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Co-creative development of an eHealth nursing intervention: Self-management support for outpatients with cancer pain

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Abstract

Introduction Co-creative methods, having an iterative character and including different perspectives, allow for the development of complex nursing interventions. Information about the development process is essential in providing justification for the ultimate intervention and crucial in interpreting the outcomes of subsequent evaluations. This paper describes a co-creative method directed towards the development of an eHealth intervention delivered by registered nurses to support self-management in outpatients with cancer pain.

Methods Intervention development was divided into three consecutive phases (exploration of context, specification of content, organisation of care). In each phase, researchers and technicians addressed five iterative steps: research, ideas, prototyping, evaluation, and documentation. Health professionals and patients were consulted during research and evaluation steps.

Results Collaboration of researchers, health professionals, patients, and technicians was positive and valuable in optimising outcomes. The intervention includes a mobile application for patients and a web application for nurses. Patients are requested to monitor pain, adverse effects and medication intake, while being provided with graphical feedback, education and contact possibilities. Nurses monitor data, advise patients, and collaborate with the treating physician.

Conclusions Integration of patient self-management and professional care by means of eHealth key into well-known barriers and seem promising in improving cancer pain follow-up. Nurses are able to make substantial contributions because of their expertise, focus on daily living, and their bridging function between patients and health professionals in different care settings. Insights from the intervention development as well as the intervention content give thought for applications in different patients and care settings.

Keywords Cancer pain, outpatients, self-management, nursing, eHealth, intervention development

Introduction

Developing, piloting, evaluating, reporting and implementing a complex intervention can be a challenging and lengthy process (Craig et al., 2013). Although all these stages are regarded as equally important, the reporting of intervention development all too often receives only scant attention (van Hecke et al., 2011; van Meijel et al., 2004). The steps that were taken, the methodologies that were applied, the collaboration of researchers and other experts, the involvement of health professionals and patients, the questions and problems that were identified, and the answers and solutions that were considered; all information that is essential in providing justification for the ultimate intervention and crucial in interpreting the outcomes of evaluations (Hoddinott, 2015). Lack of reporting also prevents others to reproduce and improve interventions based on new insights or to translate and transfer interventions to different patients and care settings. On that account, the present paper describes a co-creative method directed towards the development of an eHealth intervention delivered by registered nurses to support self-management in outpatients with cancer pain.

Background

As cancer pain represents one of the most prevalent and distressing symptoms (Klepstad et al., 2005; van den Beuken-van Everdingen et al., 2016), adequate pain assessment and management are critical to patients' functioning and quality of life (Wool & Mor, 2005). Regardless of available treatment though, pain in many patients is still insufficiently controlled. Inadequate cancer pain management in the outpatient setting can be attributed to barriers on different levels (Jacobsen et al., 2009; Lockett et al., 2013; Oldenmenger et al., 2009). On the organisation level, fragmentation of care due to different health professionals in different healthcare settings complicates coordination and continuity of care (Schumacher et al., 2014). Particularly in the outpatient setting, health professionals are unable to monitor pain and provide adequate follow-up. On the health professional level, pain is not structurally and thoroughly discussed during consultations, due to a lack of time and knowledge (Kimberlin et al., 2004). Consequently, health professionals' are reluctant to prescribe opioids and only few patients are referred to pain or palliative care services. On the patient level, there is reservation to report pain because patients do not want to complain and keep the focus on the cure (Jacobsen et al., 2009). Insufficient knowledge causes misconceptions and fears about adverse effects, addiction, and risk of tolerance that, in turn, negatively interfere with patients' medication intake (Miaskowski et al., 2001). Much as advances are made regarding the effectiveness of cancer pain interventions, the optimal content and combination of components are still to be determined (Koller et al., 2012).

Recommendations to overcome barriers include a multidisciplinary approach that promotes collaboration between different health professionals and ongoing assessment of pain with regular follow-up appointments (Brink-Huis et al., 2009). Moreover, patient education as well as pain and medication diaries are suggested to ensure realistic expectations and appropriate medication use (Kwon, 2014). In order to address these recommendations, active patient involvement seems a prerequisite. Because different patients require different support (Barlow, 2002), multi-component interventions are proposed for self-management. Healthcare technology provides an excellent means for the integration of these different components, as it allows interventions to be tailored to the individual patient and the situation for which support is required. In addition, healthcare technology is particularly convenient for connecting patients at home with health professionals in primary or hospital care practice (Dickinson et al., 2014). In this regard, remote self-monitoring offers both patients and health professionals more accurate and timely information to improve follow-up (Meystre, 2005). Healthcare technology has been successfully implemented before to support symptom control (McCann et al., 2009), to improve patient-health professional communication (Dy et al., 2011), and to allow greater access to healthcare services (Hennemann-Krause et al., 2015).

