

Technology Assisted Self-management Support for Improving Cancer Pain Control

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Abstract—Pain continues to be a prevalent and distressing symptom in patients with cancer. Integration of patient self-management and professional care through care technology provides promising opportunities in the outpatient setting. Researchers, technicians, health professionals and patients collaborated during an iterative development process. Co-creation resulted in a technology assisted multi-component self-management support intervention delivered by specialized nurses to outpatients with cancer pain. The intervention consists of an iPad application for patients, which is connected to a web application for nurses. Both applications are embedded in a multidisciplinary care organization. This paper provides a description of the intervention.

Keywords—cancer pain; self-management support; telemonitoring; education; feedback; outpatients; nursing; eHealth intervention.

I. INTRODUCTION

Patients with cancer experience multiple physical and psychosocial symptoms, having an enormous impact on their daily functioning and quality of life [1]. Pain is considered one of the most common symptoms, reported by 59% of patients on active treatment, 64% of patients with advanced disease, and 33% of patients after curative treatment [2]. Despite available treatment options, pain control is still suboptimal in 50% of all patients with cancer pain [3]. Fragmentation of care organization, deficient pain communication, and reluctance towards pain medication contribute to inadequate pain management in the outpatient

setting [4][5][6]. Actively involving and remotely supporting patients seems conditional to improving outcomes, since the actual pain management of cancer patients is performed at home [7].

Various valuable attempts have been made in developing and evaluating interventions to support cancer pain self-management. Nurses specialized in pain were found to make substantial contributions to day-to-day pain management in the outpatient setting [8]. Due to differences in content, structure and outcomes of interventions, it remains difficult to draw firm conclusions about how to provide optimal self-management support [9]. Recommendations have been formulated with regards to the implementation of multiple components, the importance of self-efficacy and the integration of interventions into routine practice [10][11][12]. Care technologies could contribute to the integration of patient self-management and professional care.

Therefore, this project is focused on the development and evaluation of a self-management support intervention that integrates multiple components and is delivered by specialized nurses to outpatients with moderate to severe cancer pain. Requirements for self-management support [13] include assisting patients to access information about their pain and adverse effects and telling them what is normal and when and how to get help. It also involves empowering patients to recognize and monitor their symptoms and providing them with insight and feedback about how they are doing. Supporting patients to undertake strategies to manage their symptoms better and to have confidence is extremely important. Based on these requirements, researchers and

technicians as well as health professionals and patients collaborated in an iterative development process. Involving these different perspectives was meant to ensure an intervention fit with daily practice and preferences in order to increase implementation success, while at the same time taking previous research and technological opportunities into account. This paper provides a description of the intervention.

II. INTERVENTION

The intervention consists of an iPad application for patients, which is connected to a web application for nurses. Both applications are embedded in a multidisciplinary care organization. Patients receive the intervention alongside the pain treatment that is provided to them by their treating physician.

Patients and nurses obtain log-in information to gain access to the applications. Accordingly, pain medication can be entered into the nurse application and activated to be visible in the patient application. Monitored data are saved on secured servers.

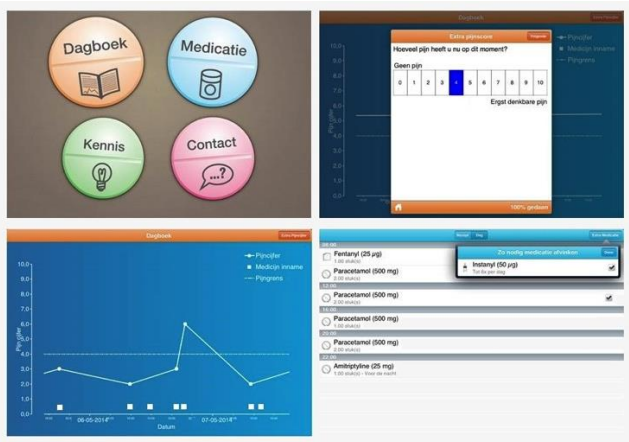


Figure 1. Screenshots of the application for patients (in Dutch): a) home screen, b) extra pain intensity score, c) graphical feedback, and d) medication intake schedule

A. Patient application

The application for patients involves pain, side effects and medication monitoring, graphical feedback, education, and nurse support (Fig. 1). Patients are reminded to complete diaries, take medication, read education materials and check text messages from the nurse by visual and sound notifications.

1) *Diary*: The pain diary is presented to patients twice daily and involves questions about their pain, adverse effects, interference of pain with activity or sleep, and satisfaction with pain treatment. Diary questions were based on the present-day pain anamnesis and composed together

with a multidisciplinary palliative team. Providing nurses with enough information without burdening patients too much was considered important. The pain diary contains a skip pattern; affirmative answers on particular questions result in sub-questions to obtain more information. In between, these diaries, registration of extra pain intensity scores is optional. These optional scores may provide a better reflection of pain over time, as cancer pain is characterized by fluctuations.

