



Original article

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



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

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

^b Centre of Expertise for Innovative Care and Technology (EIZI), Zuyd University of Applied Sciences, Heerlen, The Netherlands

^c Centre of Expertise for Palliative Care (EPZM), Department of Patient and Care, Maastricht University Medical Centre (MUMC+), Maastricht, The Netherlands

^d School for Mental Health and Neuroscience (MHeNs), Department of Anaesthesiology, Maastricht University Medical Centre (MUMC+), Maastricht, The Netherlands

^e Centre for Assistive Technology and Connected Healthcare (CATCH), University of Sheffield, Sheffield, United Kingdom

ARTICLE INFO

Article history:

Received 9 September 2016

Revised 17 March 2017

Accepted 18 March 2017

Keywords:

Cancer pain

Outpatients

Self-management

Nursing

eHealth

Intervention development

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.

Conclusion: 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.

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1. 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, Gamel, van Swieten-Duijfjes, & Grypdonck, 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.

2. Background

As cancer pain represents one of the most prevalent and distressing symptoms (Klepstad et al., 2005; Van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016), adequate pain assessment and management are critical to patients' functioning and

* Corresponding author at: Zuyd University of Applied Sciences, Heerlen, The Netherlands.
E-mail address: laura.hochstenbach@zuyd.nl (L.M.J. Hochstenbach).

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, Moldrup, Christrup, & Sjogren, 2009; Luckett et al., 2013; Oldenmenger, Sillevs Smitt, van Dooren, Stoter, & van der Rijt, 2009). On the organisation level, fragmentation of care due to different health professionals in different care 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, Brushwood, Allen, Radson, & Wilson, 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, Miaskowski, De Geest, Opitz, & Spichiger, 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, van Achterberg, & Schoonhoven, 2008). 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, Wright, Sheasby, Turner, & Hainsworth, 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, Hall, Sinclair, Bond, & Murchie, 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, Maguire, Miller, & Kearney, 2009), to improve patient-health professional communication (Dy et al., 2011), and to allow greater access to healthcare services (Hennemann-Krause, Lopes, Araujo, Petersen, & Nunes, 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, Musto, & Polomano, 2011).

3. Methods

3.1. 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 visualize ideas and solutions. Integration of the intervention into routine clinical practice was organized in parallel and evaluations were performed in real life as much as possible.

3.2. 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).

3.3. 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, Maunsell, Labbe, & Dorval, 2001; Bennett, Bagnall, & Jose Closs, 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 Fig. 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.

3.3.1. 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).

3.3.2. Phase 2 - Specification of content

Document analysis (protocols for pain assessment, education materials) and three consultation sessions with a multidisciplinary palliative team provided input for the content of the intervention in terms of

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