Although promising for multi-component interventions, healthcare technologies need embedding into routine clinical practice in order to be accepted and successfully implemented (Taylor et al., 2015). For this purpose, nurses can perform a coordinating role along the care process and across care settings (Courtenay & Carey, 2008). With their expertise and focus on patients' daily living, nurses are able to make substantial contributions to day-to-day pain management in the outpatient setting (Schumacher et al. 2002). The important role of nurses in delivering self-management interventions has been demonstrated with positive outcomes (Vallerand et al., 2011).

Methods

Development approach

Based on key principles of user centered design (Gulliksen et al., 2003; van Gemert-Pijnen et al., 2011), intervention development was carried out by a multidisciplinary team in an iterative and incremental process. Health professionals and patients were actively involved; their context as well as their wishes and needs guided the process early and continuously. Intervention options were explained in easy-to-understand language and prototypes were used to support the creative process, elicit requirements, and visualise ideas and solutions. Integration of the intervention into routine clinical practice was organised in parallel and evaluations were performed in real life as much as possible.

Development team

Different perspectives were considered important to provide multiple views on problems and solutions. On that account, three researchers and three technicians with different expertise (cancer pain and palliative care, e-health and self-management, software development and design) collaborated in the translation of conceptual ideas into clinical practice. Ten health professionals working in primary and hospital care as well as five patients with current or past cancer pain were consulted during the development process. Decisions about the content and format of the intervention were based on their experiences and opinions, while remaining within practical and financial boundaries. Ethical principles that are outlined in the Dutch "Medical Research Involving Human Subjects Act" were followed throughout the development process (CCMO, 1998).

Development process

A review of the literature provided helpful guidance for identifying roles, tasks and responsibilities of self-management by patients and self-management support by health professionals. Theories about self-management for chronic conditions in general (Barlow et al., 2002; Lorig & Holman, 2003; Richard & Shea, 2011) and evidence about (educational) interventions for cancer pain specifically were taken into account (Allard et al., 2001; Bennett et al., 2009; Devine, 2003; Koller et al., 2012). To tailor the intervention to the characteristics of outpatients with cancer pain, the applicability of different components was screened and a selection was made. Table 1 outlines the conceptual framework with a description of the selected components, including information, skills, insight, self-efficacy, and supportive environment.

The development process consisted of three consecutive phases: exploration of context, specification of content, and organisation of care. As presented in Figure 1, an iterative cycle consisting of five steps was addressed in each of these phases: research, ideas, prototyping, evaluation, and documentation. User and technical requirements were formulated, specified, and prioritised during the development process.

Phase 1 - Exploration of context

Document analysis (guidelines, case reports) and semi-structured interviews with ten health professionals (two registered nurses specialised in pain and palliative care, a home care nurse, two oncologists, a pain specialist, a general practitioner, and three pharmacists) and two outpatients conveniently sampled by a pain specialist (a 64-year old male with squamous cell cancer and a 73-year old female with breast cancer) were performed to collect information about patient characteristics, usual care, and intervention needs (step 1). Information was discussed with the development team in two brainstorming sessions. Personas (fictitious characters that represent the patient population) and scenarios (activities, perceptions and desires from these personas in

daily life) were used to explore solutions (step 2). Paper drafts of the applications for patients and nurses were made (step 3) and evaluated during a development team meeting and separately with two researchers. Evaluations were observed and notes were taken by the main researcher (step 4). Data were documented and a first draft of the user requirements was made (step 5).

Phase 2 - Specification of content

Document analysis (protocols for pain anamnesis, education materials) and three consultation sessions with a multidisciplinary palliative team provided input for the content of the intervention in terms of what to monitor, how to measure pain, how to assess medication use, and how to provide feedback (step 1). Ideas were discussed in two brainstorming sessions with the development team (step 2) and results were processed in a paper-based prototype for patients (step 3). This prototype was evaluated in three development team meetings. During these evaluations notes were taken by the main researcher (step 4). Data were processed and user requirements were formulated more precisely (step 5).

