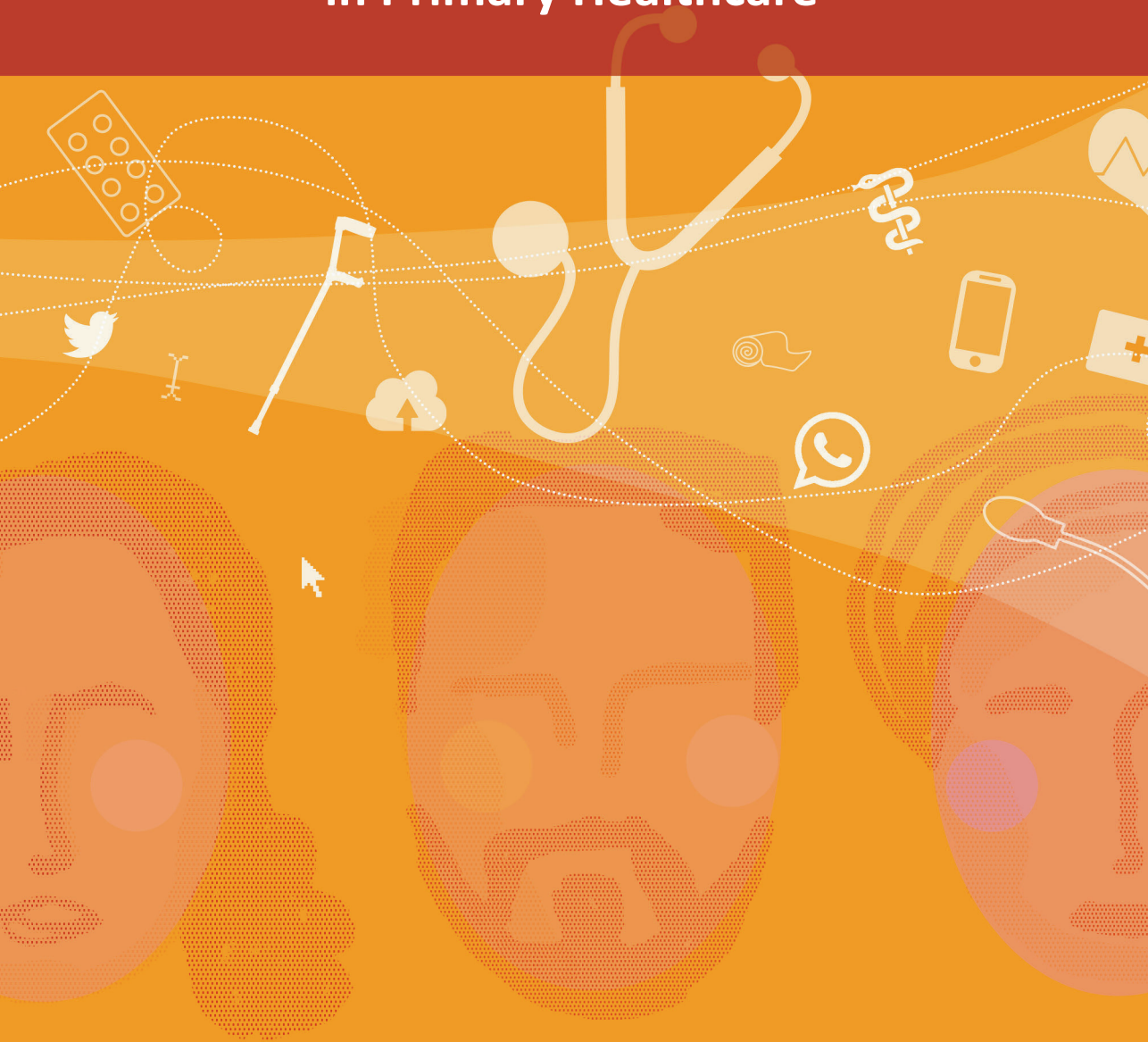# The Challenge of E-Communication in Primary Healthcare

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THE CHALLENGE OF E-COMMUNICATION IN PRIMARY HEALTHCARE

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. ir. K.I.J. Maex

ten overstaan van een door het College voor Promoties ingestelde commissie,

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CONTENTS

1

Introduction

SOCIAL RELEVANCE OF THIS STUDY

More people with multimorbidity and more healthcare providers per patient

The primary care patient population is changing. It is getting older: worldwide, the number of people over 80 will triple until 2050. [1] Consequently primary healthcare is faced with chronic conditions and multimorbidity more frequently. [2-4] At the same time, people have the desire and opportunity to live at home for longer. [5] Due to these two factors, more caregivers become involved with these primary healthcare patients. [6] On the one hand, these caregivers are professionals that can be divided into generalists (such as GPs, pharmacists and district nurses) and specialists (such as lung specialists and wound care nurses), who often work from different organizations. On the other hand, informal carers, such as children and partners, often play a role; they do not always live in close proximity to the person they are taking care of. [7] Due to the increasing number of actors involved in the care for home-dwelling elderly and people with chronic conditions, care becomes more complicated and the necessity for mutual communication increases. [8-10]

New development

In recent years, patients have increasingly taken more control of their own care, together with their informal carers. In this study, 'informal carers' refers to the patient's children and partners. Taking more control is what patients/informal carer's want, but it is also expected of them. [11,12] This development has also become evident in attitudes towards health. The focus is shifting from disease and care to health and behaviour: increasingly, professionals focus on patients' ability to deal with their own physical, emotional and social challenges and to manage their lives as well as possible. [13,14] Gradually, the roles and tasks in the interplay between professionals and patients/informal carers are changing, in healthcare in general and in primary healthcare in particular. Patients are increasingly acquiring a steering role and the role of the professional shifts towards that of information provider and coach. [11,15] It is important to ensure that primary healthcare patients/informal carers receive sufficient support in their active role.

Necessity of communication

In primary healthcare, communication and coordination of care become complex due to (i) the large number of patients, and the actors involved in their care, and (ii) the changing roles and tasks of professionals and patients/informal carers. The risk of insufficiently coordinated care is fragmentation of care. [9,10] There is an increasing necessity for communication that leads to more coordination of care. [16] This applies to both the mutual communication between professionals and the communication between patients and professionals. [17]

FINDINGS FROM LITERATURE

Communication between professionals

Good communication and coordination of care are essential; but things do not always go according to plan. An example is the number of errors in electronic medication files, caused by inadequate communication between professionals; in a quarter of the cases the medication files seemed to be incorrect. [18,19] Another example concerns home-dwelling elderly for whom certain risks were perceived too late, as a result of shortcomings in the coordination of care. [4,6,8] Some studies suggested improvements in the form of communication agreements, such as the periodical medication review in pharmacies or multidisciplinary consultation concerning certain groups of patients in general practices. However, literature did not yield publications that show whether professionals are able to uphold these agreements and what their effects are.[20-22]

Communication often still takes place in the traditional form of face-to-face consultation (communication at the same time and place). In a face-to-face multidisciplinary consultation (MDC), the involved professionals sit together, communicate confidentially with each other and collectively determine the care plan. Secure communication and sharing the care plan with involved parties are the prerequisites for a productive MDC, and these are realized in the face-to-face consultation and, incidentally, also over the phone. Nowadays, it seems almost impossible to still realize this form of face-to-face MDC; synchronous communication and coordination (being present at the same time, as required for consultation in person or over the phone) is often not achievable due to busy schedules, long distances and the large number of people involved. Inevitably, the MDC, and the corresponding coordination, occurs less often.

Another barrier for communication between professionals who deliver care to the same patient arises when professionals use digital medication files or patient records that are not mutually connected. As their number increases, the different professionals involved with a certain patient are more likely to work for different organizations (e.g., general practices, home care organizations, pharmacies, hospitals, physiotherapy practices) and do not have access to each other's digital medication files or patient records. [23] Due to the limited interoperability of digital systems, it is not possible to share patient data. It is to be expected that this barrier for communication between professionals will be solved in the future, but, considering the large number of involved parties in healthcare (and involved data systems), this might take a while. [24]

Communication between patients and professionals

In healthcare patient engagement is supported as a vision, but is still mainly a promise rather than a reality. [17,25,26] In the current healthcare system, patients/informal carers are

not structurally involved in the MDCs. As a result, the proven effects of active involvement of patients/informal carers on outcomes are not used optimally. [27-32]

E-communication

Nowadays, information and communication sharing technologies are widely used in all parts of society to improve processes (e.g., in e-commerce, e-banking and e-public transport). Although (cost) effectivity was increasingly demonstrated, implementation in the healthcare sector lagged behind. [22,25,26]. In healthcare, the term eHealth was introduced for a very broad range of activities for which information technology was used, such as making consultation appointments, monitoring symptoms or sharing data. This myriad of different meanings made the concept of eHealth hard to define. [27] This thesis follows the widely used definition created by Eysenbach:

> "E-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology". [33-37]

Seen from the perspective of Michael Porter's 'care delivery value chains', eHealth seems applicable to many aspects in the care process to increase its quality. [29] Thus far, findings are not unambiguous, but due to current expectations and the first promising results it will be useful to conduct further research. [18,35-39] EHealth, in the form of e-communication technology, can possibly be used to facilitate communication between professionals, and between professionals and patients/informal carers. [19,39]

Ambiguities remain regarding the use and scaling of e-communication in healthcare. Only a few studies exist, but they are still limited. [40,41] Initial experiences emphasize the importance of developing solutions in co-creation, together with all users. [33] At present, the scaling is still only making slow progress; (as of yet) there are no large numbers of e-communication users. [42]

E-communication offers a possible solution for the aforementioned communication problems among professionals and between professionals and patients/informal carers. E-communication is essentially comparable to regular communication, but has the added advantage of making data transparent and accessible to all parties involved; the a-synchronicity of the method enables all users to communicate and to have access to the correct data at a time and place of their own choice. For professionals, this could mean that the multidisciplinary face-to-

face MDC, currently the standard method of care coordination, is supplemented with a virtual MDC (users are able to see data and to communicate continuously and securely about them).

Digital communication already occurs within healthcare. For practical reasons, healthcare providers use options, such as email and WhatsApp, to exchange data and information. [34] These services, however, have not been adapted for use within the healthcare sector and their security does not meet the necessary requirements. Nevertheless, these services are widely used due to the substantial advantages experienced by users. Firstly, communication occurs asynchronously and, secondly, communication is documented and visible to multiple parties, which makes coordination possible. This facilitates consultation with professionals from other organizations about shared patients, without the need to spend hours on travel or telephone calls. The digital sharing of data also enables better coordination of different care services, which prevents double work and enables a more timely recognition of risks.

For patients/informal carers, the implementation of e-communication also offers possibilities for the facilitation of communication with the professional team. [43] A virtual MDC, for example, offers the possibility of adjusting care to the needs and goals of patients/informal carers in a practical fashion. For them, it becomes possible to become involved in monitoring the data in their own files, since they are experts on their own illness. Another example is keeping the pharmacist's medication file up to date with the help of the patient. It is customary for pharmacists to ask patients to check their personal details when they are in the pharmacy. Patients can play a vigilant role if they have virtual access to their medication overview because they can indicate at any time if the information presented is still correct. It is expected that the integration of e-communication in the care process will substantially change the professional-patient/informal carer relationship thanks to greater transparency. [11,33,38,44,45]

For a systematic approach to the use of e-communication tools in healthcare, it is primarily relevant to find out whether the technology works in practice; the focus lies both on the actual use of the technology and on factors that hinder or facilitate this use. If the technology works and a sufficient number of people use it, the second systematic step is to study its effects on patient outcomes and economic outcomes. This thesis focuses on the first question: whether the technology works in practice.

CONCEPTS AND MODELS

In this thesis the following terms are regularly used: e-communication, eHealth enhanced Chronic Care Model, productive interactions and the continual feedback loop.

E-communication is defined in this study as sharing data about healthcare problems and care actions, available for inspection by all parties involved in the care process and combined with a secure communication environment by using electronic tools.

The following conditions are important for the use of **e-communication**.

1. *All relevant healthcare providers are connected to the e-communication tool.*
   This facilitates involvement in the communication and coordination regarding a shared patient.

2. *The users (professionals as well as patients and carers) use the e-communication tool as intended.*
   A prerequisite for communication is that people are connected, but also that the instrument is used correctly. For example, involved parties share collective problems through a "secure channel of communication" or in a "shared care plan" and note down changes.

3. *The users (professionals and patients/informal carers) respond to the input of others*
   Effective communication requires a good dynamic; within e-communication, involved parties are expected to respond to the input of others.

