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Chapter 1

General introduction

eHealth in primary care
From chronic disease management to person-centered eHealth: the necessity for blended care
Non-communicable chronic diseases

The number of individuals with chronic illness and multimorbidity is growing due to rapid ageing of the population and longer individual lifespan. By 2050 the number of people 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 above. This aging will provoke an increase in the rate of chronic illnesses; in 2010 eighty-six percent of all health care expenses in the US were already spent on people with one or more chronic medical conditions. In the Netherlands thirty-two percent of the total population had a chronic illness in 2014, which will rise to forty percent in 2030. Chronic illnesses are expected to be the primary cause of death and disability in the world by 2020.

The increase in chronic diseases leads to a higher workload in care, which results in a growing need for structural changes of the health care system. This thesis addresses self-management programs including eHealth integrated into regular care, known as ‘blended care’. Both self-management as well as integrated eHealth are frequently suggested additions to the portfolio of solutions for the increasing burden of healthcare. More specifically, this thesis will focus on eHealth solutions for two chronic patient groups: patients with chronic obstructive pulmonary disease (COPD) and patients that use oral anticoagulants.

Integrated disease management

In the past decades, integrated disease management (IDM) was introduced with positive effects on the quality of care. The aim of an IDM program is to reduce fragmentation and improve continuity and coordination of care, through several core components: education of patients, multidisciplinary approach, structured clinical follow-up, evidence-based clinical pathways and feedback information for healthcare providers regarding care for patients. Healthcare providers co-operate to provide patients with chronic diseases with education, exercise, behavioral therapy, smoking cessation advice, medication, nutrition advice and follow-up. The last decades integrated disease management has evolved to person centered care in many countries. Co-creation of care between the patients, their families, caregivers, and health professionals is the core component of person-centered care, which is becoming a widely-used concept.
Self-management
Finding the best management for chronic diseases is imperative to deal effectively with increasing numbers of patients and escalating costs. Today's management of most chronic illnesses must be characterized by responsibility that patients need to take and by empowering the patients to take charge in measures improving their own health. Such management could entail better compliance in taking medication, effectively implementing essential lifestyle changes, or undertaking preventive actions. Patients, their caregivers, or both make daily decisions about these necessary actions. Patients' involvement in the management of their own care is referred to as self-management, which has been defined as “the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition”. Effective self-management therefore includes the “ability to monitor one's condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life” [1]. This definition implies that self-management is more than the adherence to treatment guidelines because it also incorporates the psychological and social management of living with a chronic disease.

Self-management provides more freedom for the patient, improves quality of life and self-efficacy and it lightens the burden of specialized centers. The core components of self-management include education, eliciting personalized goals, psychological coping strategies, formulating strategies to support adherence to treatment, behavioral change, together with practical and social support. Unfortunately, for many patients, optimal self-management is often difficult to achieve, as indicated by low adherence to treatment guidelines, reduced quality of life, and poor psychological wellbeing, which are frequently reported across several chronic illnesses. However, chronically ill patients who have experience with person-centered, high-quality chronic illness care that focuses on patient activation, decision support, goal setting, problem solving and coordination of care, are better self-managers. Patients that use self-management programs are nowadays usually supported by tailor-made eHealth platforms.

eHealth
Given the impact of chronic illnesses on society, new and improved concepts of personalized disease management should be implemented and evaluated. One way of supervising and coaching patients is by use of electronic health
(eHealth), which helps patients manage and control their disease.

Generally, eHealth interventions are effective in stimulating self-management because they allow patients to cope better with their illness at the time and place of their choice, enabling them to adapt their lifestyle to their condition. Subsequently, eHealth support can reduce medical staff consultations [22]. The deployment of eHealth applications facilitates accessibility to healthcare which in turn enhances patients’ understanding of their disease, their sense of control, and willingness to engage in self-management activities [23, 24].

