



## Feasibility of a mobile and web-based intervention to support self-management in outpatients with cancer pain



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### ABSTRACT

**Purpose:** Cancer pain is a prevalent and distressing symptom. To enhance self-management in outpatients, a multi-component intervention was developed, integrating patient self-management and professional care through healthcare technology. This article describes feasibility of the intervention in everyday practice.

**Method:** Patients with moderate to severe cancer pain ( $n = 11$ ) and registered nurses specialized in pain and palliative care ( $n = 3$ ) participated in a four-week study. The intervention involved daily monitoring, graphical feedback, education, and advice by means of a mobile application for patients and a web application for nurses. Learnability, usability and desirability were measured in patients with a 20-item questionnaire (1–5 scale), higher scores indicating better feasibility. Patients' adherence was based on completion rates from server logs. Single semi-structured interviews with patients and a focus group interview with nurses provided insight into experiences.

**Results:** Questionnaire findings confirmed learnability (4.8), usability (4.8) and desirability (4.6) of the application for patients. Average completion rates were 76.8% for pain monitoring, 50.4% for medication monitoring and 100% for education sessions. Interviews revealed that patients were pleased with the simplicity of the mobile application and appreciated different components. Nurses agreed upon the added value and were mostly positive about the possibilities of the web application. Patients and nurses provided ideas for improvements relating to the content and technical performance of the intervention.

**Conclusions:** Study results demonstrate feasibility of the intervention in everyday practice. Provided that content-related and technical adjustments are made, the intervention enables patients with cancer pain to practice self-management and nurses to remotely support these patients.

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### 1. Introduction

Pain is a commonly experienced and inadequately controlled symptom in outpatients with cancer (Klepstad et al., 2005; van den Beuken-van Everdingen et al., 2007). Several barriers on different

levels contribute to difficulties in optimizing outcomes. First, the organisation makes coordination and continuity of pain management to be challenging. Different health professionals in different health care settings are involved and close monitoring and follow-up of pain is difficult once patients are at home (Schumacher et al., 2014). Second, pain is not structurally and thoroughly discussed by health professionals during consultations and the subjective experience of pain is difficult to measure objectively (Berry et al., 2003; Butow and Sharpe, 2013). Health professionals are also careful to prescribe opioids and reluctant to refer patients to pain or palliative care services (Kwon, 2014). Third, patients struggle with

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misconceptions about pain medication, concerns about pain communication, and beliefs about the inevitability and uncontrollability of cancer pain (Jacobsen et al., 2009). These misconceptions, concerns and beliefs influence adherence and prevent patients from taking their pain medication as prescribed (Miaskowski et al., 2001). At the same time, outpatients face more practical day-to-day challenges at home, such as coping with adverse effects and managing new or unusual pain (Schumacher et al., 2002a). Comparable to many prevalent chronic conditions, patients with cancer pain are therefore more and more encouraged to contribute actively to their own pain management and practice self-management (Bodenheimer et al., 2002; McCorkle et al., 2011). Patients themselves do want to be more active in pain management (Kimberlin et al., 2004).

Various valuable interventions have been developed and evaluated in order to improve pain control and support self-management (Bennett et al., 2009; Cummings et al., 2011; Jho et al., 2013; Koller et al., 2012; Oldenmenger et al., 2009). Interventions directed at patients commonly address knowledge by sharing information about pain, pain medication, side effects, alternative methods to control pain, and when to get help. Some of the interventions also target problem-solving skills by providing instructions on how to assess pain, how to take medication, how to manage side effects, how to apply alternative methods and how to communicate with health professionals. Because interventions are diverse and did not achieve desired effects on different outcome measures so far, questions remain about the optimal format as well as content and combination of intervention components (Adam et al., 2014; Marie et al., 2013).

Awareness and measurement of symptom progress are considered essential for effective self-management (Lorig and Holman, 2003). Self-monitoring provides patients with insight into pain variations and how these variations possibly relate to variables such as adverse effects, medication intake and daily activities. Self-monitored data could therefore support patients to make appropriate decisions, to take subsequent actions and to see the impact of these actions (Richard and Shea, 2011). Daily diaries have been helpful in outpatients with cancer pain to heighten awareness, increase their sense of control and improve communication with and assistance from health professionals (Purtzer and Hermansen-Kobulnicky, 2013; Schumacher et al., 2002b). As self-monitoring enables actual implementation of knowledge and skills to their own situation, incorporation of a complementary self-monitoring component is expected to contribute positively to patients' self-management (Wilde and Garvin, 2007).