The **eHealth enhanced Chronic Care Model (eCCM)** (figure 1) is an eHealth version of the evidence-based Chronic Care Model (CCM). [27,46] The CCM illustrates the prerequisites for communication between professionals and between professionals and patients/informal car-

Figure 1. The eHealth enhanced Chronic Care Model
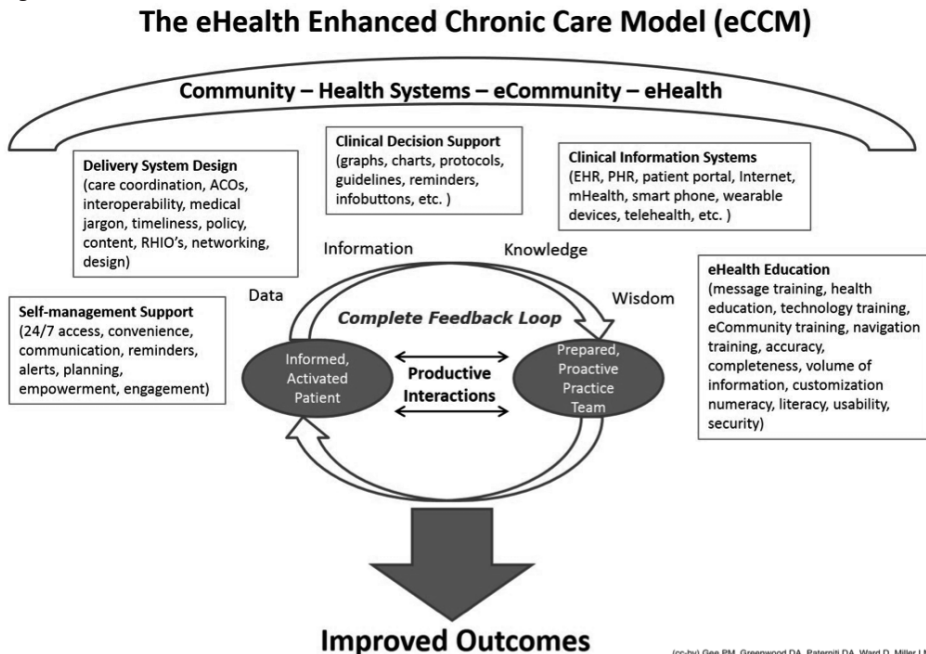
ers. It shows which elements require attention to adequately organize chronic care. [46,47] An important principle in the CCM is that positive changes in health behaviour are supported when the role patient's play in their care is acknowledged. [46,47] Patients experience communication as acknowledgement. [48] The CCM names the following six clusters that need to be specified when the CCM is applied to a specific patient group: the contextual clusters community and health systems, and the functional clusters self-management support; delivery system design; decision support; clinical information systems. [27] Together these are the functional specifications, the framework, with which care can be designed.

The eCCM (figure 1) was developed after it emerged that eHealth technologies reinforced the goals of the CCM. At its foundation lies a review of the effects of the use of eHealth and e-communication on health outcomes and the involvement of patients. [16] The review showed that adding a seventh cluster, 'eHealth Education', was recommended.

The definition of **productive interactions** used in this study was based on the Chronic Care Model (CCM). [46] Productive interactions are interactions that contribute to care. The interactions are aimed at activating and informing the patient and supporting the professionals in their specific role. To create productive interactions, patients/informal carers need to be well informed and the team of cooperating professionals needs to be prepared with means and expertise, to communicate proactively. The eCCM assigns an even more central role to the process of questioning and answering, sending and receiving between all involved parties and thus resulting in productive interactions; it adds that the process at work is a dynamic one. It is called the **Complete Feedback Loop** (CFL). [32] Participants in the CFL have an interactive role; they need to respond to each other. The CFL was explicitly emphasized in e-communication because, with the support of e-communication, this process became more accessible and visible to all parties involved. Within the traditional form of communication between care professionals, responding to the input of others was also aspired to, but interaction was limited, due to time constraints and limited access to relevant data.

Context

In the CCM and the eCCM, the importance of a supportive context for success has been made visible in the cluster Community - Health System - eCommunity - eHealth System. For this study, the decision was made to carry out field research within a recognizable administrative context: the Foundation for Transmural Care The Hague (Stichting Transmurale Zorg Den Haag), an administrative platform consisting of regional directors of healthcare providers. [49] The expectations of this context were that the implementation of the e-communication tools would be supported with information sent to all regional forums through the communication channels of the administrative platform. [50]

Throughout the course of several years, different steps made within this context have contributed to the development and implementation of these innovations. [37,51] Firstly, for the study of these tools, administrative support was sought among healthcare providers in the region with the help of the administrative platform. Support was obtained to research tools

for two high-risk domains: medication care and home-dwelling elderly. The plan was to collectively set out functional specifications for the selection of the tool. With the selected tools the members of the regional platform wanted to explore the extent of involvement patients/ informal carers are able and willing to have, to realize productive interactions. Through the regional platform, several pharmacies and primary healthcare professionals have been found willing to cooperate.

METHOD

Since the introduction of eHealth, different methods of evaluation have been applied, but their diversity does not deliver high-quality evidence. [52,53] In the early stages of the implementation of e-communication tools, it has been found helpful to apply the widely used approach of Plan-Do-Study-Act (PDSA) [42,43]. These PDSA cycles offer a structure to improve the quality of care in an iterative fashion. This is a widely accepted practical method to adapt eHealth interventions for use in practice. The PDSA method also offers support in practice to management in organizations and the care environment, as it makes it possible to recognize whether the tools are promising for use on a larger scale. This is a prerequisite for successful implementation.

Aims and scope of this thesis

The aim of this thesis is to contribute to knowledge about the implementation of e-communication in primary healthcare. The study was focused on describing the use of e-communication tools in primary healthcare among professionals and between professionals and patients/informal carers, and on the impeding and stimulating factors that play a role in this process.

Research question

The main question of this thesis is: "How is e-communication used in the practice of primary healthcare and what are stimulating and impeding factors for its use?"
- *Between professionals (chapter 3 and 4)?*
- *Between patients and professionals (chapter 5 and 6)?'*

Two tools were studied: (i) Congredi, intended for communication between the different parties (professionals and patients) involved in the care of home-dwelling elderly; (ii) eMAR-PCT, aimed at involving patients in their own digital medication file.

The Congredi tool was initially developed as a tool for communication between professional care providers. [54] Congredi encompasses a care plan, where healthcare providers note their care actions, and a safe communication channel, to which healthcare providers have access.

Congredi was used to enable asynchronous communication between involved professionals about the care for a patient. [41] The tool enabled the different users to share a care plan, in which current care problems were documented and from which actions could be planned; users could use secure communication channels. A coordinating professional can open a Congredi file and connect other involved professionals (such as GP, nurse, case manager, other paramedics). Prior to opening a Congredi file, permission must be received from the patient. The digital tool Congredi was developed from 2010 onwards by and with healthcare professionals. The initiator was a GP. In 2013, a small feasibility study was carried out in two districts in the research region. [55] At the request of the users, continuous adjustments were made by the provider during this first pilot to enhance user-friendliness. The feasibility study concluded that Congredi met the original requirements, but that improvements regarding the connection with the files of the GPs were considered important, as well as several technical improvements for the tool's usability. These technical improvements have been applied but the connection with the files of the GP has not yet been realized. These small-scale pilots have mainly been useful for the prevention of problems regarding technical user-friendliness and content aspects. In 2014, a more extensive feasibility study was started by an independent academic research team, on which this thesis reports. In this phase, Congredi was also made accessible to patients.

From the start, the eMAR-PCT tool was aimed at actively involving patients in their own care. The tool enabled patients to check their up-to-date medication file for errors, and to report any changes. They could also communicate with professionals and ask them questions about the use of the medication. [56] With eMAR-PCT, patients had digital access to their medication overview; this included a secure email connection with the pharmacy. Both professional (pharmacist) and patient were involved in the eMAR-PCT. The eMAR-PCT communication tool was originally developed in 2005 by pharmacists and (family) doctors to supervise medication use, and has been continually developed ever since. In this developmental phase pharmaco-epidemiologists performed two feasibility studies, which yielded positive user-friendliness results. [56] In 2012, the decision was made to implement eMAR-PCT in two pharmacy chains in the research region.

Professionals received training to use the tools. This training was limited to practical instructions on the use of the tool. They did not receive extensive background training about eHealth in general and its consequences for work processes, such as data sharing and openly communicating with colleagues and patients. Patients did not receive any training; they followed the instructions on the screen and could make use of a help desk.

As mentioned the research question of this thesis is: How is e-communication used in the practice of primary healthcare and what are stimulating and impeding factors for its use? To answer this question the following characteristics were studied in both groups regarding the use of e-communication tools:

1. Are relevant professionals and patients/informal carers connected?
   a. How many of them are connected?
   b. What are the characteristics of the connected professionals and patients/informal carers?
   c. Which impeding and stimulating factors do the users experience (technology, user-friendliness, motivation)?
2. Do involved parties make data available
   a. Are shared problems and changes recorded?
   b. What are the patterns of recorded healthcare data
3. Do involved parties respond to the input of others?
   a. What is the extent of use?
   b. How do patients/informal carers experience the use of the tool with professionals?

For the analysis of the use of e-communication tools by professionals, the quantitative registration in the tools was used. The aspects of technology, user-friendliness and content of the tool have not been researched in more details for professionals, because these aspects had already been addressed during the prior feasibility study. For the analysis of the use of the tool by home-dwelling elderly, a mixed methods approach was chosen; as this was the first time data were collected from patients. For the analysis of the use of the tool for patients and pharmacists this study also opted for quantitative registration from within the system, supplemented with questionnaires.

Figure 2 shows the structure of this thesis. Chapter 2 reports on the results of the literature study. Subsequently, chapters 3 and 4 focus on the use by professionals. In chapter 3 we examine in general how caregivers involved in the care of vulnerable elderly people in primary healthcare use the digital communication tool Congredi. Chapter 4 attempts to answer the question whether professionals use the tool adequately. The intensity of Congredi use by professionals is compared in low-complex and high-complex care situations of patients with dementia. A greater intensity of Congredi-use, evident from a larger number of involved professionals and larger number of care activities in the Congredi record in the high complex care situation is regarded as an indicator of adequate use.

In the following two chapters the use by patients is central. In Chapter 5, the use of Congredi by patients is evaluated in a mixed method study. Quantitative data from the registration system determine the actual use, and by means of oral (face-to-face or telephone) interviews, it is investigated which impeding and stimulating factors influence the use. In chapter 6 we examined how patients check their digital medication administration records, signal errors and communicate with their pharmacist. In doing so, it is investigated whether certain patient characteristics affect the use. It is also explored whether the use of eMAR relates to the number

of errors in the file, quality of life and self-management. Chapter 7 integrates and discusses the findings in the previous chapters.

Figure 2. Structure of the thesis

Backgrounds	
Chapter 1	*Introduction*
Literature study	
Chapter 2	*The effects on health behaviour and health outcomes of internet-based asynchronous communication between health providers and patients with a chronic condition: a systematic review.*[57]
E-Communication between different professionals	
Chapter 3	*How professionals share an e-care plan for the elderly in primary care: evaluating the use of an e-communication tool by different combinations of professionals*[58]
Chapter 4	*Professionals' use of a multidisciplinary communication tool for patients with dementia in primary care.*[59]
E-Communication between patients and professionals.	
Chapter 5	*The challenge of involving elderly patients in primary care by using an electronic communication tool with their professionals: a mixed methods study.*[60]
Chapter 6	*Exploring the effects of patients taking a vigilant role in collaborating on their e-medication administration record.*[61]
Discussion	
Chapter 7	*General discussion and conclusion*

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The effects on health behaviour and health outcomes of Internet-based asynchronous communication between health providers and patients with a chronic condition: a systematic review

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ABSTRACT

Background: In support of professional practice, asynchronous communication between the patient and the provider is implemented separately or in combination with Internet- based self-management interventions. This interaction occurs primarily through electronic messaging or discussion boards. There is little evidence as to whether it is a useful tool for chronically ill patients to support their self-management and increase the effectiveness of interventions.

Objective: The aim of our study was to review the use and usability of patient-provider asynchronous communication for chronically ill patients and the effects of such communication on health behaviour, health outcomes, and patient satisfaction.

Methods: A literature search was performed using PubMed and Embase. The quality of the articles was appraised according to the National Institute for Health and Clinical Excellence (NICE) criteria. The use and usability of the asynchronous communication was analysed by examining the frequency of use and the number of users of the interventions with asynchronous communication, as well as of separate electronic messaging. The effectiveness of asynchronous communication was analysed by examining effects on health behaviour, health outcomes, and patient satisfaction.

Results: Patients' knowledge concerning their chronic condition increased and they seemed to appreciate being able to communicate asynchronously with their providers. They not only had specific questions but also wanted to communicate about feeling ill. A decrease in visits to the physician was shown in two studies (P=. 07, P=. 07). Increases in self-management/self-efficacy for patients with back pain, dyspnoea, and heart failure were found. Positive health outcomes were shown in 12 studies, where the clinical outcomes for diabetic patients (HbA1c level) and for asthmatic patients (forced expiratory volume [FEV]) improved. Physical symptoms improved in five studies. Five studies generated a variety of positive psychosocial outcomes.

