

An mHealth Intervention Strategy for Physical Activity Coaching in Cancer Survivors

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Abstract. Many cancer survivors experience severe fatigue long after they have finished curative treatment. The aim of this study was to develop an intervention strategy that aims to decrease cancer-related fatigue by integrating a physical activity coaching system in primary care physiotherapy. This development started from the current state of the art. Therefore, firstly, an overview is given about physical activity goals for cancer-related fatigue, relevant cognitive behavioral change factors in this context, and recommendations for using mobile Health applications. Subsequently, interviews with five experienced health professionals were held to define recommendations for the first draft intervention strategy. Via an iterative process with two physiotherapists and a patient, the final intervention strategy was developed. The final result is a 9-week intervention strategy that could benefit a large variety of patients with chronic cancer-related fatigue, that has the potential to be integrated successfully in current primary health care, and is currently evaluated in a large randomized controlled trial.

Keywords: physical activity · activity monitoring · cancer-related fatigue · mHealth · behavior change

1 Introduction

1.1 Chronic Cancer-Related Fatigue

Fatigue is a frequent and debilitating residual symptom of cancer and its treatment. It is estimated that more than 20% of cancer survivors report severe fatigue one year after treatment [1]. Survival rates and life expectancies of cancer patients are rising, and cancer is increasingly often considered a chronic disease. The 10-year prevalence of cancer patients in the Netherlands is expected to grow by 40% between 2011 and 2020 [2]. As a result, the number of patients suffering from cancer-related fatigue will increase rapidly.

Currently, cognitive behavioral therapy, multidisciplinary rehabilitation programs, exercise, and energy conservation interventions seem effective in reducing fatigue. The Dutch Cancer Society recommends to partially shift such oncological aftercare to primary care, and to encourage patients' self-management with respect to their health problems. It is expected that this will make health care accessible to a larger group of

patients, and is more cost-effective. In order to achieve the necessary changes, new treatment strategies for the primary care need to be developed.

1.2 Physical Activity Coaching

Physical activity is considered an important element in treatments of chronic cancer-related fatigue. An upcoming trend to achieve changes in physical activity is the use of Mobile Health (mHealth) applications [3], such as UbiFit Garden [4] and Fish`n`Steps [5]. Such systems use information from accelerometers or pedometers to send text messages to subjects in order to encourage physical activity, based on personalized step goals. Another example is the Activity Coach, which has been developed by Roessingh Research and Development (RRD, Enschede, The Netherlands) [6]. Previous research showed that subjects with chronic fatigue syndrome and chronic obstructive pulmonary disease were able to increase their daily physical activity by using this system [7, 8]. Based on this, it is expected that patients with chronic cancer-related fatigue might benefit from using this system as well.

However, despite the short term effectiveness of the use of such mHealth systems, current research shows that adherence and longer term effects are often still limited. One reason could be that mHealth systems are often deployed as a standalone tool: It is hypothesized that the use of mHealth systems should be better integrated in the everyday care practice [9]. A motivating role of the health professional in using mHealth systems will enhance a patient to generate insight in the usefulness and rationale of its use, which will promote compliance. Also, the mHealth system can be used in a much more personalized way, and behavior change processes can be supported more effectively. Conversely, by using mHealth technology, the professional can monitor and stimulate behavioral change in a patient's home environment. Therefore, the aim of this work was to develop an mHealth intervention strategy for patients who suffer from chronic cancer-related fatigue that utilizes the Activity Coach, integrated in primary care physiotherapy.

2 Background

The next paragraphs describe the starting points for the development of the intervention strategy. First, the activity coaching system is described in more detail. Without trying to give a complete systematic review, the three subsequent paragraphs describe the state of the art considering physical activity, behavioral change principles, and experiences in the context of cancer-related fatigue with the use of mHealth systems.

2.1 The Activity Coach

The Activity Coach consists of a smartphone and a 3d-accelerometer (ProMove3D, Inertia Technology B.V., Enschede), shown in Figure 1. The sensor is worn on the hip by means of an elastic belt or clipped onto the waistband. Both devices communicate with each other real time through Bluetooth. The accelerometer converts the accelerometer

data into IMA's, Integral of the Modulus of the Accelerometer output, as described by Boerema et al. [10], which can be used as a measure of physical activity and correlates well with energy expenditure as measured with oxygen consumption for many activities [11]. The smartphone displays a real time visual of the patient's cumulative activity, relative to a line of reference, and generates automated feedback messages about the patient's current activity level relative to that line of reference. The smartphone uses its wireless internet connection to send the converted data to a database, so that the data can be retrieved on a web portal. The level and shape of the reference line, the content of the feedback messages, and functionalities on the web portal were subject to change in the development of this intervention strategy.