Healthcare technologies provide an excellent means for self-monitoring and self-management. Technology based self-monitoring for instance provides direct access to supportively composed data for both patients and health professionals (Kuijpers et al., 2013). As a result, these technologies enable collaborative care as patients at home are connected with their health professionals in primary or secondary care. The availability of accurate and timely data facilitates feedback and communication, which advances follow-up and accommodates subsequent consultations or referrals (Meystre, 2005). Especially in cancer pain, frequent monitoring of symptom progress and medication intake is valuable, as variations are characteristic and the introduction of medication requires starting slowly and titrating based on effectiveness and side effects (Lovell et al., 2014). For outpatients facing cancer pain management, the combination of different self-management enhancing components by means of healthcare technology is innovative and could be promising in overcoming existing barriers.

The overall project concerns the development and evaluation of a technology based self-management support intervention that aims to improve pain control and quality of life in outpatients with

moderate to severe cancer pain. As part of the overall project and in advance of the large-scale clinical evaluation (Hochstenbach et al., 2015), this small-scale evaluation was conducted to explore feasibility of the mobile application for patients, the web application for nurses, and the integration of both applications in routine clinical practice. The article summarizes usability, learnability and desirability as well as adherence and acceptance as evaluated by patients and nurses.

## 2. Method

The present study is a one-group post-test only design that evaluates feasibility of a mobile and web-based self-management support intervention among patients and nurses using a combination of questionnaires, observations and interviews. Ethical approval for this study was obtained from the Medical Ethical Committee Atrium-Orbis-Zuyd (NL46552.096.12).

### 2.1. Sample and setting

Patients were recruited conveniently via the outpatient oncology clinic of one academic and one regional hospital in the south of the Netherlands. The inclusion and exclusion criteria are listed in Table 1. Based on these criteria, thirteen eligible patients were invited by their treating physician to participate in the study with a four-week follow-up.

Patients received a folder before the start of the study, including an invitation, an information letter and an informed consent form. After one week the researcher contacted patients by phone to provide more information and to ask for their willingness to participate. Participation was confirmed by a returned signed informed consent form. After informed consent, the treating physician and general practitioner were informed about the participation of patients.

Nurses were recruited conveniently via the palliative care consultation team that was linked to both hospitals. Most of these regional teams consist of health professionals from various disciplines and settings, including nurses from home, hospice or hospital care; general practitioners; elderly care physicians; and medical specialists; all with extra education and practice in palliative care. Their primary aim is to inform and advise other health professionals on questions regarding palliative care by phone or bedside consultation (Kuin et al., 2004).

### 2.2. Intervention

The intervention was developed in an iterative co-creative development process with collaboration of researchers, technical experts, health professionals, and patients. As a result, the intervention consisted of a mobile application for patients that was connected to a web application for nurses. Both applications were to be embedded in routine clinical practice. More information about routine clinical practice with concern to cancer pain management can be found in Box 1.

At baseline, the nurse and the researcher visited patients at home. The nurse performed a pain assessment and checked pain medication. Patients were also provided with short oral education, of which the content was similar to the education within the application. The researcher explained to patients how to use the application, after which they were given a paper-copy manual. The mobile application ran on an iPad 2 with Internet connection that was provided on loan during the study period. Patients were not restricted to using other applications than the application under study in order to make them feel comfortable using the iPad.

**Table 1**

Inclusion and exclusion criteria.

<b>Inclusion criteria</b>
Diagnosis of cancer
Under (palliative) anti-tumour treatment in a day clinic or outpatient clinic, or having no treatment options available anymore
Moderate to severe cancer (treatment related) pain $\geq 4$ (NRS 0–10) for >2 weeks
Living at home
<b>Exclusion criteria</b>
Life expectancy <3 months
Chronic non-cancer pain
Known cognitive impairments
Participation in other studies that interfere with this study
Not being able to read and understand the Dutch language
Reduced vision
Non-accessible by telephone

**Box 1**

## Routine clinical practice

Outpatients with cancer pain enter the outpatient clinics involved in the study basically via three different routes: patients see their oncologist for follow-up and indicate having pain; patients are referred by their general practitioner with an increase in pain complaints; or patients contact the oncology department themselves.