Conclusion: The effect of asynchronous communication is not shown unequivocally in these studies. Patients seem to be interested in using email. Patients are willing to participate and are taking the initiative to discuss health issues with their providers. Additional testing of the effects of asynchronous communication on self-management in chronically ill patients is needed.

BACKGROUND

Self-management is a central concept of health care that is increasing in popularity. This is because people strive to be autonomous and also because there is an increase in the global population, in the numbers of chronic diseases people have, and in the length of time people endure a chronic disease [1]. To make health care attainable for all, it is necessary to implement self-management on as large a scale as is justifiable. The level of patient participation is a key aspect in the realization of self-management. Research shows that patient participation results in improved adherence and health outcomes [2-4]. It is therefore important to understand what makes patients participate in their own health care.

The transition towards self-management is also visible in the new definition of health that experts have recommended to the World Health Organization (WHO): "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" [5]. The earlier definition, which dates to 1948 [6], describes health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity", which today seems unattainable. Ursum gives a clear operationalization of self-management as "the individual ability of a person to prevent health problems from arising or, if they do arise, to adapt to the symptoms, the treatment, the physical, psychological and social consequences of the health problem and adjust their lifestyle. In this way persons are able to monitor their own health and to react in a way that results in a satisfactory quality of life" [7]. Thus, self-management is an on-going process in the lives of people, even when they are not receiving care from health care providers. It requires that all people, but certainly patients, need to have open communication with health care providers to be able to take responsibility. This definition suggests that an important focus of health care research should be evidence-based ways of improving self-management by patient participation [8].

Chronic Patients and Modern Communication Technology

Modern information and communication technologies (ICT) provide new ways for patients to participate in their own health care. Internet interventions have been developed to record, measure, monitor, and manage the delivery of health care [9]. These interventions enable patients to remotely supply providers with personal health information and for providers to remotely deliver instructions. For instance, patients with cardiac problems can play an active role in diagnosis by monitoring and communicating their health data so that the professional can make a diagnosis [10,11]. Another option is to give patients access to specific interactive self-care techniques such as back pain management training. A third option is inviting the patient to view their electronic health record (EHR). The patient can log in to the EHR and comment on the content. Some evidence shows that interventions via the Internet also improve self-care behaviour and health outcomes in patients with chronic diseases [12-16]. Especially in the case of chronically ill patients living at home, these Internet-based interventions are seen as a promising development to improve the quality and safety of health care [17]. However,

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robust research on the effectiveness and consequences of these interventions is needed to guide large-scale implementation [18,19].

Specifically Asynchronous Communication

The above-mentioned Internet interventions are created according to a standard pattern based on one-way communication with not much scope for interaction. However, Internet interventions can also be combined with interactive communication tailor-made for individual patients [12,20,21]. Interactive communication can be synchronous (concurrent by telephone consultation or videoconferencing) or asynchronous (non-concurrent by, for example, email or discussion board). This latter form of digital communication has the advantage that the patient and the provider do not need to use it concurrently. For example, patients can pose a question about the organization of their care or a health concern at the moment that it worries them and do not have to wait until the next planned consultation. For health care professionals, it means they can react to patient questions at a time that is suitable for them. Asynchronous communication is not suitable in urgent situations because there is a time gap in the communication. The asynchronous options make it possible to deliver tailor-made self-management support to large numbers of patients with a chronic disease [20].

Current Investigation

This review examines publications that describe the effect of digital asynchronous communication between chronically ill patients and health care providers. The first research question is whether this type of communication works: do patients and providers actually use this form of interactive communication and how do they evaluate the usability? The second question reviewed is whether this form of interactive communication helps: does it have an effect on health behaviour, health outcomes, and patient satisfaction?

METHODS

Definitions

Digital asynchronous communication is defined as electronically mediated communication in which the participants do not communicate concurrently. Examples of asynchronous communication in health care are electronic messaging (email) and bulletin boards. Patients with chronic conditions have one or more chronic diseases, which are defined as diseases with a long duration and generally slow progression [1].

Literature Searching Methods

The systematic review was conducted using the PICO method [22]. The keywords (MeSH terms [Medical Subject Headings]) used were chronic disease, telecommunications OR Internet OR telemedicine OR health services OR delivery of health care OR medical informatics OR

electronic mail, self-care, self-efficacy. The search was filtered for Randomized Controlled Trials (RCTs), adults, English language, and publication period of 2001-2013. The search was limited to studies conducted from 2001 onward because Internet access for individuals from their homes has increased since the turn of the century [23] and interactive asynchronous communication thus became an option for more people. The search procedure consisted of the following steps:

1. PubMed and Embase databases were searched.
2. Duplicates were removed.
3. Titles and abstracts were scanned for Internet-based interventions.
4. Full text analysis was undertaken to select studies
   • describing asynchronous communication between patient and provider, alone or as part of an intervention;
   • where patients were able to initiate communication at any time of the day (24/7);
   • directed at self-management;
   • where control groups were free of any digital intervention and received usual care.
5. The bibliographies of the articles included were manually searched to identify additional relevant articles.

Quality Appraisal

The methodological quality of the studies was evaluated by applying the National Institute for Health and Clinical Excellence (NICE) criteria for RCTs [1,24,25]. Selection bias, performance bias, attrition bias, and detection bias were assessed.

Research Questions

Do Patients and Providers Use Asynchronous Communication Within Internet-Based Interventions and Do They Find It Usable?

To answer this question, the use of asynchronous communication in digital interventions by patients was assessed by determining frequency of access; number of patients who use the digital intervention; number of messages; and usability of interventions, including asynchronous communication (this refers to experiences regarding the actual (technical) use of the ICT with a focus on ease of use, clarity, and attractiveness).

Does the Use of Asynchronous Communication Within Internet-Based Interventions Affect Health Behaviour and Health Outcomes?

To answer this question, the present study assessed the effects of using digital interventions, including asynchronous communication, on health behaviour (knowledge, health care utilization, and self-efficacy/self-management); health outcomes (clinical parameters, physical symptoms, quality of life); and patient satisfaction.

The results were reported as significant if $P<.05$.

RESULTS

Characteristics of the Studies

As shown in Figure 1, the search identified 311 studies in PubMed and 231 in Embase. Four additional studies were retrieved via the bibliographies of the retrieved studies. The elimination of duplicates resulted in 385 studies. All abstracts were screened and 27 studies were identified that specifically focused on Internet-based intervention. After full text analysis, 20 studies were identified that described asynchronous digital communication between patients and providers as part of the intervention. Furthermore, five studies in which the control group received usual care via the Internet were eliminated. Ultimately, 15 studies were found to meet the inclusion criteria and were thus included in the review (Figure 1).

Table 1 shows the characteristics of the samples of the studies. The studies varied in geographic location, sample size, mean age of the sample, and nature of the chronic disease (Table 1). Eleven of the 15 studies were performed in the United States, two in Europe (Portugal, The Netherlands), one in Australia, and one in Asia (Korea). The sample sizes varied from 0-50 [26], 50-100 [9,27-29], 100-150 [30-34], and more than 150 [35-39].

In 9 studies, the mean age of participants was approximately 50 years (range 45-57) [28-31,34-36,38,39]. In four studies, the mean age was over 60 years [9,27,32,33], and in two studies, the mean age was lower (range 29-36) [26,37]. The nature of the chronic disease differed in the samples, including unspecified chronic illnesses [30,35,38,39], chronic pain [27,36],

Figure 1. Search results.
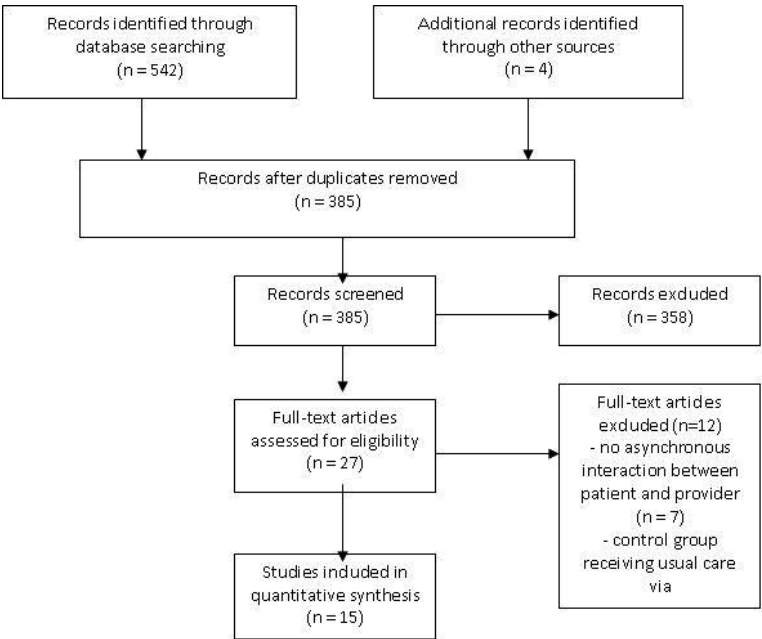
Table 1. Characteristics of the sample.

Primary author	Country	Sample size[a], n	Chronic disease	Mean age, yrs (range)	Female, %	Recruitment
Berman [27]	United States	I: 41 C: 37	Chronic pain	65.8 (55-91)	87.2	Mass media
Bond [9]	United States	I: 31 C: 31	Diabetes, type 1 and 2	67.2	45	Provider
Cruz [26]	Portugal	Cross-over I: 21	Asthma	29 (18-62)	71	Provider
Ghahari [28]	Australia	IA: 34 IB: 28 C: 33	Chronic neurological conditions: MS, Parkinson's, post-polio	50.25 (23-90)	81.1	Mass media
Hill [30]	United States	I: 61 C: 59	Chronically ill rural women	52.2 (35-65)	100	Mass media
Kwon [31]	Korea	I: 51 C: 50	Diabetes type 2	54.1	30.9	Provider
Lin [35]	United States	I: 305 C: 301	Acad. internal medicine practice	51	51	Provider
Lorig [36]	United States	I: 296 C: 284	Chronic back pain	45.5	38.5	Mass media
McMahon [32]	United States	I: 52 C: 52	Diabetes, HbA1c $\geq$ 9	63.5	0	Provider
Meer [37]	Netherlands	I: 101 C: 99	Asthma	36.5 (19-50)	69.5	Provider
Nguyen [33]	United States	IA: 43 IB: 41 C: 41	COPD	68.7	46	Mass media
Ralston [29]	United States	I: 42 C: 41	Diabetes, type 2, HbA1c$\geq$ 7	57.3	49.4	Provider
Ross [34]	United States	I: 54 C: 53	Congestive heart failure	56	77	Provider
Weinert [39]	United States	IA: 54 IB: 58 C: 64	Chronically ill rural women	51.8 (30-69)	100	Mass media
Weinert [38]	United States	I: 155 C: 154	Chronically ill rural women	55.5	100	Mass media

[a]=intervention, C=control.

Table 2. Characteristics of the intervention.

Primary author	Intervention			Description	Complement or substitute for usual care	Length, wks
	Self-care technique	Monitor disease/ symptom	Share EHR			
Berman [27]	x			Online mind-body: Facilitator sends prompts and answers questions using asynchronous communication	complement	6
Ghahari [28]	x			A. Online fatigue self-management program: Facilitators logged on daily and responded to participant entries, posed questions and provided encouragement to the intervention group. B. Online information-only self-management program: In the information-only group, facilitators checked for technical problems and sent standardized weekly reminders to read the information.	complement	13
Hill [30]	x			Computer intervention on psychological status: Online peer-led support group with health teaching; included an asynchronous chat room and an email function giving access to each other and to research team.	complement	22
Lin [35]	x			Patient portal: To send secure messages directly to their physicians and to request appointments, prescription refills and referrals; also included clinical messaging.	complement	26
Nguyen [33]	x			A. Internet-based dyspnea self-management program (eDSMP): Web diary, personalized reinforcement, feedback emails, and a discussion board. B. Face-to-face fDSMP: Paper diary, personalized reinforcement, and feedback telephone calls	complement	52
Weinert [38]	x			Peer-led support group and a self-study health coaching unit	complement	24
Weinert [39]	x			A. Computer-based intervention providing online support and health information B. Health information only	complement	53
Lorig [36]	x			Closed, moderated email discussion group; book, videotape.	complement	52
Bond [9]		x		Web-based intervention with disease monitoring, coaching, motivational, and social support	complement	26
Ralston [29]		x	x	Shared electronic record and email with providers	complement	52
Ross [34]		x	x	Web-based online review of EHR and email messaging directed at clarifying doctor's assessment and instructions	complement	52
Cruz [26]		x		E-diaries and asthma self-management with PIKO-1 e-tool: Immediate feedback using secure messaging	substitute	8
McMahon [32]		x		Care website with educational modules, monitoring system, and internal messaging system	substitute	52
Meer [37]		x		Internet-based self-management plus education and communication with an asthma nurse	substitute	52
Kwon [31]		x	x	Website for monitoring and communication	substitute	13

diabetes [9,29,31,32], asthma [26,37], chronic obstructive pulmonary disease [33], chronic neurological conditions [28], and congestive heart failure [34].