Phase 3 - Organisation of care

Semi-structured interviews from the first phase provided input for how care had to be organised for the embedding of the applications into routine clinical practice (step 1). During three brainstorming sessions, the development team considered division of roles, tasks and responsibilities among the involved health professionals (step 2). Thoughts were summarised in a software-based prototype of the patient application and in an algorithm for the nurse application (step 3). Usability and desirability of this prototype were tested with three outpatients conveniently sampled by a pain specialist (a 59-year old male with prostate cancer, a 53-year old female with neurosarcoma, and a 60-year old female with former breast cancer). This individual 1-hour session at the hospital or at the patients' home consisted of tasks, a semi-structured interview and a questionnaire. The thirteen tasks were scored on a 5-point scale, ranging from 1 (very easy to complete) to 5 (very difficult to complete), while thinking aloud. Interview questions addressed understanding and presentation of information. The questionnaire listed 118 words with positive and negative connotations of which patients were asked to select and explain all words they thought fit the application (Benedek & Miller, 2002). Evaluations were observed and audiotaped by the main researcher. Descriptive statistics were used to explore task performance. Interview notes were reviewed, initial reflections were added, and audiotapes were re-listened to uncover usability and desirability issues (Halcomb & Davidson, 2006). To examine external validity, all findings were discussed with the development team (step 4). Data were documented and together with two software engineers the final user requirements were translated into technical requirements (step 5).

Results

Development process

Phase 1 - Exploration of context (Month 1-3)

This first phase focused on patient characteristics, usual care, and intervention needs. Guidelines and case reports uncovered a variety in pain treatment. Differences in medication names, dosages, and routes of administration as well as prescription changes at short notice, would require flexibility of the medication monitoring method. Health professionals emphasised the importance of measuring pain frequently and choosing a monitoring method that was applicable outside the research setting. Patients revealed that pain reference scores facilitated pain assessment, reminders were beneficial in taking medication (on time), and frequent communication with a nurse was appreciated. Both health professionals and patients acknowledged that the collaboration of different health professionals in the home setting deserved attention (steps 1-2). The sketches of the application for patients consisted of the following components: pain diaries, medication overview, trends and feedback, pain information, and text messages. For nurses the sketches included an application with pain diaries, medication intake, data summarised in graphs, and text messages (step 3). Important themes of the evaluation were frequency of self-monitoring, content of diaries and medication overviews, formulation of feedback, and follow-up by the nurse (steps 4-5).

Phase 2 - Specification of content (Month 4-5)

During the second phase, attention was directed to the content of application components. A short pain diary was designed based on present-day pain anamnesis. In the selection of questions, the multidisciplinary palliative team aimed at providing nurses with adequate information without burdening patients too much. The diary that was presented to patients twice daily used skip patterns, where affirmative answers on particular questions resulted in sub questions to obtain more information. Patients also needed to be able to score extra pain intensity optionally, to report (the effect of medication on) breakthrough pain and to provide a better reflection of pain over time. The numerical rating scale (NRS) was chosen to measure pain intensity, because of its usefulness, proven psychometric properties and sensitivity to change in patients with cancer (Hjermstad et al., 2011). Strategies that have proven to contribute to a better diary response were incorporated in the intervention, including a paper-copy manual, visual and sound reminders, contact, and feedback (Morren et al., 2009). Pain medication was presented in a personalised day schedule with 'around the clock' medication per point in time and 'as needed' medication. A restricted 4-hour time frame was meant to motivate patients to take and register their pain medication in time. On time intake affects pain control; on time registration enables accurate feedback. Furthermore, medication icons were added to support patients visually. When providing

feedback to support self-management, different parameters in the moment and during longer periods, have to be combined. Therefore, automatically generated feedback to patients was restricted to a graph with pain intensity scores and medication intake moments, whereas the nurse should provide detailed textual feedback. Existing education about pain management was updated and divided into three sessions (steps 1-2). The paper-based prototype for patients consisted of an application with four components: diary, medication, knowledge, and contact (step 3). Important themes of the evaluation were patient expectations regarding responses and actions and, allied to that, roles, tasks and responsibilities of involved health professionals (steps 4-5).