Patients are often treated for cancer pain by their oncologist. When pain proves to be difficult to treat, the oncologist might consult a pain specialist. During an outpatient consultation the pain specialist performs a pain assessment; checks pain medication and changes prescriptions when needed. Afterwards patients are seen again at the outpatient clinic or contacted by phone for a follow-up consultation. Depending on the type of medication that has been prescribed, the timing and frequency of these follow-up consultations differ: sometimes after four days, sometimes after a week and when stabilized after two or three weeks. When pain control is adequate, follow-up is ended. When pain gets worse and treatment remains ineffective, patients might be admitted to the hospital. The general practitioner needs to be kept informed about the progress of pain treatment. Because multiple health professionals might be involved as well as different information systems, the pharmacist is often the health professional with the most current and accurate overview of a patient's pain medication.

Patients do often not receive information materials about pain and pain treatment. Usually patients are neither asked to monitor their pain scores, nor to register their medication intake on paper or to have frequent contact with a health professional about their pain.

**2.2.1. Application for the patient**

For each patient an account was created in the nurse application, which was then linked to the patient application. The home screen of the patient application contained four different components.

**Diary:** Patients registered their pain, adverse effects, interference of pain with activity or sleep, and satisfaction with pain treatment by use of a pain diary twice-daily. The diary in the morning was accessible between 7 and 12 a.m. and asked for the past night; the diary in the evening was available between 6 and 12 p.m. and reviewed the past day. Diaries were based on present-day pain assessment and included a skip pattern (Table 2). In between

these diaries, registration of extra pain intensity scores was optional in order to report (the effect of medication on) breakthrough pain and to provide a more accurate representation of pain over time. Pain intensity was measured with a numerical rating scale (NRS) numbered 0–10 with verbal anchors of “0 being no pain” and “10 being the worst pain imaginable” (Hjermstad et al., 2011).

**Medication:** Based on an overview of the pharmacist, prescriptions were entered into the nurse application and activated to be visible in the patient application. By doing so, patients were accommodated with a personalized medication day schedule for the registration of their ‘around the clock’ and ‘as needed’ pain medication. A restricted 4-h time frame was introduced to motivate patients to take and register their pain medication in time. At the time of registration, pain intensity scores and medication intake moments received an automatic time stamp. These registrations were continuously depicted in a graph that showed pain and the possible influence of medication intake and daily activities in order to support patients visually. To make sure the medication day schedule kept up to date, each diary contained the following question: ‘Has a physician changed your medication?’ In case of confirmation the nurse contacted the patient to ask for details in order to process updates.

**Knowledge:** Patients received education about causes of pain, treatment of pain, recognition of symptoms that require action, and methods that patients themselves can implement to control pain. This information to read was divided into three sessions; each session consisted of several topics (Table 3). Those who wanted to know more could access additional information about pharmacological and alternative treatments.

**Contact:** In case of questions, patients communicated with the nurse via text message functionality within the application. Nurses attempted to answer these messages within one workday. All communication remained accessible to enable patients to reread answers, advices or agreements on a later moment in time. Patients were reminded to complete diaries, take medication, read education materials and check text messages from the nurse by visual and sound notifications.

**2.2.2. Application for the nurse**

All monitored data were saved on secured servers that comply with present rules and regulations. The nurse monitored and analyzed the patient's situation once every workday, taking into account completed pain diaries, scheduled and actual medication intake and text messages. To facilitate interpretation of patients' data and to save nurses' time, information within the application was supportively presented by means of a weekly overview, a composite graph, and a decision support system of colored risk flags. Based on an algorithm of diary questions and (the duration of)

answers, different flags appeared: red flags required immediate action, yellow flags asked to keep an eye, and green flags indicated that no action was needed. In addition to sending text messages, nurses had the opportunity to consult patients by phone when more information was needed or patients specifically asked to do so. In case of pain relief being inadequate, the nurse consulted the pain specialist or the palliative care consultation team for advice. Advices were reported to the treating physician who kept responsibility and decided on follow-up, changes in prescription or other interventions. As a consequence, patients might eventually have been invited to visit the outpatient clinic or, when necessary, a home visit by the nurse might have been scheduled. Nurses had access to all patient data to facilitate patient handover and guarantee continuity of care.

Nurses took part in a 2-h instruction meeting prior to the study, after which they were provided with a paper-copy instruction manual. With approval of the management, nurses were allowed to spend on average 4–5 h a week on monitoring and follow-up

activities. Nurses were advised to log in once every workday and to pay attention to email notifications of red flags or incoming text messages. In case of emergency and when help was needed in the evening, at night, or during the weekend, patients were advised to notify their general practitioner or out-of-hours GP service.