Table 2 shows the characteristics of the interventions of the studies. The interventions were diversely directed. Eight studies focussed on self-care techniques [27,28,30,33,35,36,38,39], six on monitoring disease and symptoms [9,26,29,31,32,37], and three on sharing an EHR [29,31,34].

An assessment was carried out to determine whether the interventions were complementary or a substitute for usual care because of the consequences for the interpretation of the results. One might evaluate interventions that are complementary to usual care as effective if the study shows improved outcomes, whereas interventions that are a substitute for usual care can be evaluated as effective if the study shows no differences compared with usual care. Most interventions were complementary (n = 11), but some were a substitute for usual care (n = 4).

Methodological Quality of Studies Included

In Appendix 1, the methodological quality of the RCTs in this study is presented.

Risk for selection bias, or systematic differences between the comparison groups, existed in three studies [30,36,38]. Two studies did not describe how the participants were randomized and up to which point the investigators were blinded to allocation [30,36]. Two studies did not describe how the groups compared at baseline [30,38]. In all three studies, the participants were invited through mass media, which means that the assignment of patients to a group was partially concealed because the investigators did not know the participants [30,36,38]. The partial concealment was not considered a high risk for bias.

Risk for performance bias, or systematic differences between groups in the care provided (apart from the intervention under investigation), was low. In all studies, the comparison groups received the same care except for the intervention studied. In all 15 studies, it was clear that participants were not blinded to the treatment allocation due to the physical character of the intervention. In the studies by Ghahari [28], Nguyen [33], and Weinert [38], where two interventions (intense and less intense) were compared with usual care, patients in the intervention groups knew that they were taking part in the intervention but did not know whether they were participating in the intense or less intense intervention group.

The investigators were kept blinded in three studies. In the study by Bond [9], it was possible to keep the investigators blinded because the outcomes were measured at the beginning and the end of the intervention during a home visit. Cruz [26] used a crossover design in which all participants took part in the treatment and control group sequentially so that blinding of investigators was not an issue. In the study by Ghahari [28], the investigators were partially blind to how the outcomes were ascertained because they were involved only in one arm of the three-armed study and were blind to the survey results.

Risk of attrition bias, or systematic differences between the comparison groups with respect to dropouts, hardly existed in the studies. All groups within the studies were followed for an equal period of time. They were comparable with respect to the availability of outcome data and for treatment completion. Only Weinert [38] did not describe data on treatment completion.

Risk of detection bias, or bias in how outcomes are ascertained, diagnosed, and verified, showed more diversity. The length of follow-up was found to be on the short side in Berman (6 weeks) [27] and Cruz (8 weeks) [26]. The validity and reliability of the outcome measures was unclear in Cruz [26] because the psychometric qualities were not discussed. In Weinert [38], the quality of the outcome measures was not described. In three studies [9,28,30], the investigators were kept blind to the participants' exposure to the intervention and to other important confounding prognostic factors.

In conclusion, a total score for the studies was derived that summed up the risk for the four categories of bias, showing that Berman [27], Hill [30], and Weinert [38] have some risk to methodological quality. The other 12 studies show low risk.

Does It Work? Use and Usability

In Appendix 2, the results describing the use of the intervention, health behaviour, and health outcomes are presented. Although all 15 studies studied an intervention including asynchronous communication, outcomes concerning use of the intervention, such as accessing the intervention and the use of electronic messaging, were not reported in all studies. Twelve studies described the use of the intervention by patients. In six studies, the specific use of the asynchronous communication was also subject of the study.

To use the asynchronous communication, the patients accessed a website and then logged in to a patient portal. It was then possible for them to communicate asynchronously with their providers by using email, viewing their EHR, or using a discussion board. Three studies that examined sharing EHR [29,31,34] described data about how the intervention was accessed. These patients accessed the intervention between 1.5 times a month [29,34] and 16 times a month [31]. Ross [34] reports that the use declined and levelled off from 1.5 times per month in the beginning to 0.4 times per month after 12 months. In two studies, the percentage of the sample that used the intervention was reported as 76 % (32/43) [29] and 80 % (43/54) [34]. The pages in the EHR that were the most reviewed by patients were the clinical notes and the lab results [29,34].

The accessing of the intervention was also reported by Berman [26], who found that patients accessed their intervention 16 times a month. Lin reported that the percentage of the sample accessing the intervention was 31 % (95/305) [35], and Nguyen reported that 75 % of patients (28/37) accessed the intervention [33].

The use of electronic messaging was reported on in six studies [26,29,31,34-36]. Three were publications on sharing EHR [29,31,34], two were on self-care techniques [35,36], and one was on monitoring disease/symptoms [37].

A large percentage of subjects used electronic messaging. Ralston [29] found that 100 % of patients (39/39) used email, Ross [34] found 76 % (41/54) did, and Cruz [26] found 90 % (19/21). The intensity of messaging use varied per patient per year from 1.2 [34], to 5.9 [37], to 8.7 [35], and to 55.2 [31] times. In the latter study, electronic reminders were sent. In one study, it was reported that 73 % of messages (302/414) were sent outside of office hours [35].

In three studies, the content of the asynchronous communication [31,34,35] was reported. Kwon [31] reported that the main topics were nutrition, diabetic complications, exercise, and other aspects of diabetes management. Lin described that the main topic of 42 % of messages (32/76) was biomedical concerns, and 14 messages were "for your information" (18 %), and the latter type of message was significantly more common in electronic messaging than in telephone messaging [34]. Urgent messages were conveyed by telephone [35]. Ross [34] reported that electronic messages appear to supplement telephone messages. The main topics in electronic messaging were scheduling appointments, getting medication refills, asking questions about medication, getting test results, reporting "feeling ill", and getting assistance to interpret test results.

The usability of electronic messaging was shown for a variety of experiences, and overall, patients were positive about using electronic messaging. In one study, patients found the intervention helpful, easy to navigate, and would recommend it to others [27]. In another study, patients felt that the doctor understood their problems better and explained the information better when using email [34]. Patients prefer email as a way to send information and psychosocial messages to their doctor. In one sample, 75 % of patients (132/175) thought they would use this in the future, and 85 % (149/175) preferred email to telephone messaging [35]. Additionally, 162 out of 341 (48 %) were willing to pay for online correspondence with their physician. Of those willing to pay, the median amount cited was US $2 per message [35]. Cruz found that patients preferred using the Internet rather than paper when monitoring their health [26]. Health care utilization through a patient portal led to higher patient satisfaction [35]. Patients seemed to appreciate the fact that they could communicate with the clinic and conduct administrative actions asynchronously instead of using the telephone. In one study, the content of the communication was studied, revealing that patients had specific questions about medication and tests but also wanted to communicate about "feeling ill" [34]. Patients seemed able to estimate correctly when to use the portal or when to use the telephone for messages, as the telephone was used for urgent messages [35].

Problems concerning usability can be expected when using technology, and these problems might influence usage. Minor usability problems were described in three studies in this review [26,27,39], but none had a large effect on the use.

Does It Help? Effects on Health Behaviour

Multimedia Appendix 2 shows that of the 15 studies aimed at improving health behaviour with Internet-based interventions including asynchronous communication, seven reported results on health behaviour. The outcomes were in three different areas of health behaviour: knowledge [38], health care utilization [35-37,40], and self-efficacy/self-management [27,33,34,36].

Increased knowledge was realized in a study involving rural women with a chronic disease who lived a long distance from the clinic [38].

Health care utilization in the form of visits to physicians did not decrease significantly, but a decrease was shown in the case of back pain patients (*P*=. 07) [36] and asthma patients (*P*=. 07) [37], although not statistically significant.

In the area of Internet-based support of self-efficacy/self-management, several results were reported. In the case of pain management, Internet-based interventions seemed to increase patients' self-efficacy in using non-medical techniques [27], self-care orientation in back pain [36], and managing dyspnoea [33]. In patients with congestive heart failure, the general adherence to therapy increased when patients shared their EHR with their providers and communicated asynchronously about the content and implications of the EHR [34].

Does It Help? Effects on Health Outcomes

Health outcomes are important indicators for providers to guide the therapy of chronically ill patients. Health outcomes as a result of using an intervention with asynchronous communication were described as clinical and physical symptoms, psychosocial outcomes, and satisfaction. They were reported in 12 studies [9,27-33,35-37,39,41].

Outcomes for clinical symptoms were shown in four studies of diabetic patients. Improvements were shown in HbA1c level [9,29,31,32], weight, cholesterol, high-density lipoproteins [9], and blood pressure [32]. In a study of asthma patients, the forced expiratory volume (FEV) and the control of asthma were shown to increase with Internet-based support [37]. These were positive results for Internet-based interventions with asynchronous communication, but only McMahon looked at specific aspects of the intervention. He found that improved health outcomes were related to the frequency of use of the intervention [32].

Improved physical symptoms were also observed when using Internet-based self-care techniques. Berman and Lorig demonstrated a decrease in back pain in patients [27,36], and Ghahari demonstrated a decrease in fatigue-impact for patients with multiple sclerosis [28]. Nguyen reported increased arm endurance with exercise [33]. Berman discussed a relationship with a specific aspect of the intervention: logging on to the intervention seemed to decrease the patients' pain immediately [27].

Varied psychosocial outcomes were shown in the studies of interventions with asynchronous communication for chronically ill patients. In one study, personal well being increased [28] for both intervention groups (interactive and information only) in comparison to the control group with usual care. Meer showed improvement in quality of life for asthma patients [37].

An increased acceptance of the illness was also shown [39], as well as increased self-esteem [30,39], empowerment, and social support [30]. Weinert described a decrease in stress, depression, and loneliness [39]. Lorig found that patients felt less disabled, whereas role functioning improved and health-related distress decreased [36]. Patients seemed to feel better when they had an Internet-based connection with their providers.

Does It Help? Effects on Patient Satisfaction

Satisfaction with the overall care from the clinic increased in one study when patients used the Internet-based connection with their provider via the patient portal [35].

DISCUSSION

Results of Search

The literature search revealed that there are few studies of the effects of asynchronous communication on self-management of chronically ill patients. Only Lin had an Internet- based patient-provider communication system as the focus of an RCT [35]. The literature search yielded another 14 studies in which asynchronous communication was described as part of the intervention. The RCTs were mainly performed in the United States with patients with specific chronic conditions. To glean information about the introduction of asynchronous communication for tailor-made health care, more evidence from other countries and patients with diverse chronic conditions is required.

Quality Appraisal

When reviewing the methodological quality of the studies, a certain amount of lack of blinding was noted. This lack of blinding is inevitable for technical reasons when the use and effect of digital communication on health behaviour and health outcomes is being examined. In assessing the performance bias in RCTs using these techniques, it can be argued that not too much weight should be given to this aspect of quality appraisal.

Results on Use and Usability

Although 12 studies report on the frequency of use of the intervention, none specifically examined why and when patients log on to the intervention. The results of this review suggest that it might be interesting to find out more about the meaning of the frequency of use by patients. Comparisons with other publications about the frequency of access of Internet and communication technology by patients show varied results from increasing use [42] to declining use [34,43], but these results did not differ from those for usual care [44]. Kwon shows that the frequency of use increases when reminders are sent by the provider [31], resulting in increased health outcomes. Ross [34] showed a decline in use but an increase in adherence. Possibly the effect is not in the actual use but in having the connection to the provider, who can

be contacted if necessary. It is also possible that the patients' questions have been answered and they know what to do.

In the studies where email use was measured, a high percentage of patients (> 75 %) used it [29,34]. Patients seem to be interested, but it is not yet clear when they feel the need to use it or whether being connected is enough to feel satisfied and more in control of their health. Perhaps patients experience the connection as a supporting factor in their self- management. The virtual presence of the professional through the digital connection might have effects that could be interesting. Perhaps patients do not need to "check" the digital connection by using it after a time, as they feel confident knowing the digital connection with the provider can be made whenever they need it. The provider is always present and can be approached if the need arises. In research on social support, it is shown that merely the availability of support is helpful and related to higher levels of well being [45,46]. More understanding of the effects on patients of asynchronous communication could lead to increasingly tailor-made health care.

From the viewpoint of transition to integration of modern communication technologies, several threats to successful integration can be identified. It is certainly a threat if patients are not able to distinguish issues that are acute or (life) threatening versus non-acute, but we found no evidence to support this. We found that patients know when to use the telephone, because urgent messages were conveyed by the telephone [35]. They also know when to use asynchronous communication; patients preferred sending non-urgent messages such as "for your information/feeling ill" by email [34,35]. In addition, informational and psychosocial mes-sages are sent via email as opposed to the telephone [35].

Also with regard to integration of ICT, it is interesting that patients are prepared to pay for email service with their provider [35]. The fact that 73 % of messages (302/414) are sent outside of office hours suggests that time and place might be a factor [35].