Fig. 1. The Activity Coach. Left: Smartphone (HTC Corporation, Taiwan) showing the application. Right: ProMove 3D accelerometer (Inertia Technology, The Netherlands).

2.2 Physical Activity

Many behavioral change interventions that target fatigue in cancer survivors use physical activity goals such as increasing physical activity and/or physical exercise [12–16]. Walking programs, aerobic training, and resistance training have shown to be beneficial. For example meta-analyses by Brown et al. (2011) [15] suggest that intensity of exercise is strongly related to the effect of the intervention on cancer-related fatigue. Two other reviews on the effects of exercise interventions are more cautious in their conclusions, but acknowledge positive effects of strength training on physical functioning [17, 18]. In addition, Jacobsen et al. [19] did not find significant effect sizes of physical activity interventions on fatigue outcomes in their meta-analysis. Multiple activity types and intensities were included. However, they did find that home interventions more often had a positive effect when compared to supervised interventions.

Other examples of goals that target physical behavior to reduce fatigue in cancer survivors could include balancing activity throughout the day, or energy conservation [20, 21]. This would include the management of opportunistic activities, which are activities that a patient incorporates in their daily life, such as cycling to work and taking the stairs.

So, despite contradictory results from various meta-analyses, relevant goals for patients with chronic cancer-related fatigue could be adjusting their physical behavior by increasing the amount of opportunistic activities and the volume of aerobic or strength

training. However, energy conservation seems to be a promising focus for this population too.

2.3 Cognitive Behavioral Change Principles

Exercise interventions seem more effective in reducing fatigue in cancer survivors when they are guided by behavioral change or adaptation theory [15]. One of the relevant factors in this context is improving self-efficacy over physical activity [22, 23], as it seems to be one of the most important mediators of exercise interventions on fatigue in cancer survivors. This can be achieved by (1) setting realistic but challenging sub-goals and giving the possibility to monitor progress easily, so make sure the patient experiences ‘he can do it’, (2) social comparison: make sure the patient knows that comparable patients before him have been able to make comparable adjustments of behavior, (3) verbal persuasion per e-mail. Learning to formulate implementation intentions could help patients to change their physical behavior [24] in order to attain the goals that they have set. The use of text messages in mHealth interventions can help remind people of their implementation intentions [25].

Also, the patient’s stage of change should be acknowledged throughout the intervention in order to decide on (when to change the) the focus of the intervention: i.e. informing and raising awareness, motivating or maintenance [26]. The Activity Coach could be used to give insight in the patient’s progression in order to increase the perceived behavioral control.

Servaes et al. [27] reported on other cognitive elements that are associated with cancer-related fatigue: Patients with low sense of control over fatigue symptoms (and high anxiety and high impairments in role functioning) are more likely to suffer from persistent fatigue after cancer treatment. Therefore, targeting such cognitions could increase the effect of interventions for fatigue. The involvement of a health professional in the intervention could provide in this need, and make sure the patient is guided and coached in a personalized manner.

2.4 mHealth Recommendations

A patient’s compliance can make or break a behavioral therapy, whether or not mHealth technology is utilized. However, the use of mHealth brings new challenges considering this topic, of which some are closely related to the previously mentioned cognitive aspects. According to Fogg [28], persuasive technologies should keep in mind three factors in order to be successful in their aim: motivation, ability, trigger. His framework gives useful support for utilizing the Activity Coach. Consolvo et al. [29] formulated recommendations more specifically for activity coaching applications successfully: 1) give users proper credit for activities, 2) provide personal awareness of activity level, 3) support social influence, and 4) consider the practical constraints of users’ lifestyles. Moreover, varying and personalizing feedback messages could make it more interesting to use the system and therefore learn from it [8, 30]. It also possibly extends the patient’s use of, and compliance with, this system. Also, activity goals, when using a reference line in an mHealth application, should be based on a the individual patient’s

baseline activity pattern rather than on for example a “healthy” norm value of physical activity [7].

Finally, “increased interaction with a counselor, more frequent intended usage, more frequent updates and more extensive employment of dialogue support significantly predicted better adherence” [31].

3 Methods

Taking into consideration the existing system and background knowledge, the development of the intervention strategy started. In order to do so, the guidelines published by Huis in ‘t Veld et al. were used [32]. These guidelines suggest, as we did, to start from current state of the art and evidence based medicine, and work in close co-operation with the intended users: both professionals and patients. In order to do so, first, semi-structured interviews were held with five health professionals in the field and with one patient. The interviews allowed plenty space for discussing new ideas and followed the personal interests and concerns of the specific interviewee. The activity coaching system was presented and discussed in these sessions in order to get first ideas about how this system could be utilized successfully in their current practice. Ideas and recommendations were pooled and summarized. Then, a first version of the intervention strategy was drafted.

