A Mobile Application to Manage and Minimise the Risk of Late Effects Caused by Childhood Cancer

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Abstract. In their first 15 years of life, about 1 800 children are diagnosed with cancer each year in Germany. Their chances of survival, however, have improved significantly over the last 40 years. In Germany alone, over 30 000 survivors of childhood cancer are presently living. Therefore, the late effects caused by the therapy occur ever more frequently as chemotherapy and radiotherapy may leave traces even years later. In order to recognize and treat these late effects in survivors, structured and regular follow-up examinations are necessary from an early stage on. However, the compliance of former patients to participate in the recommended check-ups is not satisfying for multiple reasons. To enhance this compliance, an application for smartphones and tablets has been developed. The Aftercare App supplies a wide range of information regarding the aftercare and supports a reminder functionality to attend medical visits.

Keywords. Mobile health, XML, telemedicine, cancer, home care

Introduction

Thanks to advances in medicine, many patients with cancer can be cured nowadays. Particularly pleasing is the progress in the treatment of cancer in childhood and adolescence such as leukemia or malignant bone tumors. Suffering from such a disease, there is a good chance to be permanently cured [1].

For a positive outcome, aggressive treatment is necessary. Almost always, chemotherapy is administered. In some cases, an initial phase of chemotherapy is followed by an attempt to remove the tumor by surgery. Additional cycles of chemotherapy or radiotherapy treatment are sometimes necessary. But these radical treatments also affect healthy cells and organs. In some cases, health disorders due to treatment-related organ damage occur in the following years. All adolescents and young adults who had to be treated for cancer should therefore undergo a cancer follow-up and late-effects screening. Regular examinations can help to discover treatment related disorders early and treat them appropriately. This triggers an
interlocking cascade of aftercare and prevention. The follow-up care of cancer is
twofold prevention: secondary prevention of late effects and secondary prevention of
new cancer. The work group Late Effects Surveillance System (LESS) [2] has the aim
to inform patients, to systematically record and investigate the late effects possibly
occurring after childhood cancer. To detect early signs of late effects and to treat them,
a structured, periodical follow-up of the former patients is essential. As part of that
work, the study group published a range of information media, including: Information
brochures, a follow-up calendar and the website [2].

LESS estimates the number of former patients who regularly attend their follow-up
examinations to 5 years after the cancer 70 %, 10 years after the disease that number is
down to 50 %. A study in Canada showed that 71 % of the former patients visit at least
once a year a doctor, but not to a specialist [3].

The work group Late Effects Surveillance System (LESS) [2] suggested
implementing a mobile application to inform and remind former patients of follow-up
examinations. Considering their target audience's affinity to new media, the LESS
group started a project to cluster all this information, enhance the service, and reach
more affected adolescents by implementing a mobile application. The potential of
mobile applications to influence and support healthcare and collation of data for
healthcare research is tremendous [4]. Vollmer et al. state that mobile health
technologies have the potential to impact cancer survivorship research, care, and
outcome [5]. But they also noticed that few apps explicitly state a theoretical
background and that available apps rarely address post-treatment cancer survivors.

Akron Children's Hospital provides a cancer survivorship program including an
app for Android and iOS. The CancerLateFX app supplies tips and tools to minimize
potential problems [6]. However, it lacks a personal aftercare plan with automatic
reminding functionality. Downer [7] and Foley [8] proved that a reminding service can
significantly reduce a patient's failure-to-attend rate. Thus, the aim of this project is to
increase the compliance with follow-up examinations by means of a reminding service.

1. Methods

For complementing the information service on late effects of childhood cancer, the
projects aim was to implement an Aftercare App. This mobile application shall offer
the information of the brochures and the website now organized by diseases, provide a
service of reminding, and a calendar function to coordinate the dates of examination.
Furthermore it needs to allow the documentation of relevant findings from a patient
point of view and to be easily adapted to new research results, as the therapy of
childhood cancer is a subject of constant change.

The working group LESS provides special aftercare plans for each disease. These
serve as the basis for developing a format in which it is possible to model all diseases
and their examination cycles. The review of all 30 aftercare plans revealed that the in-
formation about possible late effects, their examination, and the corresponding cycles is
dependent on three parameters: the underlying disease, the prescribed therapy, and the
length of time since end of treatment.

These relevant parameters need to be stored in a user profile, including patient
demographic data such as gender as well as important details about the disease and its
process, therapy, and end of treatment. According to these parameters, the
recommended examinations and cycles are calculated.
The review of all follow-up care plans showed, that the examination period must be specified in weeks, as this was the smallest time unit in all aftercare plans. The interval between two examinations is dependent on the time elapsed since the end of the therapy. This period of time is typically divided into the following intervals: first to third year, fourth and fifth year, sixth to tenth year, eleventh to twentieth year, and thereafter. The intervals are commonly getting longer with passing time. The last factor for calculating the examination intervals is the type of examination. The aftercare recommendations differ for the following types: general examination, local and systemic tumor control, endocrine and laboratory examinations, organ-specific examinations and the annual check-up. This results in a cascade for the determination of the examination intervals, see Figure 1.