Phase 3 - Organisation of care (Month 6-9)

Integrating the applications in a structural organisation of care was the focus of the final phase. For obtaining an accurate overview of a patient's medication, the involvement of the pharmacist was considered. To facilitate interpretation of patients' data and to save nurses' time, supportive presentation of information within the nurse application was thought to be conditional. Together with the multidisciplinary palliative team, consensus was reached about a decision support system that consisted of an algorithm of diary questions, answers, and coloured risk flags (Table 2). These flags turned red, yellow, and green depending on the presence and duration of diary answers. The development team defined the tasks and responsibilities of the nurse, treating physician, general practitioner, and pharmacist (steps 1-2). The software based prototype for patients included a mobile application with four components: diary (questions and graph), medication (overview and day schedule), knowledge (sessions and topics), and contact with the nurse (history and new text messages). An already existing web application for nurses was extended with a composite graph of pain and medication data and the possibility to enter medication (step 3). Three patients evaluated usability and desirability of the patient application. After a few minutes of exploration, patients were able to navigate with little to no guidance and accomplished the tasks in less than fifteen minutes. Task difficulty was rated as 'very easy' by most patients. Table 3 includes the tasks and corresponding difficulty ratings. As revealed during the interviews, usability issues concerned inconsistent terminology, ambiguous icons, small character sizes, unchangeable graphs, and absent read aloud functionality. Discussion of the questionnaire words revealed that patients experienced the application as easy to use because of the few components and clear structure. Graphical feedback was thought to be stimulating and supportive, while the digital character of the application was believed to save time and effort. Patients felt that the application would help to adequately organise pain medication and control pain better. No negative formulated words were chosen (steps 4-5). Table 4 contains the final user requirements, as derived from the three phases.

Content of the intervention

The development process resulted in a home visit, a mobile application for patients, a web application for nurses, and follow-up activities. Both applications are to be embedded in routine clinical practice. The mobile application runs on an iPad 2 with Internet connection; the web application is accessible from each computer with a browser. Patients and nurses need log in information to gain access to the applications. Monitored data are saved on secured servers that comply with present rules and regulations.

Approval is sought from the treating physician and information is given to the general practitioner prior to the intervention. After contacting the pharmacist, the nurse enters pain medication details (name, route of administration, dosage, and timing) in the web application, while taking into account patients' daily routines. A second nurse performs a check and activation procedure, after which entered pain medication is visible in the mobile application.

Home visit

The intervention starts with a home visit, during which nurses perform a pain anamnesis, check pain medication, and provide information of which the content corresponds with the education within the application. Patients receive instructions about the iPad and the mobile application, after which they receive a paper-copy manual.

Mobile application for patients

Patients enter the application via a home screen (Figure 2). Every morning and evening they fill out a pain diary with questions about their pain, adverse effects, interference of pain with activity or sleep, and satisfaction with pain treatment. In between these diaries, registration of extra pain intensity scores is optional. Moreover, the application includes a personalised day schedule. In accordance with this schedule, patients are requested to register intake of 'around the clock' medication and 'as needed' medication in time. All pain intensity scores are presented in a graph together with the medication intake moments. The graphical information provides insight into pain patterns over time and the possible influence of medication intake and daily routines. Patients receive education about pain causes, pain treatment, recognition of symptoms that require action, and methods that patients themselves can implement to control pain. This education is divided into three sessions; each session consists of several topics. After completion of these sessions, those who want to know more can access additional information about analgesic and alternative treatments. In case of questions, patients have the opportunity to send text messages to the nurse. Patients are reminded to complete diaries, take medication, read education materials, and check text messages from the nurse by visual and sound notifications.

Web application for nurses

The nurse monitors and analyses the patients' pain situation once every workday. In addition to the composition of the medication overview, the application for nurses includes completed pain diaries, information about scheduled and actual medication intake, composite graphs, and a text message function (Figure 3). The use of coloured flags supports nurses in their monitoring tasks. Red flags require immediate action, yellow flags ask to keep an eye, and green flags indicate that no action is needed. In case of red flags or incoming text messages, nurses receive email notifications. Nurses consult patients by text messages or phone.