### 2.3. Data collection

#### 2.3.1. Learnability, usability and desirability

During a home visit after four weeks, patients received a 20-item questionnaire to assess learnability (5 items), usability (6 items) and desirability (8 items). The questionnaire was constructed for this study, based on the content of the three categories (Petrie and Bevan, 2009). Usability was defined as 'the extent to which the application could be used by outpatients with moderate to severe cancer pain to monitor their pain and medication intake effectively, efficiently and satisfactorily in everyday practice'. Learnability involved 'the time and effort required for these

**Table 2**  
Diary questions.

<b>Morning</b>			
1. Did you have a good night's sleep?			
Yes   No			
1.1 Did you experience any difficulties with falling asleep?			
Yes   No			
1.2 Did you experience any difficulties with sleeping through the night?			
Yes   No			
<b>Evening</b>			
1. How did you experience your pain today?			
Very good   Good   Not good/Not bad   Bad   Very bad			
1.1 Did the pain prevent you from position and behavior; normal eating habits; contacts with others, other activities; none of the above?			
From position and behavior   From normal eating habits   From contacts with others   From other activities   From none of the above			
1.1.1 During which other activities did the pain bother you?			
...			
<b>Morning and evening</b>			
2. How would you rate your pain at this moment?			
0   1   2   3   4   5   6   7   8   9   10			
3. How many times did you experience breakthrough pain in the last 12 h?			
...			
3.1 How would you rate your pain when you experienced the worst breakthrough pain in the last 12 h?			
0   1   2   3   4   5   6   7   8   9   10			
4. Do you experience any symptoms other than pain at the moment?			
Yes   No			
4.1 Which symptoms other than pain do you experience at the moment?			
Nausea   Vomiting   Obstipation   Tightness of the chest   Problems with sleeping   Scary dreams   Dry mouth   Dizziness   Drowsiness   Sleepiness   Other?			
4.1.1 Which other symptom that is not listed do you experience at the moment?			
...			
5. Has a physician changed your pain medication in the last 12 h?			
Yes   No			
6. Are you satisfied with your pain relief at this moment?			
Yes   No			

**Table 3**  
Educational sessions.

Session 1	Session 2	Session 3	Additional information
<i>Topics</i>	<i>Topics</i>	<i>Topics</i>	<i>Topics</i>
- What is pain?	- Why is pain different every day?	- What can be done about pain?	- Non-opioids
- What is the origin of pain?	- Why do some experience more pain than others?	- How can I best use pain medication?	- Opioids for mild to moderate pain
- What causes pain in cancer?	- Why is it important to treat pain?	- What to do when pain gets worse?	- Opioids for moderate to severe pain
- Why is it important to know the cause of pain?		- Why is it important to describe pain?	- Adjuvant analgesics
		- How do I get a clear picture of the pain?	- Nerve blocks
			- Transcutaneous electrical nerve stimulation
<i>Advices</i>	<i>Advices</i>	<i>Advices</i>	
- Take rest	- Relax with muscle relaxation exercises, breathing exercises, imagination exercises and music	- Use resources	
- Apply cold and heat		- Talk about pain	
- Get massage	- Search for distraction	- Take your own responsibility	

patients to use the application'. Desirability was regarded as 'the extent to which the application was fun and engaging to use for these patients'. Patients rated each item on a 1–5 Likert scale (completely disagree – completely agree); higher scores indicated better learnability, usability and desirability. The questionnaire contained a separate item to assess overall acceptance.

### 2.3.2. Adherence to the application

During the four-week follow-up, data from pain diaries (filled out or not, time of fill out, answers); medication intake (registered or not, time of registration); and educational session (opened or not, time of opening, how often opened) were logged on the server. These data were collected to assess patients' adherence to the application.

### 2.3.3. Experiences of patients

During a home visit after four weeks, single semi-structured interviews (30–60 min) with all patients were held by the researcher in order to gain more insight into the experiences with the application. Topics discussed included: use and acceptance of the application, supportiveness of the application regarding self-management, and technological functioning of the application. Interviews were tape-recorded and concurrently notes were taken.

### 2.3.4. Experiences of nurses

At the end of the study period, a focus group interview (90 min) with all nurses was held by the researcher about the following topics: use and acceptance of the application, supportiveness of the application in monitoring and advising patients, and technological functioning of the application. Interview notes were taken.

