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Chapter 8

Discussion

From chronic disease management to person-centered eHealth: the necessity for blended care


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Abstract

Background
A growing need for structural changes of the organization of the health care system has emerged from the fast-growing number of people with chronic illnesses. eHealth supported self-management programs offer a way to change the traditional approach into person-centered care.

Objective
Inclusion and evaluation of the studies e-Vita and PORTALS, which focused on the necessary elements for implementation of eHealth supported self-management for Chronic Obstructive Pulmonary Disease (COPD) and Oral Anticoagulation Therapy (OAT) patients.

Summary
Based on this narrative review of the e-Vita COPD study and the PORTALS study, we conclude that eHealth supported self-management integrated into usual care can help patients with COPD and OAT to manage their disease better. We assume that blended care with total integration of eHealth and usual care will provide better quality of care in the long term. While eHealth-supported self-management was not superior to usual care for health status, the studies reported no negative effects, suggesting that eHealth is a safe option for delivery of self-management support and high quality disease management.
Usage of the eHealth platforms is better under conditions of perfect integration into usual care and with personal assistance and coaching of patients. The usage is highest for the patients with platforms that add high practical value in day to day life.
The need to educate and coach patients in the use of web-based platforms and to educate healthcare professionals to take a different role, is of great importance. Furthermore, eHealth supported self-management programs need to be offered for a sufficient period to give patients the chance to change their behavior, and finally achieve a better health status.

Implications for future research and clinical practice
More studies are needed (preferably with larger sample groups, and including non-users) to gain more insight into the optimal combination of usual care and eHealth based self-management, the preferences and needs of various patients, the necessary education for healthcare professionals and patients, the best platform for patients that is easy to use, as well as the related costs.
Chapter 8

Introduction

The number of individuals with chronic illness and multimorbidity is growing due to rapid ageing of the population and a longer life expectancy of individuals. By 2050 the number of persons aged 80 or over will be tripled and all major areas of the world, except Africa, will have nearly a quarter or more of their populations aged 60 or over [1]. This rise will be associated with an increase in the rate of chronic illnesses; already in 2010 eighty-six percent of all health care expenses in the US was intended for people with one or more chronic medical conditions [2]. In the Netherlands thirty-two percent of the total population had a chronic illness in 2014, which is thought to rise to forty percent in 2030 [3]. Chronic illnesses are expected to be the primary cause of death and disability in the world by 2020 [4].

The increase in chronic diseases leads to a higher workload in health care, a substantial impact on society and an enormous burden on patients’ lives [5,6,7,8,9], which results in a growing need for structural changes of the organization of the health care system. High quality management of chronic illnesses can only be achieved if patients take responsibility. Therefore, it is important to empower them to take charge for their own health. This concept is reflected as self-management and provides more autonomy for the patient, improves quality of life and self-efficacy and it reduces the burden of specialized centers [10,11].

eHealth interventions can be effective to stimulate self-management [12,13]; patients that use self-management programs are nowadays usually supported by tailored eHealth platforms [14]. The necessity to implement self-management through eHealth is immense as the number of individuals with chronic illness and multimorbidity is growing fast.

Self-management is not only a convenient way to organize care differently, it also offers patients significant benefit by providing them with more knowledge about their disease and involvement to be able to accept and maintain a healthier lifestyle. eHealth provides the means to facilitate communication between health care providers and patients, to transfer information and to facilitate the patient to become more self-managed. Research findings on eHealth supported self-management are conflicting within and between different conditions, with positive effects on self-management in some chronic diseases such as reduction in mortality in heart failure and improvement of glycemic control in diabetes, but with insufficient or inconsistent evidence of benefit for COPD, asthma and cancer [15].

Based on the available knowledge in literature, we identified relevant factors to stimulate the use of self-management eHealth platforms to
empower patients in self-management (Chapter 2). These proved to be: good organizational conditions with integration of self-management eHealth platforms in Integrated Disease Management (IDM), ‘blended care’ (combination of digital and regular care) \cite{16,17}; conditions for education, coaching, training and support for healthcare professionals and patients \cite{18}; and optimal technical conditions with a customized and user friendly eHealth platform \cite{19}. Another necessary ingredient for self-management is a good relationship between the patient and healthcare professional with a role for the professional as a teacher or coach \cite{20}. Unfortunately, the implementation of self-management (with or without eHealth) in daily practice is complex and difficult, partly because of inadequate consideration of the relevant attitudes and possibly skills of healthcare professionals, the obstacles of time and competing priorities and because of the plurals of all necessary factors to enhance self-management \cite{21}.