Follow-up activities by nurses

When necessary, and also on a regular basis, nurses inform the treating physician about the patient's situation. In case of pain relief being inadequate, nurses consult the pain specialist or the multidisciplinary palliative team for advice. Advice is then reported to the treating physician who decides on follow-up, changes in prescriptions or other interventions. As a consequence, patients might eventually be invited to visit the outpatient clinic or, when necessary, a home visit by the nurse might be scheduled. Nurses have access to all patient data to facilitate patient handover and guarantee continuity of care.

Discussion

Assessment and management of cancer pain continue to be a common challenge in outpatient care. Actively involving patients by self-management support could provide answers to overcoming current barriers. The present paper describes a co-creative method directed towards the development of an eHealth intervention delivered by registered nurses to support self-management in outpatients with cancer pain. The development process, having an iterative character and including different perspectives, delivered promising results. The integration of patient self-management and professional care by means of healthcare technology facilitates partnership with shared responsibilities, offers valuable insights that complement usual care, and accommodates subsequent consultations or referrals.

Intervention development was based on user centred design to ensure an intervention fit with patients' and nurses' wishes, needs, and daily practices and thereby to increase implementation success (Shah & Robinson, 2007). The collaboration of researchers, health professionals, patients, and technicians was positive though challenging at times due to differences in perspectives. Researchers usually work with a framework based on previous research and conceptual ideas. Health professionals and patients then introduce a more practical view on problems and solutions. In the end, the

technical perspective brings in technological possibilities and restrictions. Taking all the perspectives into account, from research ideas to user requirements to technical functionalities, sometimes requires flexibility and concessions (Vermeulen et al., 2014).

Intervention content was derived from self-management supporting components that were considered important for patients in general (Barlow et al., 2002; Lorig & Holman, 2003; Richard & Shea, 2011) and that were selected specifically for outpatients with cancer pain. The present intervention provides patients with education to improve knowledge and understanding. Important skills for patients to implement, such as pain and medication monitoring, making appropriate decisions, and carrying out subsequent actions, are continuously encouraged by means of pain diaries, medication overviews, and graphical feedback. Being looked after by nurses needs to enable patients to practice their skills and to become more self-efficacious. Collaboration of nurses with the treating physician should further contribute to this supportive environment. Previously applied interventions focused mostly on information provision and skills instruction (Bennett et al., 2009; Koller et al., 2012; Lovell et al., 2014). Even if monitoring was part, interventions often served pain management by professionals, not self-management by patients (Kim et al., 2013; Kroenke et al., 2010; Wilkie et al., 2010).

Some limitations of the development process need to be addressed. First, the involvement of patients was restricted to the start of the first phase and the evaluation in the last phase. Ideally, patients would have been involved more frequently. Nevertheless, health professionals experienced in pain and palliative care and familiar with patient's home situation, articulated patients' ideas and experiences. Second, the development team was unable to implement all suggested changes. Patients, for one, preferred to monitor not just pain medication but also co-medication and medication for co-morbidities. However, practical and financial constraints required prioritising. After proven effective, the intervention could be optimised and serve more needs. Third, formative evaluations focused on the usability of the application for patients in terms of navigation, content, and satisfaction. Day-to-day feasibility and practical implications have yet to be explored, for which a small-scale study will be performed (Hochstenbach et al., 2016).

Conclusion

As advances in nursing practice and research are pursued, nurses are encouraged to adopt complex intervention thinking. A co-creative method, as implemented here, will help nurses to actually bring thoughts into action. An open and iterative process encourages to think outside the box and consider less obvious solutions. At the same time there is room to involve health professionals and patients in order to create interventions that actually suit their daily routines both at home and in the clinical setting. Insights from the intervention development as well as the intervention content give thought for applications in different patients and care settings.

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Conflicts of interest

Conflicts of interest: None.