## 2.4. Data analysis

### 2.4.1. Learnability, usability, desirability and adherence to the application

Mean scores were calculated for the total questionnaire as well as for the categories and items separately. Adherence to the application was based on completion rates as logged on the server; % completed with concern to pain monitoring, medication monitoring and education. Composite pain intensity scores were calculated from an average of diary ratings across one day. Ratings were derived from the diary question "How would you rate your pain at this moment?"

### 2.4.2. Experiences of patients and nurses

After each interview notes were immediately reviewed and initial reflections were added. Then audiotapes of the semi-structured interviews were re-listened several times and notes were amended in order to ensure an accurate and thorough reflection of the interviews. All notes were discussed with the co-authors after which necessary changes were made. Notes were organized and summarized into predefined categories and illustrative quotes were added (Halcomb and Davidson, 2006). No tape-recording of the focus group interview was available. A member

check was performed to ensure that the notes properly reflected the interview.

## 3. Results

Thirteen patients provided written consent. Shortly after the initial home visit, two patients decided to withdraw. One patient (male, 71 years) doubted application use and the other patient (male, 79 years) reported being too ill.

Eleven patients (5 males, 6 females) eventually completed the study and were aged between 20 and 76 (M 53, SD 15) years. Patients were diagnosed with cancers of the head and neck ( $n = 4$ ), breast ( $n = 2$ ), central nervous system ( $n = 2$ ) or other ( $n = 3$ ). All patients were prescribed pain medication 'around the clock' and 'as needed', more specifically non-opioids and strong opioids ( $n = 5$ ); along with adjuvant analgesics ( $n = 4$ ); or adjuvant analgesics only ( $n = 2$ ).

Three registered nurses specialized in pain and palliative care (1 male, 2 females) were aged between 50 and 54 (M 52, SD 2) years. Nurses had 10–15 (M 13, SD 3) years of experience in caring for outpatients with cancer pain while working within a palliative care consultation team.

### 3.1. Learnability, usability and desirability

The overall mean score as well as the mean score of the categories and items separately are presented in Table 4. Scores suggested that patients quickly learned how to manage the application, easily used the different components, and liked to work with the application. The item "I would recommend the application to other patients" gives an impression of the overall acceptance.

### 3.2. Adherence to the application

Average completion rates were 76.8% for pain monitoring, 50.4% for medication monitoring and 100% for education.

Patients completed, on average, 43 (SD 12.4) out of 56 diaries during the study period. Fig. 1 shows composite pain scores as derived from the diaries. These representations are illustrative for the clinical course of pain as experienced by participating patients; some indicated extreme pain with significant fluctuations, others experienced a constant change in average pain, still others reported moderate and fairly stable levels of pain. Important to notice in terms of feasibility is that most patients kept monitoring regardless of how they felt. Reasons for not filling out diaries included not being in time given the time frame or not being in the mood for a day. Extra pain intensity scores, to show breakthrough pain or the effect of medication taken, had a mean frequency of 6.8 (SD 4.9) during the study period. Not reporting extra scores was related to the absence of breakthrough pain, the unwillingness to report all day and the unawareness of the option to report extra scores.

Monitoring of 'around the clock' medication ranged from 0.0% to 96.4%. To illustrate, for patients who only had to change fentanyl

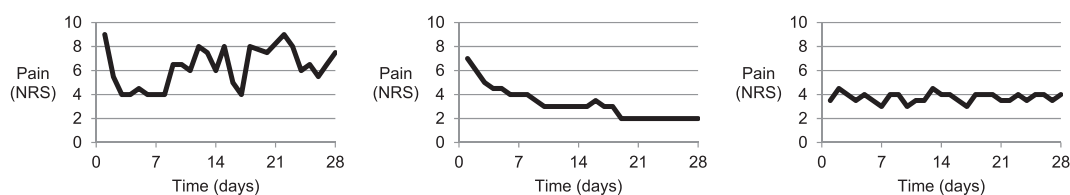


Fig. 1. Average daily pain intensity scores of three patients to illustrate the clinical course of pain as experienced by participating patients.



