



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



Laura M.J. Hochstenbach^{a, *}, Sandra M.G. Zwakhalen^{a, b}, Annemie M. Courtens^c, Maarten van Kleef^{d, e}, Luc P. de Witte^{a, f}

^a School for Public Health and Primary Care (CAPHRI), Department of Health Services Research, Maastricht University, Maastricht, The Netherlands

^b School of Health and Social Care, Department of Social Work and Health Development, University of Greenwich, London, United Kingdom

^c Department of Patient and Care, Maastricht University Medical Center, Maastricht, The Netherlands

^d School for Mental Health and Neuroscience (MHeNs), Department of Anesthesiology, Maastricht University Medical Center, Maastricht, The Netherlands

^e Department of Anesthesiology, VU University Medical Center, Amsterdam, The Netherlands

^f Research Center Technology in Care, Zuyd University of Applied Sciences, Heerlen, The Netherlands

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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

* Corresponding author.

E-mail addresses: l.hochstenbach@maastrichtuniversity.nl (L.M.J. Hochstenbach), s.zwakhalen@maastrichtuniversity.nl (S.M.G. Zwakhalen), a.courtens@mumc.nl (A.M. Courtens), maarten.van.kleef@mumc.nl (M. van Kleef), l.dewitte@maastrichtuniversity.nl (L.P. de Witte).

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.

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