Figures and tables

Figure 1. Iterative cycle of five steps that were performed in each of the three phases

Table 1. Conceptual framework of intervention components

Table 2. Algorithm of diary questions, answers, colored risk flags and follow-up questions

Table 3. Basic tasks and difficulty ratings of the usability evaluation

Table 4. User requirements as derived from the three phases

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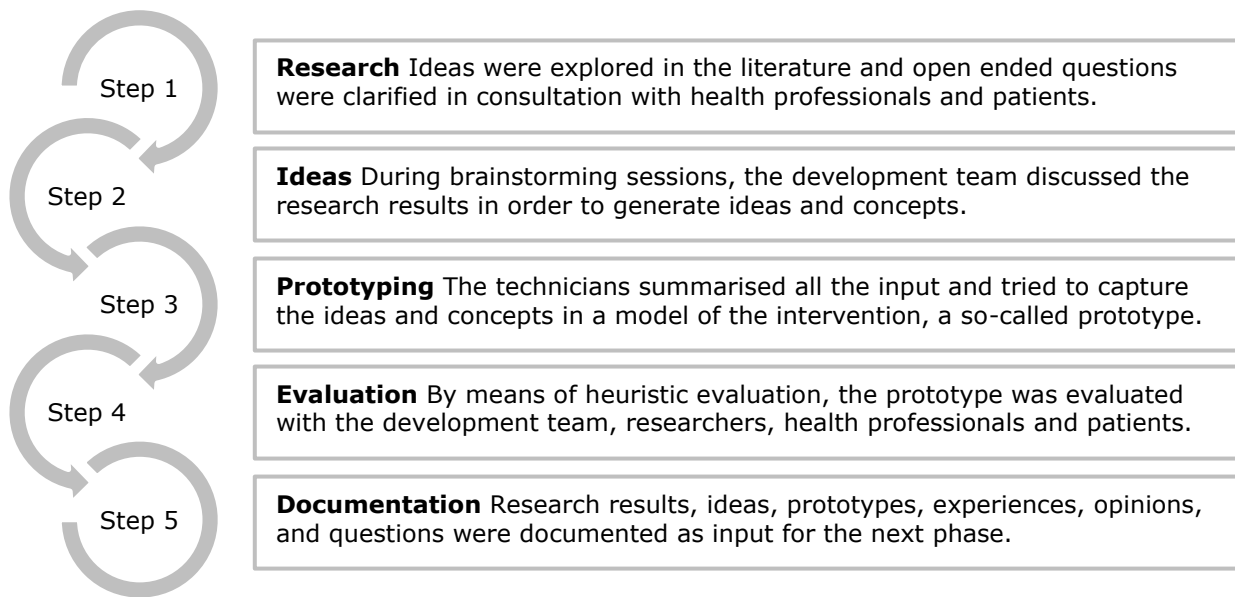


Figure 1. Iterative cycle of five steps that were performed in each of the three phases

Table 1. Conceptual framework of intervention components

Component	Tailored to the characteristics of outpatient with cancer pain
Information (Lorig & Holman, 2003)	Patients need knowledge about cancer pain, its treatment, and the factors that cause variations in pain levels including medication intake, adverse effects, daily activities, psychological status, and support.
Skills (Holman & Lorig, 2004)	Skills important for patients include the capability to self-monitor pain progress, use medication properly, contact health professionals when needed, adjust behaviours, and cope with consequences of pain.
Insight (Wilde & Garvin, 2007)	Insight into their own situation is a prerequisite to implement skills, because self-monitored data enable patients to become aware of pain trends and influential factors on the basis of which they can make decisions and act accordingly.
Self-efficacy (Porter et al., 2008)	Self-confidence, or self-efficacy, is critical in managing physical and psychosocial consequences of pain. Interventions with a focus on self-efficacy are believed to be advantageous, as patients high in self-efficacy report lower levels of pain.
Supportive environment (Bodenheimer et al., 2002)	A supportive environment of formal and informal caregivers makes patients feel they are not on their own and simultaneously allows them to practice and gain confidence in their abilities to perform self-management and better control their symptoms.