Because of these difficulties of implementation in daily practice, we aimed to investigate the effect of different approaches of eHealth implementation on the use of platforms and on health status. Moreover, we aimed to examine if the effect depends on (1) subjectively experienced practical added value for patients, thereby making their everyday lives easier; and (2) the level of organization as an integral part of existing care. Therefore, we designed the studies e-Vita and PORTALS to study the effectiveness of different implementation methods of eHealth platforms into disease management of Chronic Obstructive Pulmonary Disease (COPD) and Oral Anticoagulation Therapy (OAT) patients (Chapter 3 and chapter 4) \cite{22,23}. We consider the results of both studies, we interpret them in the light of developments in the current literature and discuss the clinical implications of the findings.

Methods

Methods of the narrative review
In this narrative review, we included and evaluated two studies which focused on the necessary elements for implementation of eHealth supported self-management. We described the methods of the studies, the results and compared them with the literature.
Methods of the included studies

The e-Vita COPD study is a multi-level study of an eHealth intervention integrated in primary care disease management for Chronic Obstructive Pulmonary Disease (COPD) patients. In the e-Vita COPD study, three levels of integration into usual care were used; high and medium level of integration (‘blended care’) and no integration (independent self-management component). High level of integration meant tailored education for the healthcare professionals on COPD, theory and practice of self-management and coaching of patients; a tailored start of the intervention for patients supported by a specialized nurse; and the eHealth platform as an integrated element of the disease management program. Medium level of integration meant a standard education for the healthcare professionals on COPD, a tailored start of the intervention for patients supported by a specialized nurse, and the eHealth platform as an integrated element of the disease management program. No integration meant a single offer and question to patients to use the eHealth platform. Furthermore, we used different levels of personal assistance and training for the patients; the support varied from home visits by a research nurse who coached and assisted in use of the platform, telephone consultation by a research nurse who explained the use of the platform, no support at all and explanation of the primary care nurse how to use the platform. The supportive elements were used in different combinations (Chapter 3).

The PORTALS study is a study on the effectiveness of support by an eHealth platform for OAT. Three different programs were offered to three groups of patients, with standard usual care as the baseline for all patients. Two groups received a self-management program (including self-monitoring and self-dosage of medication) for OAT patients including the use of an eHealth platform, organized as blended care. For those two groups, different implementation methods were used; after inclusion patients were randomly divided in subgroups with e-Learning as their education and with group training as education. Both trainings were developed tailor-made by experts in OAT. The platform was necessary for the patients in the self-management groups to monitor the diagnostic test results of blood clotting and to calculate and determine the dosage of the medication. The third parallel cohort group received only regular care (Chapter 6).
Results
The e-Vita COPD showed that patients used the self-management web-based platform significantly more in the blended care groups (high and medium level of integration in IDM) than the patients in the group without any integration of the eHealth platform (no integration in IDM) (Chapter 4) [24]. The usage of the platform was higher when patients received more personal assistance in learning how to use the platform. Furthermore, no changes in health status were found before and after introduction of the eHealth platforms, and no differences were found between the groups with a high vs. a low level of personal assistance for patients. There was also no deterioration of the health status (Chapter 5).

The strength of this study lies in the combination of different study designs, thereby enabling simultaneous investigation of clinical effects, as well as the effects of different organizational implementation methods. The design was tailor-made for implementation in real-life healthcare settings, with a good support from healthcare professionals. Randomization was carried out for the level of assistance of patients.

The limitations are associated with the relatively new field of research in eHealth. The eHealth platforms are not perfectly matched to the needs of healthcare professionals and patients; usability, adaptability and compatibility with existing systems were insufficient. Because general practitioners, as well as patients, were free to volunteer, bias might have occurred in our research groups. Users were self-selected and were presumably motivated to use the platform, as would be expected in a real-life setting.

In the PORTALS study, no differences were found in health status and usage of the platform between anticoagulation self-management patients trained by e-Learning and by group training (Chapter 7). Moreover, the health status of self-management patients was equal to those of patients receiving regular care without any deterioration. From this study it was concluded that, with adequate training through e-Learning or group training, self-management is safe and reliable for a selected proportion of motivated patients receiving OAT. All approaches are equivalent and result in good clinical outcomes (Chapter 7).

The most important strength of the study is the investigation of the effect of different education programs in a situation as close to ‘real life’ as possible, integrated in a self-management program including eHealth, on clinical outcomes and self-management skills.