**Table 4**  
Mean (SD) learnability, usability and desirability scores.

<b>Learnability</b>	<b>4.8 (0.4)</b>
It was easy to learn how to use the application.	4.9 (0.3)
I think the application was very complicated. <sup>a</sup>	4.6 (0.9)
I needed a lot of help to learn using the application. <sup>a</sup>	4.9 (0.3)
I needed to learn a lot before I could use the application. <sup>a</sup>	4.9 (0.3)
I am confident that I used the application in the right way.	4.4 (1.2)
<b>Usability</b>	<b>4.8 (0.5)</b>
I could easily report my pain and adverse effects with the application.	4.8 (0.6)
I could easily report my medication intake with the application.	4.8 (0.6)
I could easily recall my pain scores and medication intake with the application.	4.5 (0.9)
I understood the information about my pain scores and medication intake.	4.7 (0.6)
I could easily search for information about pain with the application.	4.8 (0.4)
I could easily leave a message for the nurse via the application.	4.6 (0.6)
<b>Desirability</b>	<b>4.6 (0.4)</b>
I liked using the application.	4.9 (0.3)
I liked using the pain diary.	4.7 (0.6)
I liked using the medication overview.	4.6 (0.7)
I liked using the educational sessions.	4.1 (0.7)
I liked using the contact function.	4.3 (1.0)
I liked the idea that the nurse monitors my pain, adverse effects and medication use.	4.8 (0.4)
I liked the idea that my treating physician keeps track of my pain treatment.	4.8 (0.4)
I liked the idea that my pharmacist cooperates regarding my medication overview.	4.7 (0.4)
<b>I would recommend the application to other patients.</b>	<b>4.8 (0.4)</b>
Total	4.7 (0.3)

<sup>a</sup> Negatively-keyed items were reversed-scored before data analyses.

patches once every three days, and forgot or were not able to register these changes in time, completion rates were low. 'As needed' medication was registered between 0 and 80 times. Some patients did not use 'as needed' medication, others were not aware of the option to report it.

All patients completed the educational sessions; seven patients re-read some of the topics, more specifically the topics about what is pain, what causes pain in cancer, why is pain different every day, and non-opioids and opioids.

On average, patients and nurses interacted on 11 (SD 4.8) out of 28 days via text messages. Both patients and nurses started conversations with various content. Patients often elaborated on their diary answers; asked questions about side effects; and explained why they were not able to monitor. In turn, nurses mostly used these conversations to make agreements on what to monitor and when to have contact; to acquire more information if there was a need to do so based on diaries or medication intake; and to advise patients about prescribed pain medication. Aside from pain and pain medication, a patient's good day ("The sun is shining, I'm doing the laundry.") and "Congratulations with your wife's birthday!") or a bad test result ("The scan was not that good today, on the liver a small spot was seen." and "Because of the results from last Monday, metastasis and surgery, I needed some distraction.") were also discussed.

### 3.3. Experiences of patients

#### 3.3.1. Use and acceptance of the application

Semi-structured interviews revealed that patients considered the application clear and simple. Navigating worked well and the application required limited effort and energy. Patients made most use of the diary and the medication overview and less use of the opportunity to reread education. Patients experienced comfort using the application and the iPad. Registering and monitoring with the application was seen as "fun to do" (P08) and as "a positive challenge" (P06), without making patients focused on their pain.

*"I concentrate on pain only when completing diaries and registering medication, that's all." (P05)*

Completing pain diaries twice-daily was feasible for patients. Diary questions were understandable and considered nearly complete; monitoring pain in different body locations was not possible and an open question to better describe pain and adverse effects was lacking. Two patients indicated that they got a little bit bored, because diary questions were the same every day. Others acknowledged that alike diaries were good, because variation would unnecessarily make things difficult. Medication overviews for 'around the clock' medication were clear. Registration of 'as needed' medication seemed less obvious. Almost all patients indicated that not incorporating co-medication and medication for comorbidities in the overview was a missed opportunity. All patients finished the educational sessions. Information was partly new, dosed well and easy to understand.

*"When the physician prescribes pain medication.. patients just take it. I think it is interesting to learn, to know at least what's going on." (P12)*

The home visit with pain assessment and instructions about the application was highly appreciated. Some patients looked for information once more, though most paper-copy manuals were returned unopened. Patients liked having seen faces and knowing how nurses respond.

*"It has a reassuring effect, someone looking over your shoulder every day. It is meaningful and you really can't do anything wrong." (P08)*

#### 3.3.2. Supportiveness of the application regarding self-management

Patients emphasized the added value of the application in self-managing their pain and pain medication. The medication overview was supportive because registered medication was visible. Especially in cases where patients tended to forget what medication was taken. The 4-h time frame to encourage on time intake and registration was effective for some and less effective for others. Patients' experiences with the reminders were different as well. Some patients took medication based on the clock, for them visual and sound reminders were useful. Others took medication based on

their daily routines or pain experiences and found the reminders less useful. The graph provided insight into pain trends and activated patients to organize medication differently.