Table 2. Algorithm of diary questions, answers, colored risk flags and follow-up questions

Morning	Flag	Next
Q1 Did you have a good night's sleep?		
Yes	■	Q2
No	-	Q1.1
Q1.1 Did you experience any difficulties with falling asleep?		
No	■	Q1.2
Yes in <2 morning diaries	■	Q1.2
Yes in ≥2 morning diaries	■	Q1.2
Q1.2 Did you experience any difficulties with sleeping through the night?		
No	■	Q2
Yes in <2 morning diaries	■	Q2
Yes in ≥2 morning diaries	■	Q2
Evening	Flag	Next
Q1 How did you experience your pain today?		
Very good or good	■	Q2
Not good, not bad or bad or very bad	■	Q1.1
Q1.1 Did the pain prevent you from position and behavior; normal eating habits; contacts with others, other activities; none of these?		
No	■	Q2
Yes to the same activity in <2 evening diaries	■	Q2
Yes to the same activity in ≥2 evening diaries	■	Q2
Other activities	-	Q1.1.1
Q1.1.1 During which other activities did the pain bother you?		
-	-	Q2
Morning and evening	Flag	Next
Q2 How would you rate your pain at this moment?		
NRS 0<4	■	Q3
NRS ≥4-10 in 1<4 diaries	■	Q3
NRS ≥4-10 in 4 diaries	■	Q3
Q3 How many breakthrough pain attacks did you experience in the last 12 hours?		
0	■	Q4
1<4	-	Q3.1
Q3.1 How would you rate your pain when your pain was at its worst in the last 12 hours?		
<4	■	Q4
≥4 in 1<4 diaries	■	Q4
≥4 in ≥4 diaries	■	Q4
Q4 Do you experience any symptoms other than pain at the moment?		
No	■	Q5
Yes	-	Q4.1
Q4.1 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?		
Yes to the same symptom in 1<4 diaries	■	Q5
Yes to the same symptom in ≥4 diaries	■	Q5

Other symptoms	-	Q4.1.1
Q4.1.1 Which other symptom that is not listed do you experience at the moment?		
-	-	Q5
Q5 Has a physician changed your pain medication in the last 12 hours?		
No	■	Q6
Yes	■	Q6
Q6 Are you satisfied with your pain relief at this moment?		
Yes	■	-
No	■	-

Table 3. Tasks and difficulty ratings of the usability evaluations

Task	P1	P2	P3
1. Look up the pain diary.	2	1	1
2. Look up where to get insight into your pain progress.	2	1	3
3. Look up your pain medication prescription.	1	1	1
4. Read up a message from the nurse.	1	1	1
5. Find information about pain.	1	1	1
6. Look up your pain medication for today.	1	1	3
7. Look up where to leave a message for the nurse.	1	1	1
8. Go from home to diary to medication to knowledge to contact.	1	1	1
9. Fill out the pain diary.	2	3	3
10. Register your medication.	2	2	3
11. Read up the information about causes of cancer pain.	1	1	1
12. Look up your pain progress.	1	2	1
13. Leave a message for the nurse.	1	1	1

Difficulty ratings ranged from 1 (very easy to complete) to 5 (very difficult to complete)

Table 4. User requirements as derived from the three phases

Information

Patients require information about pain and pain management.

Information to be included: causes of pain, treatment of pain, recognition of symptoms that require action, and self-management methods to control pain.

Information needs to be presented dosed and in a logical sequence.

Skills

Patients need to receive a pain diary every morning and every evening.

Diaries have to ask for pain at this moment, pain attacks, adverse effects, satisfaction with pain treatment, and interference of pain with activity or sleep.

Patients need to be able to register extra pain intensity scores at any moment.

Medication monitoring should fit the complexity of pharmacological pain treatment.

Patients have to monitor intake of 'around the clock' and 'as needed' medication.

'Around the clock' medication should be registered within a restricted time frame.

Medication overviews have to be entered and adjusted by a health professional.

Patients and nurses need to be able to interact via the application.

Insight

Patients should be able to view pain intensity over time, also related to medication intake and daily routines, in order to see trends and patterns.

Automatically generated information about pain intensity and medication intake has to be depicted in a graph.

Nurses need to provide more detailed feedback in text messages.

Self-efficacy

The mobile application should be easy to use and easy to learn for a variety of patients with cancer pain independent of age, education level, or computer experience.

Patients should be able to practice with the application.

Patients need to receive feedback about pain self-management.

Supportive environment

Patients need to be reminded to complete diaries and take medication.

Nurses need to monitor pain diaries and medication intake every workday.

Supportive presentation of information and coloured risk flags needs to facilitate tasks.

Nurses should have access to all patient data to guarantee continuity of care.

Room for documentation needs to facilitate carry-over and follow-up of pain treatment.

The treating physician keeps responsibility for pain treatment.

Treating physicians need access to data of their own patients.