This study also has limitations typically associated with eHealth trials.
Patients were free to volunteer: bias might have occurred in our study groups. Users were self-selected and were, presumably, motivated to use the education program (including the web-based platform) as would be expected in a real-life setting.

**Discussion**

To understand more of the underlying mechanisms of a successful introduction of eHealth supported self-management programs, we interpret the results of the e-Vita COPD study and the PORTALS study in light of the current literature.

The results of the e-Vita COPD study showed the importance of blended care, combining face-to-face patient consultations with dedicated eHealth support, with a different usage of the platform in different patient groups, that depends on the level of blended care. In the patient group with the highest level of blended care and with the highest amount of training, patients used the platform the most, and they used more different components of the platform. In the PORTALS study, the usage of the platform remained high during the whole intervention period in both self-management groups with blended care. We conclude from both studies that blended care, with a thorough integration of eHealth into disease management programs including personal assistance for patients, leads to higher and better use of an eHealth platform. Most evidence in literature on blended care arises from the domain of mental health care. This evidence shows that face-to-face and online mental care should be combined in such a way that the potentials of both treatment modalities are used optimally, depending on patient abilities, needs, and preferences [25]. Most systematic reviews on depression found that online psychological treatments for depression are as effective as face-to-face psychological treatments and that offering support or guidance during online treatment increases its effectiveness and is associated with higher levels of completion [26,27,28]. Even in mental care, with years of experience and evidence in blended care, more insight is needed into what suits whom and how technology features and treatment operationalization via technology can be optimized [25]. In literature on chronic care, the impact of eHealth supported self-management on disease control and health care utilization was inconsistent, without a thorough description of and focus on the organization of blended care [25]. Even though, more intensive and multifaceted interventions were associated with greater improvements in diabetes, heart failure, and asthma [25].
For blended care, motivation and training of healthcare professionals is an indispensable factor; it is important to teach and support them to deliver care in a person-centered way. Our studies show that coaching and training of both healthcare professionals and patients are important for the adoption of eHealth supported self-management programs. In the e-Vita and the PORTALS study, we started with training and support of the healthcare professionals in the self-management or blended care groups; they were trained on the medical aspects of the diseases and on the necessary skills to stimulate self-management. The need to approach their patients in an equivalent and coaching way, lead to the most vivid discussions; exercising with their colleagues in role plays, helped them to approach patients differently. The goal was that healthcare professionals could support and assist their patients in an appropriate coaching way.

In literature, several studies focused on several predictors for eHealth usage, as also described in the introduction. Results are fragmented across multiple subspecialty areas, but it is evident that embedding eHealth into healthcare involves complex processes of change [29]. Nevertheless, in most eHealth studies and reviews the provision of training and education to all those involved with implementation is a key success factor [30]. In a Dutch survey for primary care professionals it was concluded that future interventions on self-management programs should incorporate strategies to enhance motivation in unmotivated patients; to reach that goal, healthcare professionals should be better equipped to promote motivational change in their patients [31]. In a study on COPD and asthma patients, the online app was used on a more regular basis with a higher involvement of the healthcare provider and more assistance of the patients [32].

In our studies the results were inconsistent concerning the usage pattern of the platform during the intervention period. In the PORTALS study, the usage of the platform remained high during the whole intervention period in contrast to the e-Vita study and in contrast to most eHealth studies, there was no ‘attrition’. Normally in eHealth studies, a substantial proportion of users drop out before completion, or stop using the application [33]. In literature, this drop out is explained by real-life adoption problems [34]; in our opinion it is important that patients experience practical added value in their daily life to stay motivated for using the eHealth platform. In the case of OAT patients, it is necessary to use the platform to monitor the diagnostic test results of blood clotting and to calculate and determine the dosage of the medication. For COPD patients, there is no need to use the
platform to facilitate daily life activities. For patients, the use of an eHealth platform should have the function to facilitate daily life to motivate them to use it permanently.

In literature, several studies focused on predictors for eHealth usage. In a process analysis of the actual usage of web-based applications, it became clear that innovations in health care will diffuse more rapidly when technology is employed that is simple to use and has applicable components for interactivity [34]. For clinically significant improvements in diabetes self-management a range of components need to be incorporated into telehealth interventions: patient education, health care provider education, self-monitoring profile, blood test goals, easy use of blood diagnostic data to modify behavior, feedback to patients, and 2-way interaction [35]. These components are relevant for all chronic illnesses and should be incorporated in platforms. In a study on eHealth usage among healthy adults, it was illustrated that lower SES, older, and male online US adults were less likely to engage in several eHealth activities compared to their counterparts [36]. We can confirm that in our PORTALS study, the percentage of male participants was significantly higher. In all eHealth studies these determinants are important to involve in the design; in our studies, we analyzed demographic features on baseline and corrected for them in the statistical analysis.