*“Due to the medication overview and the graph, we concluded that the time between medication in the morning and the afternoon was too short and between the afternoon and evening was too long. To better control the pain we adapted the schedule, it worked!” (P04)*

To get better insight into trends it would have been helpful if patients could review completed diaries and medication overviews. Moreover, a wider graphical view would enable patients to compare days, weeks or even months.

*“It is helpful when the physician calls. I look at the graph to get a good picture. It also gives justification that I’m not exaggerating my pain.” (P06)*

Asking patients for the most valuable component resulted in different answers. Contact with the nurse and the insight from the graph were often reported. Patients also mentioned the educational sessions, sound reminders and the collaboration between nurses and treating physicians. One patient even concluded, *“Not a single component, but the combination of components is valuable” (P08).*

### 3.4. Technological functioning of the application

The most important technological problems experienced by patients included not receiving a diary, not being able to register medication, not having an up-to-date graph and not being able to access knowledge; these problems were caused by connectivity and software issues. Because opportunities to register extra pain intensity scores or extra medications were not often used, these need to be made better visible or better explained in the instructions.

*“This intervention makes remote health care personal, it breaks down barriers.” (P05).*

### 3.5. Experiences of nurses

#### 3.5.1. Use and acceptance of the application

The instruction meeting before the start of the study was clear and the timing was right. Nurses agreed on the abstractness at first, though their application became clearer over the course of the study. Sometimes diary answers were ambiguous. In case a patient had a difficult night’s sleep, this could be caused by pain but also by many other factors. The application lacked room to write down the initial pain assessment; something that was necessary to actually facilitate patient handover and guarantee continuity of care.

#### 3.5.2. Supportiveness of the application in monitoring and advising

Critical remarks were made regarding the identification of tasks and responsibilities. The application provided nurses with risk flags, yet how to act accordingly was up to the nurses based on their expertise and judgment. Especially diary answers or text messages that possibly, though not necessarily, related to cancer pain caused difficulties.

*“At times I’m not sure.. What is allowed? When do I intervene? Should I focus only on pain? Also when complaints are not caused by pain or pain medication, though influence pain?” (N01)*

*“Important as well, what do patients wish for? What does the treating physician want? When do I interfere and take over care?” (N03)*

As a consequence nurses acknowledged differences in their response to patients and situations. In particular, the one had telephone contact more often and the other visited patients at home more frequently. Based on their experiences during the study, however, nurses would prefer more uniformity for the sake of both clinical and research practice.

*“There is need for a guideline on when, how and in what order, nothing conclusive, though some recommendations that provide guidance.” (N02)*

Independency of patients was another somewhat related topic that was extensively discussed. On the one hand, advices from the nurse might have made patients more dependent than necessary; on the other hand, these advices might have ensured that patients could move on and made them in fact less dependent.

For nurses to perform their monitoring and advisory role well, collaboration with the treating physician, general practitioner and pharmacist was crucial. Nurses emphasized the importance of communication and commitment of all parties involved in case of a large-scale evaluation in the future.

#### 3.5.3. Satisfaction with the application

Nurses were enthusiastic about the application and considered their new way of working as a real challenge. It brought about new tasks, different responsibilities and unknown technologies; something that needed a little time to get used to. The expectation that monitoring and advising would improve pain control in these patients showed nurses’ trust in the intervention.

#### 3.5.4. Technological functioning of the application

Nurses came up with some points for improvement that would have facilitated their tasks: graphs needed to contain more information to see trends and diary questions needed to be adapted (“Did you experience any difficulties with falling asleep caused by pain?”; “Did you experience any difficulties with sleeping through the night caused by pain?”) or added (“Do you want the nurse to contact you based on the diary answers that you have given?”).

## 4. Discussion

Small-scale feasibility evaluation in everyday life is a crucial first step in the development and testing of complex interventions before use in clinical and research practice (Craig et al., 2013). The current study provides insight into the feasibility of a multi-component technology supported self-management intervention delivered by nurses specialized in pain and palliative care to out-patients with cancer pain in everyday practice. Patients learned to use the application quickly, practiced tasks easily and liked to work with the application. Nurses had to get acquainted to their new way of working, though were positive about the possibilities of the intervention specifically and the idea of self-management support in general.