Although patients’ attitudes and receptiveness towards eHealth applications are promising with people of a certain age and education level [25, 26, 27], large-scale adoption of self-management and eHealth in daily practice lags behind expectations [28]. Implementation of eHealth applications and integration into regular care are still subject of research. Pre-conditions for starting eHealth are thorough organization within regular care, benefits for patients and technical sound applications. Organization of ‘blended care’ is difficult, mainly because clinicians experience barriers and resistance towards eHealth; therefore, the eHealth evidence base needs strengthening and a learning process (including staff training) must be instituted [29]. In addition, it is necessary to inform patients more adequately about the possibilities and consequences of eHealth [10]. Furthermore, poor user-friendliness of web-based applications and the lack of ‘push’ factors (e.g. automated reminders, or messages from healthcare professionals) are a common cause of low usage or decline in the usage of web-based applications [31]. In any eHealth study, a substantial proportion of users drop out before completion, or stop using the application, which should be analyzed to provide insight for real-life adoption problems [32]. One of the major challenges of eHealth in care is to make it beneficial and easy to use for healthcare providers and patients, otherwise professionals nor patients will use it [33].

COPD

Chronic obstructive pulmonary disease (COPD) is a slowly progressive lung disease, and one of the main causes of morbidity and mortality in high, middle, and lowincome countries [34]. Worldwide nearly 3 million people die from COPD every year which, in 2012, was equal to about 6% of all deaths globally [35, 36]. The burden of COPD on patients’ lives is enormous and the impact on society is substantial [37].
According to current COPD guidelines, symptoms and airflow obstruction should be monitored regularly to guide modification of treatment and for early identification of complications. Routine monitoring should contribute to achieving management goals in COPD: the delay of disease progression and alleviation of its manifestations. The most important primary care objective should be to improve the quality of life (QoL) of patients.

IDM for people with COPD does not only improve disease-specific QoL and exercise capacity, but can also reduce hospital admissions and hospital days per person. IDM for COPD is of high quality but the responsibility for the program lies largely with the healthcare professional, with a modest role for the patient.

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**Oral Anticoagulation Patients**

Venous thromboembolism (VTE) and atrial fibrillation (AF) are common causes of mortality and morbidity. The economic and disease burden of AF and VTE is considerable; oral anticoagulation therapy (OAT) is crucial to prevent morbidity and adverse effects of AF and VTE. Oral anticoagulation therapy (OAT) has shown to reduce thromboembolic events in AF, prosthetic heart valves, acute myocardial infarction, and other conditions and is effective as treatment of VTE. The major risks of OAT are bleeding complications with a rate of major bleeding among long-term users of vitamin K antagonists (VKAs) of 1.5% to 5.2% per year. There is a narrow therapeutic range for OAT expressed as the International Normalized Ratio (INR); INR values over 4.5 increase the risk of major bleeding and values less than 2 increase the risk of thromboembolism. This is relevant as patients have substantial difficulties maintaining adequate adherence to VKA regimens with a significant effect on anticoagulation control. OAT is only effective with high adherence to medication and an active role for the patient. Structured monitoring and coaching of patients using VKA is therefore essential. This may be carried out by specialized centers in primary care or hospitals. Alternatively, patients might choose to self-manage their VKA-monitoring.

Recently other anticoagulants, Novel or Non-Vitamin-K-antagonist or Direct oral anticoagulants (NOACs or DOACs), have been introduced and are increasingly preferred as an alternative for VKA as they do not require frequent monitoring. However, many data concerning effects of NOAC use...
in routine clinical practice are still missing; disadvantages and risks have been reported. Monitoring of kidney function is necessary, and compliance to medication intake is very important for NOACs too \cite{58, 59}.

**Self-management with eHealth in COPD and OAT**

Self-management of COPD has been introduced as an effective method to improve the quality and efficiency of IDM, and to reduce healthcare costs \cite{60, 61, 62}. Interventions to support self-management have shown reductions in hospital admissions, and fewer sick days because of exacerbations \cite{63, 64}. Self-efficacy includes the emotional functioning and coping ability of an individual, to act or solve problems \cite{65}. Self-efficacy is thought to be a strong predictor of health behaviors of COPD patients \cite{66}. In a Dutch study on adherence to an online self-management application for patients with COPD or asthma, patients tended to use the online application on a regular basis when the healthcare professional provided coaching and training for them, whereas patients without assistance used the application only sporadically \cite{67}.