In both studies, the eHealth supported self-management programs had no positive and no negative effect on the health status. Like in other literature we presume that the intervention period was too short to achieve a change in behavior for patients with subsequently an amelioration of the health status [18]. Although it did not lead to an improvement of health status during the study period, we expect that a long-term exposure to ‘blended care’ will lead to a better health status for COPD and OAT patients. In a recent systematic meta-review of chronic illnesses, telehealth-mediated self-management was not consistently superior to usual care, none of the reviews reported any negative effects, suggesting that telehealth is a safe option for delivery of self-management support, particularly in conditions such as heart failure and type 2 diabetes, where the evidence base is more developed [15]. Our findings of a long process of behavioral change and positive effect on health status match with the theory of ‘health literacy’, which means the individuals’ capacity to obtain, process and understand basic health information and services that are needed to make appropriate health decisions [37]. People have a different basic level of health literacy. Further-
more, improving health literacy means more than transmitting information, and developing skills to be able to read folders and successfully make appointments; in the future emphasis should be given to more personal forms of communication, and community-based educational outreach, as well as more focus on equipping patients to overcome structural barriers to health \[18\]. eHealth of the future should be tailored for people with different health literacy, different chronic illnesses and be focused on empowering them to obtain a healthier lifestyle.

Chronic care of the future should contain an optimal involvement of the patient. Depending on their skills, the role of the patient should be tailor-made. Enhancement of self-management is necessary for patients to take charge of their own health and disease. eHealth is a practical tool to help patients have more control over daily decisions concerning their disease at the time and place of their choosing; the information concerning their health status facilitates to understand their disease, to have an adult conversation with their healthcare professional and to adapt an appropriate lifestyle. Self-management programs with eHealth technologies for chronic conditions can be used to enhance self-management and revise the Chronic Care Model; patients who actively participate in their care achieve valuable and sustained improvement in wellbeing \[39,40\]. In many eHealth studys, use of a Personal Health Record or self-management platform can promote an informed/activated patient and augment the Chronic Care Model for self-management support and productive interactions; even though a direct dosage-effect relation (usually analyzed in a classical RCT) is not common in eHealth \[41\]. Self-management programs with good training and practical eHealth platforms have the potential to make chronic care personalized in a blended care model; every patient needs a different approach for an optimal health status. Healthcare providers need to embrace a different role and release tight protocols in blended care \[42\]. Individual patients have different expectations and wishes, which should be a topic of conversation with each patient.

What’s in it for healthcare professionals? A more challenging and satisfactory profession with a meaningful relationship with their patients.

What’s in it for patients? Tailored and accessible care, digitally supported, with appropriate lead over their own health, lifestyle and illness.

eHealth based self-management improves quality of care. It does not replace usual care.
Recommendations for future research

The present results provide additional insight into the organizational aspects of the implementation of a self-management program with an eHealth platform, including training programs. The need to educate and coach patients in the use of web-based platforms and to educate healthcare professionals to take a different role, is of great importance. Furthermore, eHealth supported self-management programs need to be offered for a sufficient period to give patients the chance to change their behavior, and finally achieve a better health status. Therefore, more studies are needed (preferably with larger sample groups, and including non-users) to gain more insight into the optimal combination of usual care and eHealth based self-management, the preferences and needs of various patients, the necessary education for healthcare professionals and patients, the best platform for patients that is easy to use, as well as the related costs.

The substantial workload generated by integrating a web-based platform in a self-management program emphasizes the importance of piloting and assessing workforce implications for care centers.
Conclusion

Based on this narrative review of the e-Vita COPD study and the PORTALS study, we conclude that eHealth supported self-management integrated into usual care can help patients with Chronic Obstructive Pulmonary Disease (COPD) and Oral Anticoagulation Therapy (OAT) to manage their disease better. We assume that blended care with total integration of eHealth and usual care will provide better quality of care in the long term. While eHealth-supported self-management was not superior to usual care for health status, the studies reported no negative effects, suggesting that eHealth is a safe option for delivery of self-management support and high quality disease management.

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