Different patients are in need of different support in self-managing their health (Trappenburg et al., 2013; van Houtum et al., 2013). Multicomponent interventions are recommended (Kravitz et al., 2011; Lovell et al., 2014). Patients who practice effective self-management will select the type of support that fits with their wishes and needs at a given point in time and in a given situation (Barlow et al., 2002). Patients in this study valued and

made use of different components, emphasizing the need for a multi-component self-management approach: it better suits the reality of living with cancer pain. Aside from the multicomponent nature, counseling of the nurses and the collaboration of nurses with treating physicians was well received by patients, which emphasizes the need for embedding of self-management within routine multidisciplinary care practice (Bennett et al., 2009). When self-management support is challenging and further complicated by comorbidities and polypharmacy, integration of patient self-management and professional care is advisable.

Although health professionals are often not educated to support patients in self-management, nurses specialized in pain and palliative care are very well able to make substantial contributions based on their knowledge, expertise and focus on patients' daily living (Courtenay and Carey, 2008). The uptake of self-management and self-monitoring forms part of a process of change regarding roles and expectations (Segar et al., 2013; Taylor et al., 2014). In accepting the intervention, nurses gave up parts of their present role, previously delivered face to face, to remote healthcare technology, but also to patients on which they had to rely on for information, and to treating physicians who kept responsibility for follow-up. Nurses' confidence and trust was instilled by training on technological aspects; by getting to know patients during home visits; and by making plain agreements with all those concerned.

Technical problems were taken into considerations during rework, as well as patients' and nurses' suggestions for improvement. As connectivity issues were mostly related to the software or patients' rural place of living, adjustments in synchronizing data and local storage of data were the answer to most technical problems. These adjustments made the application for patients more stable and less dependent on the continuous availability of Internet. In response to patients' experiences, the look and feel of the application was optimized and the task to reply shortly to all text messages from patients was added to the nurse instructions. Patients' instructions were completed with the task to use the extra pain intensity score and to register 'as needed' medication taken. Based on the experiences of nurses, arrangements were made on how to respond to patients and situations. Diary questions were adapted and room was created within the application to write down the initial pain assessment.

Because simplicity of the applications is highly important, also taking into account the target population, not all ideas could be incorporated. The addition of questions about pain in different body locations and other symptoms makes the diary long; the review of completed diaries and medication overviews makes the application more complex; the monitoring of medication for comorbidities requires nurses to have different knowledge and expertise. Not incorporating these changes might limit clinical use of the intervention, though for the intended aim of this project these improvements were thought to be less relevant. Nevertheless, with a broader rationale and a somewhat different patient population in the future, these functionalities are worth considering and relatively easy to incorporate.

Some limitations of this study need to be acknowledged. First, text messages to the nurses revealed that patients were not always able to register their medication intake. Reasons mentioned included the 4-h time frame, connectivity issues, not taking the iPad with them when they left home or simply just that they forgot to register. Consequently, percentages summarize medication monitoring, but not medication adherence. Second, the small convenience sample of patients could have introduced selection bias. The study was first and foremost conducted to explore feasibility of the intervention. Patients in poor health or experiencing extreme pain might therefore not have been included. However, with a small sample of patients who differed in demographic and

clinical characteristics an attempt was made to get a fairly complete impression. Last, follow-up activities were not recorded. Data collection on the number of times nurses consult patients by phone and collaborate with the treating physician, pain specialist or the palliative care consultation team needs to be included in future evaluations.

## 5. Conclusions

The intervention under study provided patients with information and instructions; enabled them to monitor their pain and side effects as well as and medication intake; allowed them insight and feedback on their situation; and created a supportive and collaborative environment. Findings demonstrate that patients with moderate to severe cancer pain are well able to take up this intervention. The need for self-management approaches to include multiple components is endorsed, as patients in this study valued and made use of different intervention components. Moreover, monitoring and advising by nurses as well as their collaboration with treating physicians impacted patient experiences positively, which emphasizes the importance of involving nurses to deliver self-management support as well as integrating these interventions into routine clinical practice. Findings also revealed important information with regard to feasibility and technological functioning of the intervention as well as recruitment and methodological issues for research practice. Once again, small-scale evaluation in everyday life turned out to be extremely important; despite extensive evaluation by the development team unexpected issues and situations still occurred. Clinical effectiveness with regard to pain intensity and quality of life still needs to be evaluated (Hochstenbach et al., 2015), though the intervention is believed to impact both patient self-management as well as pain management by health professionals.

## Conflict of interest

The authors declare that there are no conflicts of interest.

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