASyMS-YG allows patients to record and send symptom reports to the hospital, and receive back tailored (based on the severity of symptoms) self-care advice from healthcare providers. The evaluation results indicated that the application is feasible and acceptable to young people and healthcare professionals [29].

Two of the reviewed applications provided pain assessment, reporting and feedback or strategies for the users of the app.

Pain Squad+ [30] provides pain self-management for adolescents suffering from cancer. The app generates real-time algorithm-based feedback in form of self-management recommendations. It also features automatic alerts to a trained nurse if the pain is repeatedly rated above the limit. Pain Squad+ is gamified and gives rewards to the users for adherence to pain assessment and treatment recommendation completion. The users found the app understandable, easy to use and helpful in describing or treatment of the pain [30].

Pain Buddy [31] application aims to provide children with real-time pain management strategies and feedback. The app includes daily pain and symptom diaries, remote monitoring of symptoms (with the alert for health care providers), cognitive and behavioural skills training, interactive guidance through the program, and motivating incentive system. The cognitive and behavioural skill training sessions use an animated avatar that educates children on strategies for self-managing their pain and symptoms. The application trial revealed that the app and the support provided were highly satisfying and useful in improving pain management [31].

One of the reviewed applications provided assessment and reporting of broader patient-reported outcomes, one app provided customisable medication management and reminder functions for increasing medication adherence. Paediatric PROMIS App [32] is a smartphone app that tracks Patient-Reported Outcomes (PROs) of children with chronic disease. The app, designed in cartoon styles, uses audio and on-screen text to guide the user to report its symptoms and receive feedback regarding its status and care suggestions. All usability test participants (children diagnosed with a kind of cancer currently under treatment and its parents) found the app easy to use with a child-friendly interface [32].

Dosecast [21] is a smartphone app for medication adherence. The application includes visual and audible medication reminders and a log of responses to those reminders. The evaluation study (with adolescents and young adults with cancer) found that most users tended to take their medication immediately upon receiving the reminder. The application was found to be easy to use and perceived as useful in terms of taking oral medications as prescribed and increasing the user's independence in taking medications [21].

**Table 1.** The aim and Persuasive Systems Design features included in the reviewed applications.

Application/ Article	App's aim	Study type / length	Sample size	PSD features
The Oncology Family App [19]	Informative support for parents/caregiv- ers in remote loca- tions.	Post release evaluation / 6 months after release	24 families (38 parents /caregivers)	Tailoring, Tunneling, Self-monitoring

Fitbit and Facebook [22]	Promote physical activity using monitoring and social support	Pilot ran- domised con- trol study / 10 weeks	59 patients (29-intervention, 30-control group) 14-18 years (mean 16.6)	Self-monitoring, Reward badges, Social support (discussion fo- rums)
Care Assistant [23,24]	Assist parents/ caregivers with information and management tools	Pilot (quantitative and qualita- tive) study / 2 weeks	15 parents/ caregivers 23-42 years	Tunneling, Social support (WeChat discus- sion forum), Reminders
Tue Aftercare App [25]	Follow-up care information and reminders for former patients	Usability study / N/A	13 patients (15 years) 9 relatives	Personalisation (recommenda- tion), Reminders
Cherry [26]	Provide information and sharable eDiary	N/A	N/A	Self-monitoring, Personalization (feedback), Social support
EAT! [20]	Provide symptom management strategies	Pilot study / 60 days	16 patients 11-18 years (mean 14)	Tunneling
eChIMES [27]	Symptom reporting eDiary	Pilot (cross- sectional) study / N/A	10 patients (mean 15.3 years) 40 patients (mean 12.4 years)	Self-monitoring
mOST [28]	Symptom assessment eDiary	Pilot study / 3 weeks	10 patients 13-21 years (mean 18.2)	Self-monitoring, Reminders
ASyMS-YG [29]	Symptom assessment and feedback	Pilot randomised control study / 14 days	4 patients (2-intervention, 2-control group) 13-15 years	Self-monitoring, Personalisation (advice and sup- port)
Pain Squad+ [30]	Pain assessment and management	Pilot study / 28 days	38 patients 12-18 years (mean 14.2)	Self-monitoring, Personalisation (self-manage- ment, recommen- dations), Rewards
Pain Buddy [31]	Pain and symptom reporting with feedback and management	Pilot study / 10 days	12 patients 8-18 years	Self-monitoring, Tunneling, Personalisation (alerts), Rewards
Paediatric PROMIS App [32]	Reporting and feedback	Usability study / N/A	10 patients (8-13 years) 5 parents/	Self-monitoring, Personalisation

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			caregivers (21-33 years)	(feedback and suggestions)
Dosecast [21]	Medication reminders	Feasibility and accepta- bility study / 12 weeks	23 patients 15-29 years (mean 19.7)	Reminders

### 5 Discussion

Applications for support and self-management of cancer patients and their families found in the literature cover a variety of areas and functions. The most frequent area deals with the management and reporting of patient-reported outcomes. This can be focused on specific aspects of the patient experience such as the management of pain and symptoms using tools such as eDiaries, electronic quizzes, or electronic forms for patients to record their pain and symptom experiences [27,28]. These applications not only support the patient in their treatment, but often provide the means for sharing that information with caregivers, healthcare providers, and support networks [23,26,29].