The content of the electronic messages suggests that patients are willing to participate actively because they share more information than strictly necessary. They have a variety of issues they want to communicate about when using asynchronous communication. Under-standing what these issues are is important for further implementation. In addition to "for your information/feeling ill" messages, they have health issues that they want to clarify, such as biomedical and medication concerns and receiving test results and assistance to interpret them. What seems to be happening is that asynchronous communication is used to commu-nicate information that may or may not be relevant, but it satisfies patients to send it. They have taken action by sending the information, and it is now up to the health care provider to say whether it is relevant and if action is needed. This is the start of "shared- decision making". With asynchronous communication, patients seem to make use of the option to share their worries and their psychosocial condition with their provider. This is an indication for willingness for further patient participation.

Age does not seem to be a factor in the use of asynchronous communication, given the advanced age of the participants. This is relevant because most patients with a chronic disease

belong to the older segment of the population [1]. In the literature, older age has been identified as a barrier to the use of Internet communication technology [47-49]. It can of course be argued that patients who are included in the sample must have Internet access and minimum competencies to use it. It does show, however, that age is not an unsurpassable barrier. It may even be so that the benefits of having a virtual connection with the provider stimulates patients to use the Internet connection or at least understand how to use it, no matter what their age.

Results Relating to Health Behaviour

In the seven studies where health behaviour is described, improvements are shown when using the interventions [27,33-38]. The Internet-based intervention is therefore an option in regard to providing support self-management at a distance.

The meaning to the patient of the digital connection to the provider is interesting. Does having the connection at your fingertips give a reassuring feeling? Does sitting down and logging on to the connection feel like the first step in self-management and being assertive about your needs? Some results on health behaviour may point in this direction. The two studies that used an intense (with an online coach) and a less intense intervention (without an online coach) show that a less intense intervention is just as effective [28,38]. This again raises the question of whether the connection alone is enough to improve health behaviour, or whether a more complex intervention is necessary to gain an effect. In another study, it is suggested that logging on has an immediate impact on pain reduction [27]. This stresses the need to clarify which aspects of eHealth interventions are effective for patients. Is it the direct connection via Internet with the provider, is it the online coach, or is it the tailored information? The latter may be a very interesting point, as this interactive communication makes it possible to obtain detailed information about health management from the provider and the patient. In all other settings, such as in the consulting room, using the telephone or writing letters, it requires more effort to obtain the information necessary for tailor-made intervention.

Two studies found a trend to a significant decrease of health care utilization in the form of visits to physicians when using an Internet-based intervention [36,37]. It may be that asynchronous communication plays a role in this change in health behaviour because patients can discuss their health concerns interactively with their provider. The triggers for this health behaviour might be less time spent travelling to the physician and in the waiting room; the convenience and fact that no travel is required make the interaction more economical. However, this aspect has not been studied.

The content of the communication in the study by Ross shows that patients have precise questions about medication and tests, but that they also want to communicate about "feeling ill". The results show that general adherence increases. However, the question of whether asynchronous communication about these issues affects the general adherence is not raised [34]. There may be some support for this conclusion in the Lin study, where patient satisfaction increased when they were able to communicate "for your information" messages through electronic messaging [35].

Results on Health Outcomes

Improved health outcomes were shown in 11 studies using Internet-based interventions, including electronic messaging. In studies where the intervention was complementary to usual care, an improvement could be expected. In studies with an intervention as a substitute for usual care, similar outcomes from intervention and usual care can be seen as a positive result. However, improvements were also reported in studies in which the intervention was a substitute, thus showing that the Internet intervention has better results than face-to-face care. This calls for more testing of these interventions as a substitute for usual care in larger samples of diverse patients.

Limitations

The Internet-based interventions in the studies consisted of different components, such as peer-support groups, sharing medical records, self-management programs, and patient portals. The component they all had in common was electronic messaging. The multicomponent aspect of the studies made it difficult to trace the exclusive effect of the intervention to the asynchronous communication.

Electronic messaging was not evaluated separately in these studies. It can be concluded that the effect of asynchronous communication is not adequately shown in these studies and that many questions can be raised about the precise effect of Internet-based asynchronous communication between patients with a chronic condition and their providers. This is a limitation. However, there were many positive findings about electronic messaging in relation to telephone messages and other forms of messaging.

Future Research

Research is needed to determine the technical characteristics of effective asynchronous communication with patients for specific disease categories where specific health behaviour is needed by specific patients. The meaning of the virtual connection with the provider should be explored. This may be a very basic intervention with a large effect.

Additional testing is needed to clarify what patients want to discuss with their providers and how shared decision making about these issues can be effective.

The effects of asynchronous communication on self-management for larger samples of diverse patients with a chronic condition require examination. A clear definition of desirable outcomes is needed. The desired results for health behaviour should be operationalized with regard to "the ability to adapt and self-manage in the face of social, physical, and emotional challenges" [5]. In this review, three categories of health behaviour could be distinguished as outcomes: knowledge, health care utilization, and self-management/self-efficacy.

We also advise further testing of Internet interventions as a substitute for usual care because significant health outcomes were found in this review.

CONCLUSION

It can be concluded that using asynchronous communication in health care may be an important instrument to increase patient participation leading to self-management. After reviewing the literature, the answer to both research questions seems to be positive:

asynchronous communication is used by patients and it helps to increase the effects on health behaviour and health outcomes, at least for some. Patients seem to be interested in using email and understand how to use it. They use email for questions about biomedical concerns, medication, and test results, as well as to inform the providers about non-urgent health issues. They tend to prefer email to telephone for this communication. They also understand when they can use email or when contact by telephone is needed.

From the viewpoint of the new definition of health with an emphasis on self-management and patient participation, it seems possible to take steps towards sustainable health care by implementing asynchronous communication, as it enables patients to communicate effectively about their perceived health problems and their adaptation to health problems.

2

Appendix 1. Methodological quality randomized clinical trials.

Bias	Selection					Performance					Attrition					Detection							Total
Author	A1	A2	A3	risk	dir.	B1	B2	B3	risk	dir.	C1	C2	C3	risk	dir.	D1	D2	D3	D4	D5	risk	dir.	score
1. Berman [62]	y	y	y	–		n	np	np	?		y	y	y	–		n	±	±	np	np	h	0	±
2. Bond [63]	y	y	y	–		y	np	y	–		y	y	y	–		y	y	y	y	y	–		–
3. Cruz [64]	y	y	y	–		y	np	y	–		y	y	y	–		n	y	?	np	np	h	?	|-
4. Ghahari [65]	y	y	y	–		y	±	y	–		y	y	±	–		n	y	y	y	y	?		–
5. Hill [66]	?	?	?	h	0	y	np	?	?		y	y	y	–		y	±	y	np	y	–		±
6. Kwon [67]	y	y	y	–		y	np	n	–		y	y	y	–		±	y	y	n	n	–		–
7. Lin [68]	y	y	y	–		y	np	np	–		y	y	y	–		y	y	±	np	np	?	0	–
8. Lorig [69]	?	?	y	±	0	y	np	?	–		y	y	y	–		y	y	y	?	?	–		–
9. McMahon [70]	y	y	y	–		y	np	?	–		y	y	y	–		y	y	y	n	n	–		–
10. Meer[71]	y	y	y	–		y	np	n	–		y	y	y	–		y	y	y	np	y	–		–
11. Nguyen [72]	y	?	y	–		y	np	np	–		y	y	y	–		y	y	y	np	?	–		–
12. Ralston [73]	y	y	y	–		y	np	n	–		y	y	y	–		y	y	y	np	np	–		–
13. Ross [74]	y	y	y	–		y	np	±	–		y	y	y	–		y	y	y	np	np	–		–
14. Weinert [75]	y	y	?	?	?	y	±	?	–		y	?	y	?	0	y	y	n	np	np	h	?	±
15. Weinert [76]	y	y	y	–		y	np	np	–		y	y	y	–		y	±	?	np	?	–		–

Y=yes, N=no, ±=more or less, na=not applicable, np=not possible, ?= unclear, l=low risk of bias, h= high risk of bias, 0= no effect expected of the increased risk of bias.,. In each category (A1-3, B1-3, C1-3, D1-5) questions are asked to determine the risk of bias.

Risk: If all questions in one category are answered with a yes the risk of that type of bias is low. If this is not the case the risk has been analyzed by two researchers separately and the outcomes were discussed so that a decision could be made.

Dir.: The likely direction of effect of the bias is assessed.

Total score: If all categories score low risk of bias, the total score is low. When three categories score low risk of bias and one category scores a high risk, the total score is low-. If two categories score low risk of bias and the other two are unknown or have a high risk with a 0 direction, the total score is ±.

Selection bias: systematic differences between the comparison groups.

A1 An appropriate method of randomization was used to allocate participants to treatment A2 There was adequate concealment of allocation A3 The groups were comparable at baseline, including all major confounding and prognostic factors

Performance bias: systematic difference between groups in the care provided, apart from the intervention under investigation.

B1 The comparison groups received the same care apart from the intervention(s) studied B2 Participants receiving care were kept 'blind' to treatment allocation B3 Individuals administering care were kept 'blind' to treatment allocation

Attrition bias: systematic differences between the comparison groups with respect to loss of participants.

C1 All groups were followed up for an equal length of time C2 The groups were comparable for treatment completion C3 The groups were comparable with respect to the availability of outcome data.

Detection bias: bias in how outcomes are ascertained, diagnosed or verified.

D1 The study had an appropriate length of follow-up D2 The study used a precise definition of outcome D3 A valid and reliable method was used to determine the outcome D4 Investigator were kept 'blind' to participants' exposure to the intervention D5 Investigators were kept 'blind' to other important confounding and prognostic factors

Appendix 2. Results reported on use of the intervention, health behaviour and health outcomes.

Primary author	Outcomes usage digital intervention/ asynchronous communication A actual use B asynchronous communication C usability	Outcomes health behaviour A knowledge B healthcare utilization C self efficacy/self-management	Outcomes health A clinical B physical C psychosocial	Patient satisfaction
Berman 2009	A median use over 6 wks 22.5 times. One visited 211 times, A 78% had intention to do exercise at log off. In follow-up survey 95.3% said they did the exercises without going on line B not reported C 81% believed intervention to be helpful C 88.4% easy to use C 95.3% would recommend intervention to others C all modules were perceived as helpful C 10 had limited difficulties using site: log on and navigating or downloading C 2 people did not appreciate the intervention C "having the intervention handy confirmed that someone was anxious about their pain" C "felt like you were talking to me" C made them more aware of their pain experience and made them focus on self care C suggestions to add more content, additional introductory text, changing layout, communication with other users	P = 0.05 C Awareness of responses to pain + C Confidence using non-medical techniques +	P = 0.05 B Pain intensity + B Pain scores at log on/off suggests immediate impact on reduction of pain	
Bond 2007	B not reported		P = 0.001 A HbA1c p= .01 A Weight p= .001 A Cholesterol p= .05 A HDL p= .05	
Cruz 2007	A minor technical problems 9 with internet connection 5 with PIKO 5 with paper diaries A Patients tried both diaries. Internet could only be entered daily, whereas paper more days could be entered at a time A looking at previous data was considered easier on internet B not analyzed C Preference for internet diaries C Internet diaries less complete C most important features of intervention according to patient: - asthma diary 93% - educational content 82% - receiving information about asthma 85% - exchanging messages with doctor 85% - self-assessment tool before consultation 79% - receiving messages about medication 69% - receiving messages about consultation 67% - 50% were prepared to monitor always - 33% prepared to monitor daily, rest less			

Appendix 2. Results reported on use of the intervention, health behaviour and health outcomes. (continued)

Primary author	Outcomes usage digital intervention/ asynchronous communication A actual use B asynchronous communication C usability	Outcomes health behaviour A knowledge B healthcare utilization C self efficacy/self-management	Outcomes health A clinical B physical C psychosocial	Patient satisfaction
Ghahari 2010	A no sign diff participation rate (nr of sessions completed) IA/IB B not reported		B Physical subscale Fatigue Impact p=.04 C Personal Wellbeing (for I B) p=.03	
Hill 2006	B not reported		C Self-esteem p= . 016 C Social support p= . 038 C Empowerment p= .016	
Kwon 2004	A average frequency monitoring 71.5 ± 36.2 (I) and 38.1 ± 24.8 (C) A mean Logon 42.3 ± 32.2/ patient A have more contact with physician. A received medical advice according to recent data B Total number of e-mail questions was 167. Mean number of questions posted per patient in 12 weeks was 13.5 ± 14.7. Detailed list of questions asked via the Internet		A I HbA1c p= .001	
	homepage by the patients in the intervention group to their health care providers			

Appendix 2. Results reported on use of the intervention, health behaviour and health outcomes. (continued)