Secondly, an iterative process of discussions and testing with two other physiotherapists was performed. This was completed with a test session with a patient, after which the intervention strategy was finalized.

4 Results

4.1 Step 1: Insights from Health Professionals

One psychotherapist, three physiotherapists, and an occupational therapist of the multidisciplinary cancer-rehabilitation team of Rehabilitation Centre Roessingh (Enschede, The Netherlands) were approached for interviews, and all agreed to cooperate. The health professionals were all very experienced with treating patients that suffer from either chronic fatigue syndrome or chronic cancer-related fatigue, and two of them also had prior experience with using a previous version of the activity coaching system. These semi-structured interviews focused on three aspects: “How would you use the activity coaching system in an intervention for chronic cancer-related fatigue”, “Given the fact that such an intervention takes place at home solely, would e-mail be an appropriate means of communication?”, and “What would enable the system to be incorporated successfully in current primary health care?” The following issues arose:

1. E-mail was generally considered an efficient and effective medium to communicate between patient and health professional.
2. In the Netherlands, complementary health insurance packages for physiotherapy often cover up to nine consults, this should be taken into account.

3. Two therapists would recommend at least one face-to-face contact.
4. One therapist was concerned about whether patients would like to be monitored all over again, and questioned if patients would appreciate to wear the system.
5. There should be weeks planned in which the patient does not have to wear the system. In that way, the patient will have to translate what he has learned to daily living and compliance to the system in the other weeks might increase.
6. Personalized and well-justified goals are easier to attain than acting upon a standard, “healthy” reference line, so a therapist should be able to adjust that line. In that way, the end goal can be divided into sub-goals and adjusted throughout the intervention in order to support the patient in a flexible manner.
7. Large inter-individual differences exist in baseline activity patterns and personal goals should be set, which requires tailoring of the automated feedback.

4.2 Draft of the Intervention Strategy after Step 1

Based on the background knowledge and the results of the interviews, a first draft of the intervention strategy was developed with as main characteristics that it includes a theoretical framework, weekly instructions, e-mail examples, and guidelines for the incorporation and use of the activity coaching system.

The Activity Coach. Adjustments to the technology were made to the web portal and the software on the smartphone that generates the feedback messages.

Web Portal. The therapist enters the web portal at the home page, which shows a “traffic light”-visual of each patient’s compliance to wearing the accelerometer of the current week. More detailed information on each patient is shown in three tabs:

1. “Patient”: a summary of demographics and contact details of the patient;
2. “Activity monitor”: tab on which different graphs of the patient’s activity are shown in line charts that show either the cumulative (Figure 2) or raw IMA data from each day, or in a bar plot that represent the three day-parts or separate days.
3. “Measurement settings”: tab in which the Activity Coach can be set up for patients: level and shape of the reference line and the content of the feedback messages on the smartphone.

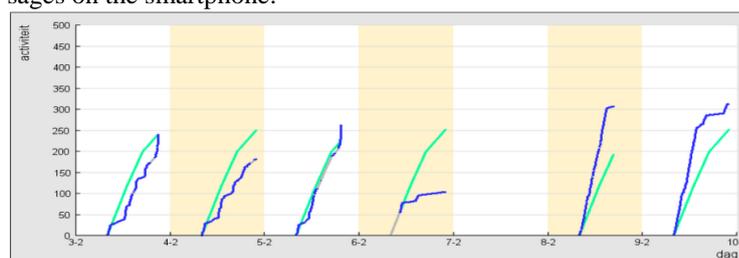


Fig. 2. Screenshot of the activity viewer on the therapist portal, showing the reference line (green) and the actual cumulative activity (blue). Grey segments represent missing data, which are inter- or extrapolations of the reference line.

Feedback Scenarios. In order to create flexibility for the therapist, and acknowledging the great inter-individual differences between patients, three different feedback scenarios were created. They differ from each other in terms of content of the feedback messages. The first scenario is for persons who are prone to being not physically active enough (activate). The second scenario is meant for patients who are used to push their boundaries, and could use encouragement of taking rest above a certain point (temper). The third scenario (balance) is the most neutral scenario, and can be used for patients who require to balance their activities throughout the day, and especially to conserve energy in the morning. Figure 3 shows a visual of the classification of the three scenarios. The messages differ on three scales. Firstly, the goal of the feedback message can be to reward or acknowledge the physical behavior (green), or to stimulate the patient to change the physical behavior (yellow, orange, red). These messages differ in rigorosity of the feedback or the proposed behavior (for example “a nice stroll” (yellow) versus “a brisk walk” (red)), as can be seen in the intensity of the colors in Figure 3. Boundaries for all three scenarios are set at a deviation of respectively +/-10 and +/-20% from the reference line. Secondly, the messages can either be suggestive or imposing, for example “Is there any chance that you can plan a brisk walk this afternoon?” or “Is your current activity in line with your intentions?” versus “Time for a brisk walk”.