![Figure 1](image1.png)

**Figure 1.** Example cascade for calculating the examination interval for the general examination and the examination of the tumour location.

An XML file exists for each considered type of cancer in which, for the respective treatment protocol and the respective examinations, the examination intervals are documented. The export of this information to an external file has the advantage that adaptations can be easily made without changing the application source code. The XML file has its own format with the schema shown in Figure 2.

![XML Schema](image2.png)

**Figure 2.** Structure of the XML file to represent the time period between the repetitions of one examination. In this example the examination of the local area around the primary tumour has to be repeated every 12 weeks.

A similar XML schema is used to model the information about the late effects. It is a great advantage of the app to process the information adapted to the user, in contrast to the generic information brochure and follow-up calendar. The information about long-term consequences, for example, can be shown gender-specific. Additionally, the application offers former patients the possibility to inform themselves about the examination itself, such as what components the annual check-up should include. All this knowledge is taken from the already mentioned aftercare booklet and transferred to XML files. For each considered disease, an XML file exists, which organizes the late effects by organs and organ systems. The reason for the export of the text into XML
files is the separation of declarative knowledge in the XML files and work-flows or interaction in the program code, which increases the app's flexibility and adaptability.

The application offers - in addition to the information service - a reminder service and a calendar function to coordinate the follow-up care. To manage the examinations, the application provides its own calendar, which supports management of past and future appointments. Furthermore, it provides the functionality to remind about necessary examinations color-coding recommended periods in the personal calendar. If the user has made an appointment, he or she can enter the date and will be reminded of it. This feature can be turned off. The repeating reminders and the required user feedback are expected to improve the compliance with the aftercare plan.

2. Evaluation

Two target groups of the application are former patients cured of childhood cancer. Our target audience includes both male and female patients from the age of 15 and their relatives. The evaluation attended a total of 22 subjects, 13 former patients and 9 relatives. The application was evaluated at two locations: the University Medical Center in Lübeck and the University Hospital Hamburg-Eppendorf, Germany.

The evaluation featured usability questionnaires following the ISO 9241/110 norm. With the help of this questionnaire, it can be determined how effective, efficient and satisfactory the users achieve their goals. The questionnaire was published by Prümper in 1993 and considers the seven principles of evaluation of software: suitability for the task, self-descriptiveness, controllability, conformity with user expectations, error robustness, customizability and suitability for learning. The questionnaire ISONORM 9241-110-S [9] includes 21 questions, a brief introduction, and a standardized description of the task. Each question can be evaluated with a score from one to seven, with seven being the best rating, so that a maximum score of 147 can be achieved per questionnaire. To guarantee comparable results, the app-usage was restricted to the application case osteosarcoma. The reminding functionality was simulated, as long trial periods are not feasible within the scope of this evaluation.

According to the evaluation instructions two arrays, one for each group of users, were created to analyze the results. The evaluation of the questionnaire gains 130,5/147 points among former patients and 131,8/147 points among relatives. Which results in the first category of ISONORM rating from 115 up to 147 points, meaning a software solution with very good software ergonomics and functionality. In particular, the relatives were very impressed as they take over and coordinate most of the aftercare plans despite the age of their children. To keep a better overview of the events, the app could be a very good support for the former patients to take over responsibility. Probands state that mediating knowledge about aftercare plays an important role to strengthen the high priority of aftercare. Emerging privacy concerns could be debilitated because all entered data is stored exclusively on the mobile device itself.

The evaluation results of both groups, former patients and relatives are clearly positive. The app performed above average, as a whole and in each of the seven categories.
3. Conclusion

We introduced an Android application for former patients of childhood cancer to provide them with information about possible late effects organized by disease, a reminder service for follow-up examinations, and a calendar function to coordinate these examinations. The application is thus expected to increase the awareness of former patients for follow-up visits. The Aftercare App will help them to structure their personal long term follow-up care and to survey the key information they require.

As the LESS group also studies clinical evidence of childhood cancer late effects, it would be interesting to receive feedback directly from the application. For example, the user could document the outcome of an examination and transmit these results to LESS. The quality of this feedback, however, needs to be the subject of a long term evaluation.

Figure 3. The evaluation is currently in phase I, measuring the satisfaction of users. Phase II deals with the question as to whether the app does actually have an impact on the compliance of former patients to attend the follow-up examinations. Even more important is phase III in which results of the examinations are automatically returned to LESS to identify unknown late effects.

References