Primary author	Outcomes usage digital intervention/ asynchronous communication A actual use B asynchronous communication C usability	Outcomes health behaviour A knowledge B healthcare utilization C self-efficacy/self-management	Outcomes health A clinical B physical C psychosocial	Patient satisfaction
Lin 2005	A 85% obtained user account for portal A 31% used the portal A 175 admin. requests and 239 clinical messages (phone and e-mail) sent by portal patients (1 message/day for every 250 patients) A 27% sent during and 73% outside clinic hours. B n = 76 asynchronous messages Urgent message 3% (of n) Medication question 1% Medication action 21% Biomedical concerns/questions 42% Test results 17 Test action 7 Psychosocial concerns 9% "for your information" 18% Home monitoring 5% Prevention 5% Miscellaneous 18% C Patients more likely to send informational and psychosocial messages by portal than by phone C 75% likely to use portal in future C 85% prefer portal to phone C Of all surveyed patients, 162/341 (48%) were willing to pay for online correspondence with their physician. Of those willing to pay, the median amount cited was US $2 a message C 81% of users said it saved them a phone call C 33% said it saved them a visit C weak positive correlation between frequent users and - satisfaction with portal services p=.02 - improved comm. with clinic p=.01 - satisfaction with physician messaging p=.03	B improved communication with clinic p = .001		Patient satisfaction overall care p= .04
Lorig 2002	A 69% sent 1 or more emails to the group. A Active members posted a mean of 8 messages in a year. B not reported C 41% read most of the email messages, 37% read only emails with subjects of interest.	B Health care utilization decreased but ns p= .07 C self care orientation p= .002 C self efficacy p= .02	B Pain p= .045 C Disability p= .02 C Role function p= . 007 C Health distress p= . 001	

2

Appendix 2. Results reported on use of the intervention, health behaviour and health outcomes. (continued)

Primary author	Outcomes usage digital intervention/ asynchronous communication A actual use B asynchronous communication C usability	Outcomes health behaviour A knowledge B healthcare utilization C self efficacy/self-management	Outcomes health A clinical B physical C psychosocial	Patient satisfaction
McMahon 2005	A Frequent intervention use was related to improved health outcomes A greater amount of uploads of monitoring data related to improved health outcomes p= .02 B not reported		A HbA1c p= .05 A persistent users greater improvement HbA1c than intermittent p= .05 or education and usual care p= .05 A Blood pressure p= . 01 A cholesterol p= .05	
Meer 2009	A 5.9 contacts/pat asthma nurse (1yr) A Report lung function scores 108 days B not reported	B physician visits p= .07	A FEV p= .025 A Asthma control p= .001 C Asthma QOL p= .001	
Nguyen 2012	A Logins median 148 over 12 mths (n = 43) A 75% used website at least once B not reported C preferred using website to smart phone for recording daily exercises and symptoms	B high levels support perceived C arm endurance p= .04 C self efficacy trend p= .06	A Severity of dyspnoea no difference	

Appendix 2. Results reported on use of the intervention, health behaviour and health outcomes. (continued)

Primary author	Outcomes usage digital intervention/ asynchronous communication A actual use B asynchronous communication C usability	Outcomes health behaviour A knowledge B healthcare utilization C self efficacy/self-management	Outcomes health A clinical B physical C psychosocial	Patient satisfaction
Ralston 2009	A 76 % accessed EHR (n = 39) A 43% HbA1c upload A 33 % entered other data A Uploads of HbA1c levels show trend to improvement A 1146 web pages EHR viewed in 12 mths (= 2.3/ mth) - 26 % transcribed notes - 20% labresults - 9 % problem lists A number of page views is not related to HbA1c improvement A uploads of blood glucose levels (n = 189) trend to improvement p= .09 B 69 % used Email		A HbA1c p= .01	
Ross 2004	A Logins 581 by 43 pat. (n = 54) A 0.4 hitdays/pat/mth A Clinical notes and lab results viewed 95 % A Educ.guide reviewed 63 % A Use high first 3 mths B 24 % use e-mail B e-Mail volume 63 by 95% patients C Doctor-patient comm. satisfaction trend	C Adherence general p= .01		
Weinert 2008	B not reported	A Health knowledge (A+B gained sign.) p= .000		
Weinert 2011	A 4 had problems with using computer 2 had problems with internet B not reported		C Stress p= .005 C Depression p= .01 C Self-esteem p= .018 C Acceptance of illness p= .001 C Loneliness p= .04	

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2

E-Communication amongst professionals

3

How professionals share an e-care plan for the elderly in primary care: evaluating the use of an e-communication tool by different combinations of professionals

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ABSTRACT

Background: Home-dwelling elderly patients with multimorbidity are at risk of fragmentation of care because of the many different professionals involved and a potentially unclear level of communication. Multidisciplinary communication seems to occur incidentally. Mutual feedback is needed for a professional team to provide consistent care and adequate support to the patient system. EHealth technology can improve outcomes.

Objective: The aim of this study was to evaluate the use of a tool, Congredi, for electronic communication by professionals for the care of home-dwelling elderly patients.

Methods: The research group was recruited through general practices and homecare organizations. Congredi, a tool designed for multidisciplinary communication, was made available for professionals in primary care. It consists of a care plan and a communication channel (secure emailing). Professionals opened Congredi records for elderly patients who had 2 or more professionals involved. The records were the unit of analysis. Data were gathered from the Congredi system over a period of 42 weeks.

Results: An inclusion rate of 21.4 % (203/950) was achieved; nearly half of the participants were nurses. During the study, professionals were active in 448 patient records; female professionals were prevalent. In the patient records, 3 types of actions (care activities, emailing, and process activities) were registered. Most activities occurred in the multidisciplinary records (mean 12.2), which had twice the number of activities of monodisciplinary records (6.35), and solo records had a mean of 3.43 activities. Most activities were care activities (mean 9.14), emailing had a mean of 0.89 activities, and process activities had a mean of 0.29.

Conclusions: An e-communication tool (Congredi) was usable for improving multidisciplinary communication among professionals. It even seemed to yield results for 40 % of the professionals who used the e-care plan on their own. The content of the tool provided an active communication practice, with significant increases observed in the actions that must be shared for the effective coordination of care.

Practice implications
An electronic communication tool for professionals is recommended
It supports the work process of healthcare professionals
It offers new functions that have potential for improving the quality of care because it links relevant professionals and increases the transparency of relevant information.

INTRODUCTION

Worldwide the population of people older than 60 years will grow from 12 % to 22 % between 2015 and 2050 [1]. People over the whole world are living longer and live in their own homes as long as possible [1]. Many of the elderly will, at some point in time, need multidisciplinary professional care as a result of function loss and decreased self-care capabilities because of multimorbidity and problems in the physical, psychological, and social domains [2]. This group is at risk for the timely signaling of health risks, for aligning treatments, and for coordinating their care [2 -4]. In the Netherlands in 2007, approximately 500,000 home-dwelling older persons with increased risk were identified; this is approximately a quarter of the population aged 65+ years [3]. This number is expected to increase to 1 million in 2030 in the Netherlands [5]. Among the older persons, 80 % have been in recent contact with their general practitioner and half receive professional care [5]. A Dutch study shows that approximately 300,000 older persons are admitted to hospitals every year, often with nonexistent or poor multidisciplinary handover information [6]. A substantial part (20 %-32 %) of these hospital admissions seem to be avoidable by improving the continuity and organization of care [7]. However, because of the multidisciplinary character of care for this patient group, the care tends to be fragmented, and professionals seem to be unaware of each other's involvement [3,8,9].

The quality of primary care could improve if it were less fragmented [10]. Wagner's chronic care model (CCM) forms a theoretical base for multidisciplinary collaboration. It focuses on a well-informed, active patient system collaborating with a prepared, proactive, and professional team to align treatment in multidisciplinary practices [2,11]. Gee et al [12] found that with the recent advancements in technology, adding eHealth options can strengthen the CCM. They developed an eHealth Enhanced Chronic Care Model (eCCM) and added a Complete Feedback Loop between the patient system and professional team (Figure 1) [12,13]. This Complete Feedback Loop encompasses productive interactions between the patient system and professionals about the data and information on which they can reflect from the perspectives of knowledge and wisdom by using eHealth technologies. Collaboration between the patient system and the professional team is the basis of the model, for which effective collaboration among the professionals is a precondition.

Continuity and alignment of care are improved by effective communication among professionals [14,15].

Multidisciplinary collaboration in primary care is aimed at monitoring health risks and developing care plans; it is, however, unclear how such collaboration takes place [2]. The general practitioner or district nurse indicates the increasing needs of the elderly and makes an individual care plan. Usually, there are casual contacts among the involved professionals, and the contact frequency varies per case [15]. Some quantification was found in a report from 2010, which showed that for patients with diabetes and chronic obstructive pulmonary disease, multidisciplinary consultation occurs approximately once a month [10]. Communication among

Figure 1. The eHealth Enhanced Chronic Care Model. ACO: accountable care organizations; RHIO: regional health information organization; EHR: electronic health record; PHR: electronic patient health record or patient portal.
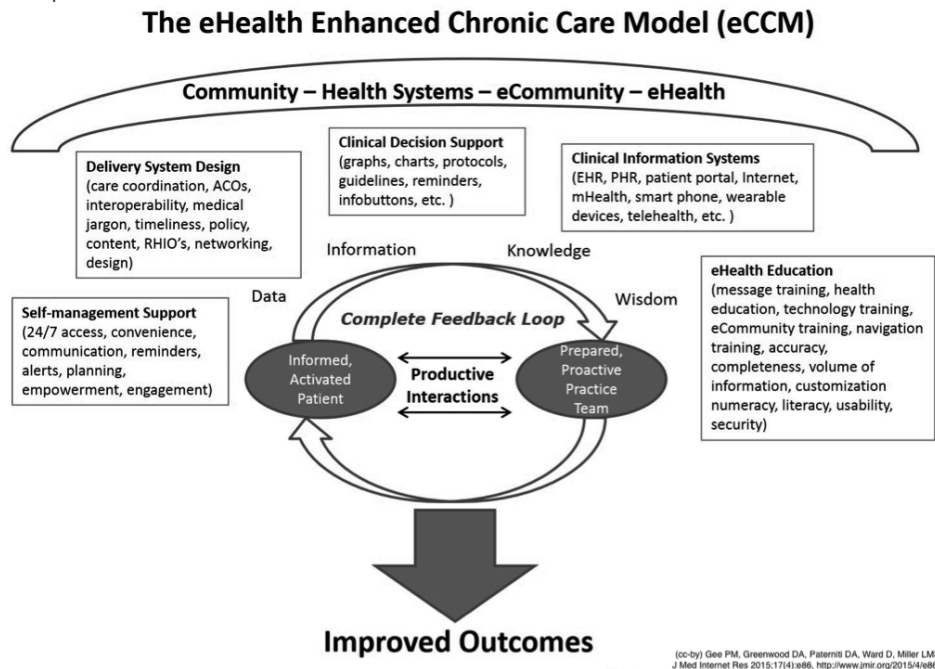
professionals is hampered by busy agendas, and if such contacts do take place, they are often incidental, with information being exchanged orally and not shared with others involved.

To improve the coordination of care for elderly and chronically ill patients, eHealth tools show potential, such as the sharing of care plans and online health communities [12,16-18]. Health care providers in The Hague realized this and started experimenting with a communication tool developed by a general practitioner, Congredi (Convenient Fastguide BV) in 2012 [19]. They surmised that the coordination of care would benefit if multidisciplinary communication increased. In 2013, a feasibility study of Congredi was performed on a sample in 2 neighborhoods. This showed that Congredi lived up to the original functional specifications and that professionals were motivated to continue exploring the use of Congredi. Also, a larger number of professionals than expected took part because of active early adopters who inspired their colleagues (41 instead of the expected 15). They were motivated to continue in cocreation as they had important requirements to be included in the new version of the tool and the supplier was perceived as cooperative [20]. An important requirement for these professionals was a link to their own administration system; adjustments in this area were made in the next release of Congredi, which was used for this study. The question was then raised whether an electronic communication tool for professionals could improve multidisciplinary communication and

whether this would affect the integration of care. A precondition is that such a tool is actually used by professionals.

The aim of this study was to evaluate the use of a tool for electronic communication and coordination (Congredi) by professionals in the care of home-dwelling elderly patients.

METHODS

Design

In this descriptive study, data were gathered from the Congredi system over a period of 10 months (42 weeks) and analysed.

The following research questions were addressed:
1. How many and which professionals are linked to Congredi records?
2. How many and which actions are performed by the professionals in Congredi records?
3. Is there a relationship between the combination of professionals in the care plan and performed actions?

Intervention

Congredi is a communication tool that was designed for multidisciplinary communication among professionals in primary care [19]. It is an easily accessible Web-based application and is compatible with existing health information technology but can also function as a stand-alone solution. It can be used on mobile phones, tablets, and computers. Congredi consists of a care plan that is usable at any moment in time. Within the care plan tasks can be delegated and feedback is received immediately. In addition, there is a communication channel (secure emailing) so the professionals can communicate asynchronously and at their own convenience.