In the case of OAT, self-management includes monitoring INR values by patients (*self-monitoring*) and, as a possible next step, self-adjustment of the medication dosage (*self-dosage*). Research shows a reduction of thromboembolic events and a reduction in all-cause mortality for patients with self-management \cite{68}. These improvements can be explained by the fact that patients are provided with greater responsibility in their disease management with an increase of awareness, commitment, and interest in their condition \cite{69}. Adequate self-management is very important for all patients with OAT, despite the type of medicine they use. In a study on an internet-based self-management program for OAT patients, web-based and usual coaching by healthcare professionals remained very important for the quality of care \cite{70}.

Based on the described research results regarding integration of eHealth in regular care for COPD and OAT patients, we believe that online self-management support needs to be a fully integrated element of IDM with good assistance and coaching for patients. Because of the unanswered questions about the organization of 'blended care' and about the involvement of patients, we designed two implementation studies to learn more about the implementation of eHealth.
Aims of this thesis

The objective of the implementation studies described in this thesis, was to investigate the effect of chronic obstructive pulmonary disease (COPD) and Oral Anticoagulation Therapy (OAT) eHealth-supported programs applied in primary care.

Based on the available knowledge described, the aims of this thesis were:

- Evaluate the effect of different approaches of eHealth implementation on use of the eHealth platforms and patients’ outcomes, particularly health status.
- Examine whether the effects found depend 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.

To achieve our research aims, we designed two studies on the implementation of self-management programs with eHealth, ´e-Vita COPD´ and PORTALS.

The e-Vita COPD study

Because low usage of eHealth is an ongoing problem, we designed a multilevel study to investigate the implementation of a self-management web platform to support patients with COPD in primary care. As the web platform provides continuous education and contact with healthcare professionals, it is expected to help patients recognize and self-manage exacerbations better in an early phase, thereby helping to stabilize their health status.

This study, called ´e-Vita COPD´, compares three different approaches to incorporate eHealth via web-based self-management platforms into the integrated disease management of COPD using a parallel cohort design. First, an eHealth platform was highly integrated into regular care; second, a platform was integrated into regular care on a medium scale; third, a platform was not integrated into regular care. Also, participants are randomly allocated in two of the cohorts, using the same platform to different levels of personal assistance. The two levels of personal assistance for patients contained a group with high assistance and a group with low assistance. The main aim is to analyze the factors that successfully promote the use of a self-management web platform for patients with COPD.
From an organizational perspective, our hypothesis is that a self-management platform will be better adopted if the platform is an integrated part of IDM, with trained healthcare professionals who encourage patients to use the platform. From a human perspective, our hypothesis is that a self-management platform will be better adopted by patients if they receive sufficient personal assistance in how to use the platform.

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As education is the basic approach in development of self-management skills for oral anticoagulation patients, we expect that the strategy to implement educational support largely affects the individual level of self-management and thereby clinical outcomes. To test this hypothesis, we designed the PORTALS study. The aim of this study was to analyze the effect of the implementation of a self-management program including eHealth by e-Learning versus a group training for oral anticoagulation patients. In addition, we aimed to investigate the relationship between the implementation strategy, health status, self-management skills and individual patient characteristics. In the design of the PORTALS study we considered self-monitoring and self-dosage of medication both as important self-management skills.

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This thesis describes the results of the e-Vita and PORTALS study. In chapter 2 of this thesis, our general viewpoint on the management of chronic diseases is presented. In chapter 3, 4 and 5 of the thesis the e-Vita COPD study is presented, with the design (chapter 3), the results on usage (chapter 4) and the results on health status (chapter 5). In chapters 6 and 7 of the thesis the PORTALS study is presented, with the design (chapter 6) and the results on health status and usage (chapter 7). In the general discussion (chapter 8) we consider our results, interpreter them in the light of developments in the current literature and discuss our methods, consequences and implications of our findings.
References


7 Health Foundation. www.health.org.uk/areas-of-work/topics/person-centredcare/.


9 Richards T. Listen to patients first. BMJ 2014;349:g5765.


Hofstede J, de Bie J, van Wijngaarden B, Heijmans M. Knowledge, use and attitude toward eHealth among patients with chronic lung diseases. Int J Med Inform 2014 Dec;83(12):967-74. PMID: 25269992


In ‘t Veen JCCM, Mennema B, van Noort E. Online self-management in COPD or asthma: with or without the healthcare provider? Eur Respir J 2012; 40 (suppl 56): 2375.