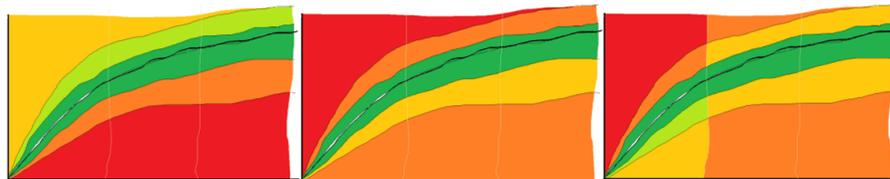


Fig. 3. Visual representation of the feedback scenarios. Left: activate, middle: temper, right: balance. The black line in the middle of the green strip represents the reference line.

Process Guidelines. The intervention strategy starts as the patient completes an intake questionnaire about demographics, medical condition, and fatigue complaints. Questionnaires can be administered online, and the hardware can be sent by direct mail easily. The patient wears the system for a week to create a baseline activity measurement. In this week, the smartphone does not display any feedback about the patient’s activity. However, the therapist should keep in mind that the simple act of wearing the device might influence the results of this measurement.

After the baseline week, the therapist logs into the web portal to see the results of the baseline measurement, and to change the settings of the Activity Coach. The therapist selects a reference line that is equal to, or is based on the patient’s average daily activity during the baseline week. In that way, the patient can get used to using the Activity Coach. Subsequently, the therapist approaches the patient through e-mail, gives an introduction about himself and the intervention, and gives a rough planning for the upcoming 9 weeks. The patient is asked to introduce himself too and to use the system for a minimum of three days to get used to the feedback scenario.

For the patient, the first feedback period now starts. Each hour, a feedback message is selected and pops up at the smartphone. The patient can retrieve the message the entire hour, until another message is generated.

In the second week, by phone contact, the patient and the therapist set personal goals for the upcoming eight weeks, and define and plan tasks to accomplish these goals. Goals and sub-goals can vary from “doing groceries independently by bike in week 9” to “Being able to take effective rest moments during the week”. Accordingly, the therapist translates sub-goals into a set of reference activity patterns that will be adjusted throughout the nine weeks of intervention. When desired, also the feedback scenario can be adjusted by the therapist.

The intervention strategy suggests to change the reference activity pattern of the Activity Coach in at least three steps throughout the 9-week intervention. This likely stimulates the use of feasible goals and consequently increases the self-efficacy of the patient. The therapist supports and coaches the patient with weekly e-mails during nine weeks. The intervention strategy suggests that in week 7, the patient is asked to not wear the system, and the patient is stimulated to translate his experiences and future goals in terms that relate to day-to-day activities and planning. Exercises that could be used in this week include keeping a fatigue or energy diary. The intervention is concluded by evaluating the progress of the patient, the benefits and difficult parts of the intervention, and setting goals for the future.

4.3 Step 2: Feedback from the iterative test phase

The first draft of the intervention strategy was presented, explained, and discussed extensively with two physiotherapists (PMI Rembrandt, Veenendaal, The Netherlands), after which it was tested and evaluated with these therapists and a patient.

The most important results from the therapists are that it is difficult to formulate goals and tasks for the intervention, and to explain the use of the system by e-mail. Also, it was recommended that the patient should get access to an online environment in which he can look up his past physical behavior in order to monitor and evaluate his own progress. Finally, it was suggested that a normative reference line could support the therapist to value a patient’s activity level.

The patient’s feedback was that the system is bulky and can be bothering to wear during exercise. Also, it is sometimes short of power for an entire day. Furthermore, more information about the reasoning behind the suggested activities in the automated feedback messages would be considered useful. The informative feedback messages were preferred over the direct messages. Finally, the lacking recognition of activities, and underestimations of certain physical activities was sometimes frustrating for them.

4.4 Adjustments to the draft intervention strategy after Step 2

The Activity Coach. Power-saving software adjustments were made to ensure that the battery of both devices will last an entire day. However, no adjustments to address the bulkiness of the system were made, because the choice for hardware was among the starting points for this study. Also, the system was not adapted to recognize activities. It is expected that this issue will be only a minor limitation in the current intervention, because individual goals are based on patients’ own baseline activity patterns, which likely incorporate a constant underestimation throughout the intervention.