As shown in Table 1, some applications perform real-time or remote monitoring of health data, allowing transmission of the data to a healthcare provider and immediate response with appropriate supportive information or actions [30-32]. Other applications take a more informative role providing the patients or their parents/caregivers with support, such as contact information, emergency indicators, diet and fitness strategies, to promote healthy recovery [19,20,22,23]. Finally, some applications provide organisational tools to help patients manage their treatment including reminders for medication adherence and follow-up appointments [21,25].

Different applications introduce specific features allowing users to set a goal [22], receive feedback in form of advice, recommendation or suggestion [25,26,29,32], provide reinforcement like reminders or rewards [21-25,28,30,31], or offer social support thru discussion forums [22,23]. Healthy lifestyle behaviour information with symptom and pain management strategies are being common in patients reporting apps, with some apps specifically focusing on physical activity and mitigating treatment effects that interrupted patient diets [20,22]. However, despite the importance of meeting parents/caregivers' needs for more specific condition related information and to reduce their distress, only two applications, The Oncology Family App [19] and Care Assistant [23] focus on parents/caregivers. Both applications were information banks that support users' role as caregivers, but only Care Assistant [23,24] took the parent/caregiver own healthcare into account by providing a module with self-assessment questionnaires for evaluation of their well-being.

Specific Persuasive Systems Design elements can be seen in different functionalities provided by the reviewed applications, such as an automatic alert to trained nurse or care provider [30,31], gamification with cartoon characters or animated avatars [31,32], audio and on-screen text guides, or customisable visual and audio medication reminders [21,32].

Also, all applications have features designed in accordance with one or few PSD features of Primary Task, Dialog or Social Support category (Table 1). Most of the applications support self-management through self-monitoring or providing reminders.

From the Primary Task Support Category, Tailoring can be identified in one application, while Tunneling is present in four applications. Even though the Tailoring of the information is used only in one application, we can see that the Personalisation (in the form of personalised feedback, advice or suggestions) is implemented in six applications. The Reminder is one of the features implemented from the Dialogue Category, and it is implemented in four applications. Another feature is Reward, implemented in the other three apps.

Further observation is related to the social elements present in the applications. Three applications have implemented social support for sharing the information with caregivers, health providers or friends. The specific social peer support function is the solution proposed by Mendoza et al. [22] that uses a Facebook group where patients could talk, share progress, and win badges for milestones. Even in this case, the authors found that active participation in the support group was low, so these social interactions need to be further addressed. Even though implemented social elements can be seen as PSD features of Social Learning, Comparison or Facilitation, it should be further refined and enhanced.

Based on the analyses, reviewed applications for support and self-management of childhood and young adult cancer patients can further support behaviour changes of patients and their caregivers. This can be done by extending the apps' and introducing PSD features that will provide customised information, interactivity and reinforce social influence, guiding the user towards targeted behaviour.

A significant limitation of the provided literature review is the overall lack of evidence as the studies tended to have small sample sizes and short trial periods (only one application had a trial length of 6 months). Most of the applications were found to be acceptable, feasible and easy to use. But even though the users were satisfied with the applications, the evaluation of some applications [19-22] showed that adherence rates remained high early on but became far less consistent over time. Potential reasons for these cases can be the technological novelty wearing off, patients becoming more familiarized with their disease and treatment habits, usability issues, or users finding a better application with similar functions [20,33]. Additionally, some studies were only single-use trials, others only performed a usability study that did not measure effectiveness. This long-term adherence drop is something the short or one-off trials may fail to examine, leading to higher adherence rates and usability impressions than in actual use. However, implementation of PSD features can assist in continued support for users by providing incremental motivation, thus retain high adherence rates for the apps.

## 6 Conclusion

The review provided in this paper found a number of mobile health applications fulfilling a variety of functions and needs for childhood and young adult cancer patients and their families. Most of the analysed applications provide one or few features from the Persuasive Systems Design primary task support, dialogue or social support category.

Even though the applications have provided a range of information as well as tools to achieve self-management, such as eDiaries, reporting and monitoring mechanisms, data management tools, feedback, reminders or rewards, there are still areas of unmet needs and a lack of evidence on how significantly the apps will impact self-management behaviours. These open needs and areas must continue to be explored, and there is a distinct need for more large-scale studies to ensure the applications are successfully realised. Despite this, the applications have been seen as usable, acceptable, and feasible or effective in the trials presented in the reviewed articles, which provides a positive outlook for the future of the field.

To address the comprehensive support for the users, future research directions should explore the potential for mobile health to provide long-term care to current and former patients of childhood and adolescent cancer through informative support about follow-up treatment processes and potential late effects and how they can be managed. Another area is to focus on the unmet social interaction and peer support needs of patients. These issues can be addressed in the designing phase by the established principles of Persuasive Systems Design used in the context of the patient's parent/caregiver and family perspective.

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