2) *Medication*: The application includes a personalized medication day schedule. In accordance with this schedule, patients are requested to register intake of medication in time. A restricted 4-hour time frame, starting 2-hours before and finishing 2-hours after the scheduled intake time should motivate patients to take and register their medication on time. Accurate registrations are important for graphical feedback as well as nurse advice. General medication icons were added to support patients visually.

Pain intensity scores from the diaries, as well as the extra pain intensity scores, are depicted in a graph together with the medication intake moments. Pain scores are indicated with bullets, closed and open squares represent intakes of respectively ‘around the clock’ and ‘as needed’ medication. The graphical information provides insight into pain patterns over time and the possible influence of medication intake and daily routines.

3) *Education*: Patients receive education about causes of pain, treatment of pain, recognition of symptoms that require action, and methods that patients themselves can implement to better control pain. The education is divided into three ‘obligatory’ sessions, in which information is presented dosed and in a logical sequence. Each session consists of several topics. After completion of these sessions, specific topics, as well as additional information about pharmacological and non-pharmacological treatments, can be ‘voluntarily’ reread. Based on prescriptions of patients, the information about pain medication is tailored by “The information presented here is (is not) applicable to your situation, since you do (do not) take this medication”.

4) *Contact*: In case of questions, patients have the opportunity to send text messages to the nurse via the application. Nurses attempt to answer these messages within one workday.

B. Nurse application

Nurses enter the application to monitor and analyze the situation of patients regarding pain once every workday. In addition to the composition of the medication overview, the application for nurses includes completed pain diaries, composite graphs, information about scheduled and actual medication intake, and a text message function (Fig. 2).

In case of red flags or text messages from patients, nurses receive an email notification.

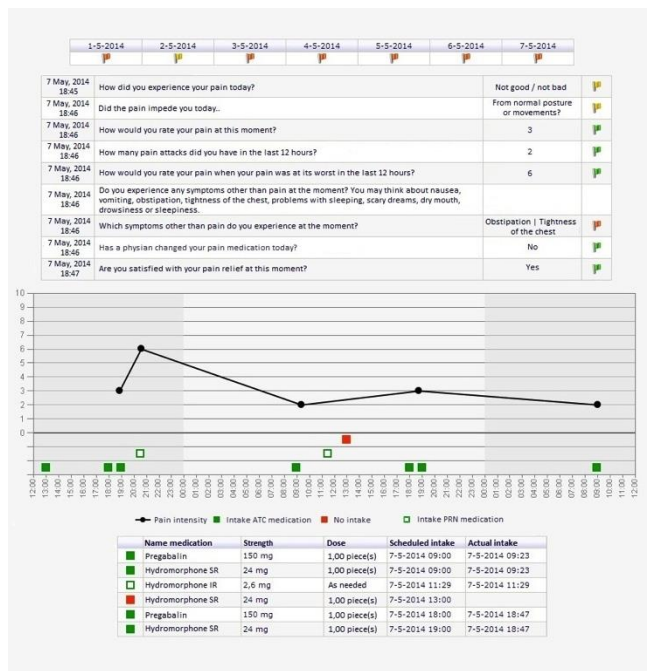


Figure 2. Screenshots of the application for nurses: a) weekly overview of overall risk flags, b) evening diary, c) composite graph with pain intensity scores and medication intake moments and d) medication intake details

1) *Completed diaries:* Diary questions and answers are tagged with colored flags that support nurses in their monitoring tasks: red flags required immediate action, yellow flags asked to keep an eye, and green flags indicated everything is okay. Frequency of certain answers during subsequent diaries determines the color of flags.

2) *Composite graph and medication details:* Pain intensity scores as registered by patients are summarized in a composite graph together with their pain medication intake. Pain scores are depicted with bullets. Squares differentiate between registration of ‘around the clock’ medication (green, closed) and ‘as needed’ medication (green, open) as well as medication that has not been registered (red, closed). The graphic view can be adapted by changing the date. Pain medication details, including strength, dose, scheduled and actual intake time provide nurses with additional information.

3) *Multidisciplinary organisation of care:* Besides sending text messages, nurses have the opportunity to consult patients by phone. When necessary, and also on a regular basis, nurses will inform the treating physician about the situation of patients regarding pain. In case pain relief is inadequate, the nurse consults the pain specialist or the multidisciplinary palliative team for advice. Advice is

reported to the treating physician who decides on follow-up, changes in prescription or other interventions.

III. CONCLUSION

The intervention integrates patient self-management and professional care through care technology, facilitating partnership with shared responsibilities. The proposed intervention, which is to be tested in a randomised controlled trial, is believed to improve pain management in outpatients with cancer.

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