To start Congredi, a professional opens a record for a patient and starts making a care plan, which is based on the patient-centred SFMPC (social, functional, mental, physical, and communication) domain model [8]. The professionals involved with this patient can be invited to link and can thus view the record, including the shared care plan. The activities that the professionals perform within the patient records are grouped into 3 categories. First, there are care activities, which consist of the following: (1) assessment of the current problems, structured by applying colours to current problems and automatically organizing according to SFMPC domain (Figure 2); (2) care actions, actions needed to address the problems of the patient (Figure 3); (3) observations of the care process and evaluation; and (4) care action adaption is performed after evaluating the care actions. Second, there is communication by secure emailing for sending and receiving emails to colleagues within Congredi (Figure 4). The content of the emails is only visible to those directly involved. Third, some process activities are also registered, namely, (1) becoming a coordinator, as it is possible to change the person who coordinates the record; a general practitioner occasionally starts the record and later "hands over" to the nurse; and (2) inviting involved professionals to link, which can occur at different

Figure 2. Congredi problem inventory: problems listed in text and in the social, functional, mental, physical, and communication (SFMPC) domains.

Figure 3. Congredi care plan: problems, aims and actions shown in social, functional, mental, physical, and communication (SFMPC) action blocks.

Figure 4. Congredi email module: secure email for professionals about their patients.

Berichten Zorgmail

Ontvangen Outbox Verzonden Verwijderd

Nieuw bericht

Selecteer hieronder de persoon of personen, aan wie u een bericht wilt sturen.

meijden

○ Mijn netwerk
● Alle netwerken/regio's
○ Mijn patiënten
Uitgebreid zoeken

Dhr. Meijden Mark van der Bergen op Zoom,... ›

Aan: Mark van der Meijden ✖

Gekoppeld aan: Kies een patiënt

Onderwerp:

Bijlage: Choose File No file chosen ⊕ ⓘ

Bericht: B I U abc ☰ ☷

Verstuur

3

moments in time during the care process. Congredi operates alongside the monodisciplinary electronic health records of the diverse professionals; it makes patient-related communication about current multidisciplinary problems possible.

Because of multidisciplinary communication, all professionals can update the care plan as the care develops. Thus, professionals are informed about the actions of their colleagues.

One professional coordinates the record and is responsible for linking other professionals.

Research group and recruitment procedure

The intervention Congredi was introduced to facilitate multidisciplinary communication about mutual patients at any time and place that was convenient to each professional. For this study, all general practitioners (n = 300) and home care organizations with district nurses (n = 650 nurses) in The Hague region were approached to participate; digital media were used, and the directors of home care organizations were approached personally. Professionals entered the study by applying for access to Congredi via their managers; they were then able to log-in to Congredi and received a standard half-day training.

They were then able to open a Congredi record for each patient in their care. The criteria for the patients were that they were home-dwelling elderly patients with 2 or more professional health caregivers. Patients had to give permission to open a Congredi record and share their care plan with other professionals.

Various types of professionals could participate in Congredi. In this study, we distinguished 3 groups of professionals: nurses (N), general practitioners (G), and other professionals (O).

Others could be physiotherapists, psychiatrists, geriatricians, social workers, and elderly consultants.

Variables and measures

Data were retrieved from the Congredi system at the end of the observation period, after 10 months (42 weeks), to answer the following research questions:

1. How many and which professionals are linked to patient records?
2. How many and which actions are performed in care plans?
3. Which relationship exists between professionals and performed actions in patient records?

The following variables were measured: (1) characteristics of health care professional using Congredi, that is, demographic data (age, sex), discipline (general practitioner, nurse, other professional), and whether coordinator of patient record (yes or no); (2) characteristics of patients in Congredi, that is, demographic data (age, sex); (3) multidisciplinary combinations of health professionals in Congredi, namely, coordination of patient record, combinations of health care professionals linked in a patient record, and number of health care professionals linked to each patient record; and (4) activities performed by health care professionals in Congredi, that is, frequency of activities (care, email, and process activities) and period in which activities took place per record (number of weeks).

Statistical analysis

The results were analysed using IBM SPSS 20 (IBM Corporation). The unit of analysis is the Congredi record of a patient (patient record). The demographic statistics of the population are described in frequencies and percentages. Analyses of variance, including Bonferroni post hoc tests, were performed to examine mean differences between subgroups.

RESULTS

Characteristics of professionals and patients

Of the 300 general practitioners and 650 nurses who were approached to participate, 21.4 % (203/950) actually took part. Among the professionals, 75.9 % (154/203) were female. The age group between 30-50 years was 49.3 % (74/203).

Nearly half of the participating professionals were nurses (47.3 %, 96/203); these included different types of nurses active in primary care, such as district nurses, case managers for dementia, and nurse specialists. General practitioners (19.2 %, 39/203) and other professionals (33.5 %, 68/203), including elderly consultants, physiotherapists, gerontologists, and social workers, were also active in Congredi.

In total, professionals opened 532 patient records. Each patient record had a coordinator; the coordinator was a nurse in 80 % (423/532) of the patient records, a general practitioner in 16 % (75/532), and other professionals in 4 % (33/532).

In 84 records, no further action was taken. In the remaining 448 patient records, actions were taken. Within these records, more than half of the patients were female (63 %, 282/448). The largest age group was 80-90 years (45.1 %, 202/448), and 13.9 % (62/448) of the patients were older than 90 years.

The number of weeks the professionals were active in Congredi varied: 37.9 % (77/203) were active between 1 and 26 weeks and the rest were active between 27 and 42 weeks. A total of 32.5 % (66/203) stopped within a week.

3

Combinations of professionals and level of action in patient records

Several combinations of professionals (Table 1) were found to be active in patient records. "Active" was defined as taking 1 or more actions within a patient record. On the basis of the participation of professionals, 3 types of patient records could be distinguished. The first type is referred to as "solo" in which 1 professional was linked; 41.1 % (184/448) of the records were solo records. The second type of patient record was "mono" in which at least 2 professionals of the same discipline were linked; 14 % (63/448) were monodisciplinary records. The third type was named "multi" with professionals from different disciplines; 44.9 % (201/448) were multidisciplinary records.

In the multidisciplinary records, a nurse's participation was the most, that is, in 96.5 % (194/201) of the records. This was followed by participation of general practitioners (81.6 %, 164/201) and other professionals (36 %, 73/201). Both the solo and monodisciplinary records consisted primarily of nurses (80.9 %, 149/184 and 88.9 %, 56/63, respectively). In the multi-disciplinary records, the most frequent combination of professionals was general practitioner-nurse (GN 63.7 %, 128/201), followed by the combination nurse-other professional (NO 18.4 %, 37/201) and the combination general practitioner-nurse-other professional (GNO 14.4 %, 29/201).

Activities Undertaken by Multidisciplinary Combinations in Patient Records

In the Congredi records, 3 types of professional actions (care activities, emailing, and process activities) were registered. Most activities occurred in the multidisciplinary patient records, with a mean number of 12.2 activities per record (Table 1). When professionals worked in monodisciplinary patient records, the mean number of activities was 6.35, and in solo patient records the mean number was 3.43.

Table 2 presents the relation between the activities performed in patient records (care, email, and process activities) and the multidisciplinary combinations of professionals who performed them. Multidisciplinarity was related to the level of activity.

Problem assessment, which takes place at the beginning of a care process, was found in 84.1 % (169/201) of the patient records; in most cases it was performed once (53 %, 107/201),

with a mean number of 1.26. Care actions, which are planned on the basis of problem assessment, were registered in 72.6 % (146/201) of the patient records; in nearly 50 % (95/201), care actions occurred more than once (mean 1.72). Observations, which occur between evaluative notes during the care process, were registered in 97 % (195/201) of the patient records, mostly in records in which nurses were active (mean 4.09). Care action adaption, which takes place in relation to the goal of the care process, was found in 70 % (141/201) of the patient records (mean 2.07). Emailing was used in 31.4 % (63/201) of the patient records (mean 0.89). Handing over coordination to a colleague was registered in 28.4 % (57/201) of the patient records. Inviting involved colleagues to link occurred a mean 1.88 times, ranging from 1 to 8.

Table 1. Combinations of healthcare professionals collaborating in patient records (n = 448)

Category	Combination[a]	Combination n (%)	Actions mean	Actions SD	Actions min	Actions max
Solo		184 (41.1)	3.43	2.30	1	13
	G	23 (12.5)	1.91	1.20	1	7
	N	149 (80.9)	3.68	2.39	1	13
	O	12 (6.5)	2.40	1.14	1	5
Mono-disciplinary		63 (14.0)	6.35	3.78	1	22
	G	5 (7.9)	2.40	1.14	1	4
	N	56 (88.9)	6.64	3.79	2	22
	O	2 (3.2)	8.00	1.41	7	9
Multi-disciplinary		201 (44.9)	12.20	11.25	2	95
	GNO	29 (14.4)	21.21	14,07	7	54
	GN	128 (63.7)	9.66	7.38	2	45
	NO	37 (18.4)	15.03	15.89	4	95
	GO	7 (3.5)	7.77	2.99	3	11
Combination including		201				
	G	164 (81.6)				
	N	194 (96.5)				
	O	73 (36.3)				

[a] G = General practitioner, N = Nurse, O = Others

DISCUSSION

Principal Findings

In this study, the use of a tool for electronic communication and coordination (Congredi) by professionals in the care of home-dwelling elderly patients was evaluated. The evaluation underscores the usability of Congredi for professionals in primary care because a large group of professionals (n = 203) were active in 532 patient records. Three research questions were examined.

Table 2. Activities in multidisciplinary patient records by different combinations of professionals

Activities	Frequency or mean	Total n = 201 (%)	GNO[a] 29 (14.4)	GN[b] 128 (63.7)	GO[c] 7 (3.5)	NO[d] 37 (18.4)	P value
Care activities							
Total care activities	mean	9.14	15.79 (GN,GO)[e]	6.87 (GNO,NO)	4.86 (GNO)	12.62 (GN)	<.001
Problem assessment	mean	1.26	1.90 (GN,GO)	1.06 (GNO,NO)	0.71 (GNO)	1.54 (GN)	<.001
	0	32 (15,9)	1 (3.4)	27 (21.1)	2 (28.6)	2 (5.4)	
	1	107 (53.2)	13 (44,8)	69 (53.9)	5 (71,4)	20 (54.1)	
	2+3	59 (29.4)	12 (41.4)	32 (25.0)	0 (0.0)	15 (40.5)	
	> 4	3 (1.5)	3 (10.3)	0 (0.0)	0 (0.0)	0 (0.0)	
Care action	mean	1.72	3.59 (GN,GO,NO)	1.31 (GNO)	1.14 (GNO)	1.78 (GNO)	<.001
	0	55 (27,4)	1 (3,4)	45 (35,2)	2 (28,6)	7 (18,9)	
	1	51 (25,4)	4 (13,8)	34 (26,6)	2 (28,6)	11 (29,7)	
	2+3	70 (34,8)	12 (41,4)	39 (30,5)	3 (42,9)	16 (43,2)	
	> 4	25 (12,4)	12 (41,4)	10 (7,8)	0 (0,00)	3 (8,1)	
Observations	mean	4.09	7.24 (GN,GO)	3.21 (GNO,NO)	2.00 (GNO)	5.08 (GN)	.006
	0	6 (3.0)	0 (0.0)	5 (3.9)	1 (14.3)	0 (0.0)	
	1-3	124 (61.7)	11 (37.9)	92 (71.9)	6 (85.7)	15 (40.5)	
	4-6	35 (17.4)	6 (20.7)	18 (14.1)	0 (0.0)	11 (29.7)	
	> 6	36 (17.9)	12 (41.4)	13 (10.2)	0 (0.0)	11 (29.7)	
Care action adaption	mean	2.07	3.07	1.28	1.00	4.22	.07
	0	60 (29.9)	3 (10.3)	47 (36.7)	3 (42.9)	7 (18.9)	
	1	49 (24.4)	5 (17.2)	35 (27.3)	1 (14.3)	8 (21.6)	
	2+3	69 (34.3)	11 (37.9)	38 (29.7)	3 (42.9)	17 (45.9)	
	> 4	23 (11.4)	10 (34.5)	8 (6.3)	0 (0.0)	5 (13.5)	
E-mailing							
Emails sent	mean	0.89	1.83	0.70	0.43	0.89	.13
	0	138 (68.7)	16 (55.2)	94 (73.4)	5 (71.4)	23 (62.2)	
	1	33 (16.4)	4 (13.8)	22 (17.2)	1 (14.3)	6 (16.2)	
	2+3	18 (9.0)	4 (13.8)	8 (6.3)	1 (14.3)	5 (13.5)	
	> 4	12 (6.0)	5 (17.2)	4 (3.1)	0 (0.0)	3 (8.1)	
Process activities							
Becoming coordinator	mean	0.29	0.31	0.32	0.14	0.19	.388
Becoming coordinator	mean	0.29	0.31	0.32	0.14	0.19	.388
	0	144 (71.6)	21 (72.4)	87 (68.0)	6 (85.7)	30 (81.1)	
	1	56 (27.9)	7 (24.1)	41 (32.0)	1 (14.3)	7 (18.9)	
	2+3	1 (0.5)	1 (3.4)	0 (0.0)	0 (0.0)	0 (0.0)	
Invite involved professionals to link	mean	1.88	3.28 (GN,GO,NO)	1.77 (GNO)	1.00 (GNO)	1.32 (GNO)	<.001
	0	15 (7.5)	0 (0.0)	9 (7.0)	1 (14.3)	5 (13.5)	
	1	74 (36.8)	5 (17.2)	43 (33.6)	5 (71.4)	21 (56.8)	
	2+3	95 (47.3)	13 (44.8)	71 (55.5)	1 (14.3)	10 (27.0)	
	> 4	17 (8.5)	11 (37.9)	5 (3.9)	0 (0.0)	1 (2.7)	

[a]GNO: general practitioner, nurse, and other professional.