Web Portal. In order to support the decision making of the therapist, a normative reference line was incorporated in the portal. It represents the average daily activity pattern of twenty patients who suffered from severe chronic cancer-related fatigue, and wore the activity coaching system for one week consecutively. This reference line is shown when the therapist reviews the baseline activity of the patient.

Patients were also enabled to have access to a web portal. For patients, it consists of an ‘activity viewer’ that is similar to the one that is shown in the therapist portal, but without plots of the raw data.

Feedback Scenarios. The content of the messages was not further adjusted as a reaction to the patient’s feedback. We hypothesize that such preferences are likely dependent on for example the stage of change of the patient, learning style, and personality. Adjusting the system to tailor the set of feedback messages for each individual was not technically feasible for this project. A mixed approach was therefore maintained.

Process Guidelines. A phone-call was implemented in the protocol during the second week in order to set goals. Also, the intervention strategy now suggests introducing the patient to the portal from the fifth week on. It is expected that from that moment on, patients are used to wearing and using the Activity Coach, and can interpret the line charts properly. The use of this portal creates an evaluation moment, and goals can be adapted accordingly if necessary. Also, example exercises were added to the intervention strategy that review earlier physical behavior and achievements during the intervention, thereby using the patient portal.

As the Activity Coach is known to underestimate the intensity of certain activities, caution should be taken when interpreting absolute IMA counts, and (any change of) type of activity should be kept in mind when doing so. The intervention strategy therefore now includes thorough recommendations for the therapist on informing patients explicitly about the possibilities, strengths and weaknesses of the system.

5 Discussion

This paper has described the development of an mHealth intervention strategy that targets chronic cancer-related fatigue. Feedback was obtained by involving potential end-users with various backgrounds in all phases of the development process. Such development was intended to result in a highly accepted intervention, contrasting technology-driven approaches that often do not come beyond the pilot stage [32].

The added value of this work is mostly the explicit involvement of a health professional for deploying the mHealth technology. Although this seems to be an obvious improvement, to our best knowledge, other examples of such use of activity coaching systems have not been published so far [33, 34]. By involving a health professional, more subtle and tailored physical behavior goals can be attained, such as creating awareness and improving energy conservation. Being able to set flexible goals is a huge advantage for the targeted population because of the population’s heterogeneous character.

Another important feature of this intervention is that it is directed at opportunistic physical activities and at low-to-moderate intensity exercise, rather than high-intensity

exercise. This serves two goals: to accommodate the diverse nature of the population, and to establish safety of the patient; physical tests cannot be performed because no face-to-face sessions were incorporated. However, we are confident that increasing the volume of opportunistic activities and actively managing their daily activities will have beneficial health outcomes for many patients. This could be strengthened by improving cognitions about physical behavior: Some argue that perceived amount of physical activity or the self-efficacy over physical activity is even more important than the amount of the physical activity itself [35]. Future research that focusses on the role of physical activity in interventions for fatigue should therefore also focus on cognitions and on other dimensions of physical behavior than just the objective daily amount.

Although the current employment of the Activity Coach was realized by extensive collaboration with experts and based on a broad spectrum of literature, many of the features have not been optimized so far. Firstly, the bulky hardware can be an important bias for the effectiveness of this intervention strategy. Also, personalizing the feedback messages to the subject's stage of change or learning style, and the way that the boundaries are set within the feedback scenarios have not been subject of this work, but could be an interesting topic for subsequent studies. Currently, the system is being adjusted to generate tailored motivational feedback messages considering for example timing and content [36]. Also, the visual representation of the activity measurement on both the smartphone and the web portal should be improved and personalized. The current visualization is rather simplistic, however, ideally they should explicitly support the goals they serve: visualize the longitudinal change or highlight improvement of the patient in order to strengthen self-efficacy and sense of control. Relevant examples for comparable goals yet exist [37]. Finally, the current experiments are limited due to the small number of patients that were involved, and the limited structure of the interviews.

Conclusion. This paper is a first step in order to develop an mHealth intervention to support patients who suffer from chronic cancer-related fatigue. The intervention strategy succeeds in meeting many of the recommendations that were extracted from relevant literature or formulated by health professionals in the field. However, the actual usefulness, acceptability, and effectiveness of the final intervention strategy have not been established yet. A randomized controlled trial (The Netherlands Trial Register, number NTR3483) is conducted currently to study the effectiveness, working mechanisms, and effect predictors of the intervention within the target group.

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