

Self-management support for outpatients with cancer pain

Citation for published version (APA):

Hochstenbach, L. M. J. (2017). *Self-management support for outpatients with cancer pain: development, feasibility and impact of an eHealth intervention*. [Doctoral Thesis, Maastricht University]. Datawyse / Universitaire Pers Maastricht. <https://doi.org/10.26481/dis.20170630lh>

Document status and date:

Published: 01/01/2017

DOI:

[10.26481/dis.20170630lh](https://doi.org/10.26481/dis.20170630lh)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

Valorisation

Research becomes valuable once being communicated not only to the scientific community, but also to the general public. The results of this thesis have led to new insights about cancer pain management; the application of self-management support and eHealth in the outpatient setting; and methodologies for intervention development and evaluation. Eventually, it is not so much the effectiveness of the intervention that is important in the context of valorisation, but much more the process both before and during the randomised controlled trial. This chapter will focus on valorisation of new insights and possible valorisation activities.

Innovation

Intervention content was derived from self-management supporting components that were considered important for patients in general and that were selected specifically for outpatients with cancer pain. In a co-creative and iterative development process, researchers and technicians collaborated in the translation of conceptual ideas. Different health professionals and patients were consulted to gain input and evaluate output. Involvement of all these perspectives was considered important in order to make sure the intervention would be an optimal solution to an actual problem.

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.

What makes the present intervention different from previously applied interventions for outpatient cancer pain management is the intervention being the result of a co-creative and iterative process in which health professionals and patients were involved as much as possible; having a multi-component nature that enables patients to select the support that is needed at a given point in time and in a given situation; making use of eHealth by which the availability of accurate and timely data facilitates communication and advance follow-up; and being integrated in clinical practice by means of including the nurse, treating physician, general practitioner, and pharmacist and arranging follow-up activities.

Relevance

Results of this thesis can be of relevance to patients, health professionals, companies, health insurance companies, and researchers.

Patients

Oncology patients are no different from patients with other chronic conditions in their search to better manage and control their situation. In this respect, self-management of patients and self-management support of health professionals seem obvious in oncology practice too. Patients that were involved in the evaluations often received antitumor therapy with palliative intent and reported moderate to severe pain intensity scores. The intervention though might be valuable for more patients. Both patients and nurses acknowledged that the timing of the intervention needs reconsideration, as self-management support already in an earlier phase would have better prepared patients for what to expect and maybe even how to prevent. Moreover it is conceivable to implement the intervention for other symptoms in oncological patients or for pain in non-oncological patients.

Health professionals

Health professionals (oncologists, urologists, gynaecologists, pulmonologists, radiotherapists, general practitioners, consultants palliative care) experience difficulties with monitoring and follow-up of cancer pain once patients are at home. The intervention offers real time data that offer better insight into the situation of patients at home, the extent to which they comply with treatment recommendations, and the effect of treatment on pain and side effects. At the same time, collaboration and coordination among involved health professionals is facilitated. All data monitored by patients as well as medication changed by health professionals is visible to health professionals who have login information. Registered nurses specialised in pain and palliative care, who can consult the pain specialist or multidisciplinary palliative team, inform and advice the treating physician. By doing so, a knowledge transfer or learning effect regarding cancer pain management in treating physicians is aimed for as well. Different health professionals might be able to fulfil the role of the registered nurse in other settings, for instance a pharmacist or practice nurse. Extra education in pain and palliative care would then be a prerequisite.

Companies

For companies with an interest in eHealth and self-management support, the development process of the intervention can be of relevance. Steps that were taken, methodologies that were applied, the collaboration of researchers and technicians, and the involvement of health professionals and patients could inspire the development of

similar interventions. As for the content, the translation of conceptual ideas into two applications that are embedded in daily clinical practice could be regarded as an example. Important with respect to this is the simplicity of such interventions; less is more. Patients clearly expressed that there was no need for bells and whistles. Pain is a serious matter and the intervention needs to be functional. Moreover, companies need to take care of clear instructions at the start and a helpdesk during implementation of the intervention. For pharmaceutical companies, the intervention offers opportunities in order to contribute to a better quality of care and quality of life of oncology patients from a social point of view.

Health insurance companies

Self-management and eHealth fit perfectly with challenges that are faced in terms of shifting tasks and roles to arrange an efficient organisation of care as well as social trends including participation and digitalisation. For health insurance companies this intervention is an example of introducing self-management and eHealth to improve quality of care and quality of life for a potentially large group of outpatients with considerable symptom burden. Although no conclusions can be drawn regarding clinical effectiveness, the eHealth intervention was well received and impacted outcomes. Implementing eHealth calls for a change of mindset. eHealth needs no longer to be seen as something extra or again another project, yet should be part of regular care for which a different organisation of care is necessary. Scaling-up eHealth requires integration of technologies and structural finance. In implementing and scaling-up eHealth health insurance companies play an important part by initiating subsequent steps and taking the actual measures, both at a national and regional level.

Researchers

Based on new insights about cancer pain management, the application of self-management support and eHealth in the outpatient setting, and methodologies for intervention development and evaluation, this thesis provided answers to certain research questions, left others open, and resulted in new ones as well. More research is needed as regards the conceptual framework for self-management support in outpatients with cancer pain, the optimisation of the intervention with concern to specific components and opportunities to further tailor the intervention, evaluation of the approach in terms of effects and costs, and successful implementation strategies.

Activities

The most obvious valorisation activity is to present research results to the research and professional community. Studies have been published in international and national peer reviewed journals. Moreover, results have been disseminated via posters, presentations, and workshops at international and national conferences on various topics (pain, oncology, eHealth, nursing). Based on this output, the project attracted the attention of different researchers and health professionals abroad working on the same topic. Following an exchange of experiences regarding eHealth interventions for symptom management in oncology, the intention has been expressed to explore future collaboration on this topic from an international perspective. The first steps for a joint proposal are being prepared.

Technological developments and advances progress quickly, while implementation in clinical practice and education stays behind. To prevent future health professionals to be educated with 'yesterday's knowledge' for 'tomorrow's healthcare', self-management and eHealth are important to be included in training for various health professionals. To create and contribute to a good understanding and positive attitude, insights from this thesis are made available through lectures and tutorials by the centre of Expertise for Innovative Care and Technology (EIZT) of Zuyd University of Applied Sciences. In the context of follow-up or refresher training, results are presented during meetings of professional groups too.

In collaboration with IDEE and Sananet, the two companies that were involved in intervention development and evaluation, future steps – upon completion of the project - were discussed. Together with Sananet, project results have been presented in a meeting of OncoZON, an oncology network in the south-east of the Netherlands, to assess whether hospitals would be interested and under what conditions they would be willing to implement the intervention in their daily practices. Basic idea is to integrate the intervention in local care pathways and protocols as much as possible. Because the integration might look different in different hospitals, it would be interesting to share experiences in a community of practice and find out what works and what does not. By doing so optimal implementation strategies might be established for these types of interventions in these groups of patients. At the moment (June, 2017), follow-up meetings with separate hospitals are taking place.