[b]GN: general practitioner and nurse.

[c]GO: general practitioner and other professional.

[d]NO: nurse and other professional.

[e]The codes in parentheses (eg, GN, GO) indicate the groups with a significant mean score.

To answer the first question, "How many and which professionals are linked to Congredi records?" a total of 203 professionals were identified, at an inclusion rate of 21.4 % (203/950). Nurses represented the largest discipline at approximately half of the sample, besides general practitioners, and various other disciplines.

The second question was "How many and which actions are performed in Congredi records?" To answer this question, the patient records were divided into 3 categories. Patient records in which professionals worked on their own were defined as solo records (184/448, 41.1 %). When several colleagues of the same discipline were linked, this was considered a monodisciplinary record (63/448, 14.0 %). The largest group involved colleagues from different disciplines; these were defined as multidisciplinary records (201/448, 44.9 %). The highest level of activity was found in the multidisciplinary records (mean 12.2), but even in the solo records there was activity at a mean level of 3.43. The majority of the activities were care activities (mean 9.14; email had a mean of 0.89 and process activities 0.29). In care activities, the action that was performed most frequently was observations (mean 4.09), and other care activities (problem assessment, care action, and care action adaption) were found to be at a mean level of approximately 2. Emailing took place at a mean level of 0.89. Within the category of process activities, "inviting involved colleagues to link," which is a new action in the care process when using e-communication, took place at a mean level of 1.88. The action that was taken the least was "handing over coordination" (mean 0.29).

In answer to the third question, activity was found to increase with multidisciplinarity within the patient record. Most activities occurred in the multidisciplinary patient records, with a mean number of 12.2 activities per record (Table 1). When professionals worked in monodisciplinary records, the mean number was 6.35, and in solo records it was 3.43.

The conclusion is that Congredi is well used; there is significantly more activity when more disciplines are present in a record, and this is a prerequisite for effective care [21]. The results of this study therefore underscore the feasibility of Congredi to facilitate multidisciplinary communication concerning the care of home-dwelling elderly patients. Congredi might also be feasible in handover situations because different professionals can look at the same record and note their observations and activities. Therefore, every professional is informed of the latest situation. The findings of other studies show that handover situations are a great risk for this population [3,22]. The results of our study show that this risk can be alleviated with a digital communication system, including a patient record. More research is needed to verify whether the quality of care does, in fact, increase.

Observations Concerning Implementation

Further diffusion of this innovation is promising. A participation rate of 21.4 % was achieved, which is quite successful for an innovative intervention. An explanation might be found in Rogers' theory on Diffusion of Innovation. He found that in the first phase of diffusion the adoption rate is generally approximately 16 %, with innovators and early adopters using it [23]. It is posited that the point at which innovations tend to diffuse in society to the level where they

can sustain themselves is when the early and late majorities become active after the innovators and early adopters (16 %) [23].

In nearly half of the patient records, multidisciplinary communication about care problems actually took place. This is a high rate. Part of the higher adoption rate in this study could be explained by the regional approach with which the context was managed. It could also be explained by the stepwise implementation based on feedback by the users (choice of communication tool, feasibility study, decision to evaluate the innovation) and support at an administrative level.

When implementing an e-communication tool in primary care, it is interesting to examine not only whether the professionals use the tool but also whether it has potential to support them in their professional work methods. In this study, we found that the care plan was used as it was intended; problems were assessed, actions were defined, observations were noted, and actions were adapted (Plan-Do-Check-Act cycle). Problems were listed in 85 % (169/201) of the patients' records. In most cases, the number of problems during the study period did not increase (in more than half of the cases, only one problem was registered); in a third, there was more than one problem, which could be a signal for higher complexity (Table 2). Care actions were defined in approximately three-fourths of the records; in half of the records more than one action was taken. Observations were found in nearly all the records; sharing them with colleagues is a form of integrating care because professionals can act on the observations of colleagues. Care actions were adapted in over two thirds of the records; in half this took place more than once. This could indicate instability. In conclusion, a relatively active multidisciplinary practice was shown in relation to the duration of the study (10 months).

New Functionalities in Care Process

Congredi also offers new functionalities for professionals compared with usual care. Understanding how professionals use these functionalities is important for the further implementation of this program.

First, it is now possible for coordinating professionals to actively invite their colleague to link to a mutual patient record. This can be viewed as strengthening the network around the elderly; in this way, the relevant professionals have a direct overview of the situation and can thus take relevant action. This was done by the professionals in more than 90 % of the patient records. In combinations with nurses and general practitioners (GN), 2 or more other professionals were invited during the 10 months. Because the relevant colleagues actively shared a care plan, it could be supposed that they perceive this functionality as supportive to their work process.

Second, sharing observations about patients took place on a large scale. Making observations was not new, but the transparency of sharing observations that could influence actions of other professionals was new. The exchange of such relevant information could result in a better-informed professional team, as indicated in the eCCM [12]. Further research could be done to determine whether this has an effect on decreasing the fragmentation of care.

Third, emailing within the patient record was a new function of the e-communication tool, which made it possible to view the care plan and the email communication together. This was expected to be experienced by the professionals as an improvement. Emailing took place in 31.4 % of the patient records at a mean level of 0.89. This level was lower than

expected, which might be explained by the fact that there are other email channels that are already in use.

All of the functionalities gained by using an e-communication tool are important prerequisites for effective communication among professionals about a patient care plan. This study shows that linking colleagues and sharing observations, which could result in stronger networks and integrated care, appealed to the users the most.

Another finding of this study was that approximately 40 % of the professionals, the solo records, did not use Congredi as a multidisciplinary communication tool; they opened patient records but did not invite colleagues to link. Half of this group did, however, perform actions within the patient records. Through some personal communications, an explanation was given that Congredi helped them structure their own work more than the tools they had at their disposal. Because electronic administration tools in home care organizations in the Netherlands are primarily directed at cost administration in contrast to supporting nurses in their nursing work and because by far the largest discipline that worked solo in the care plan was the group of nurses (80 %), this might be a motive. Most general practitioners already have an effective electronic administration tool. This could explain why a relatively small group worked alone and why the general practitioners in solo records were less active than the nurses and other professionals. Professionals continually strive for easy access between tools such as Congredi and their own professional administration systems; the feasibility study showed that not having a direct link influenced their motivation to participate actively in multidisciplinary communication. Facilitating work processes logistically should be a focus in further implementation.

Clarification Needed

During the study, the focus was on whether the professionals would use the tool and were able to use it. This goal was successfully achieved as professionals entered the study and patient records were opened. During the analysis, another question surfaced: Which frequency of actions in an electronic communication tool makes it successful? In other words, what level of activity in the patient records means that the tool is successful within the work process? In this study, the results show quite a variance in the number of actions in multidisciplinary patient records. In some patient records, there was little action, and in others there was much more. It is possible that professionals are just not using the tool. Another reason could be that factors related to the patient's situation influence the number of communications. Two studies about interprofessional communication in primary care give some indication. An observational study in primary practice stresses the fact that frequent communication through different communication channels is effective [24]. Peeters et al [25] found that there tends to be no interdisciplinary communication if nothing is wrong. The insight that, depending on the situa-

tion, patients rely more or less on the support of professionals could help with implementation. Therefore, if there is little communication in a stable situation, professionals do not need to be disappointed, and when there is deterioration in the patient's situation, more contact is expected. The findings in the literature also show that patients seem to appreciate the possibility of e-communication with their professional [26].

Strengths and Limitations

A methodological strength of the study was the large number and diversity of participating professionals and patient records. In addition to a relatively high participation rate, active communication was found among the professionals. As discussed previously, this was mainly due to the management of the context within which the innovation took place.

A limitation was that little comparison with "usual multidisciplinary communication" was found in the literature. It would be interesting to determine how the degree of peer communication within Congredi relates to multidisciplinary communication without Congredi. One study showed some quantification of structural communication on a yearly basis as perceived by the professionals, but because it was not specified per patient, a comparison with this study cannot be made [10].

In this exploratory study of multidisciplinary communication using electronic tools, quantitative data were used; this is an important first step to gain insight into the use of e-communication by professionals. Studying registered data has a limitation. For more insights into barriers and facilitators, qualitative data might be useful.

CONCLUSION

In conclusion, Congredi has the potential to improve multidisciplinary communication for home-dwelling elderly patients with 2 or more professional health caregivers. In this study, it was used by a large group of professionals for their patients. Congredi seems to support professional work processes, and it offers new functions that have the potential to improve quality of care. Further research is needed to understand its implementation for different groups of patients.

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Professionals' use of a multidisciplinary communication tool for patients with dementia in primary care

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ABSTRACT

In this descriptive study, the use of a professional e-communication tool, Congredi, is evaluated. Ninety-six Congredi records of patients with dementia could be divided into the subgroups low-complex care (n = 43) and high-complex care (n = 53). If Congredi is an adequate communication tool for professionals, the changing involvement of caregivers must also be reflected within the two subgroups.We hypothesized that use would be more intensive in the high-complex group in comparison with the low-complex group. Data were gathered during 42 weeks.

Results showed that the mean number of care activities in the high-complex group was significantly higher than in the low-complex group (10.43 vs 5.61, P = .001). The number

of professionals involved with the high-complex care group (3.58) was higher compared to the low-complex care group (2.51) (P = .000). The most frequent use was by case managers and nurses (43.4 %) in the high-complex group and by several case managers (41.9 %) in the lowcomplex group.

It was concluded that professionals used Congredi adequately in the multidisciplinary care of patients with dementia because the changing involvement of caregivers and the level of care activities were reflected in the use of Congredi.

Keywords

Care, primary nursing; eHealth; patient care continuity; dementia.

INTRODUCTION

Continuity of care for patients with multiple problems in primary care is at risk because of fragmentation. [1] Often, several different professions are involved, and multidisciplinary communication to coordinate care comes under pressure because of poor accessibility of the providerss in addition to travel time. [2]

Research based on the Chronic Care Model (CCM) has shown positive effects on health outcomes, health services use and patient-reported outcomes in chronic care when collaboration and communication amongst providers are improved. [3-5] Recent evidence on the emergent use of eHealth has led to an expansion of the CCM to the eHealth enhanced CCM (eCCM) (figure 1).[6,7]

Figure 1. The eCCM
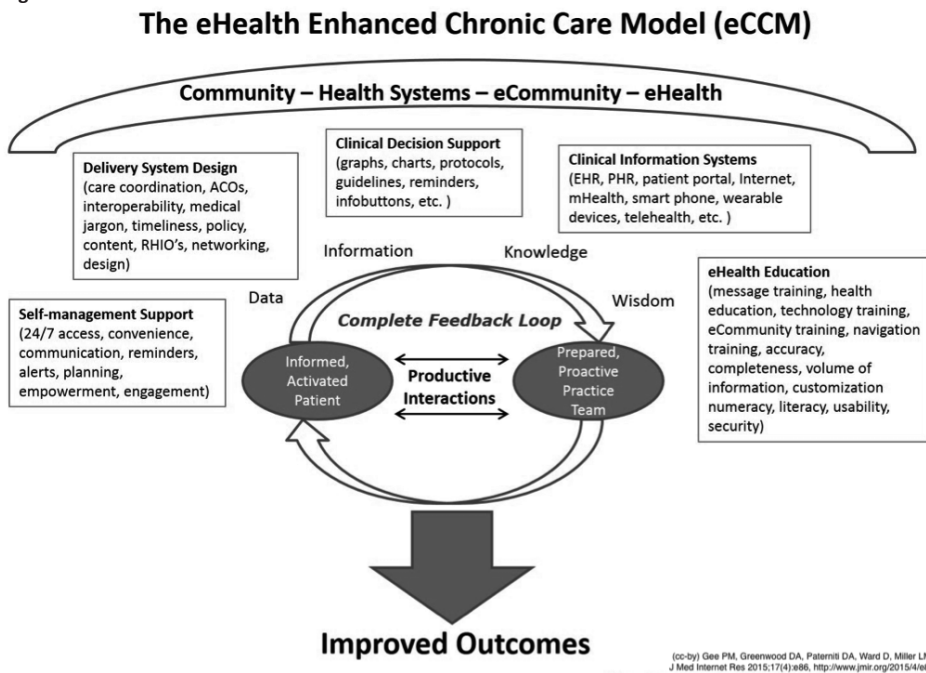
In recent years, electronic communication tools have become available in primary care to facilitate multidisciplinary communication among providers, but adoption is low [8-10] Several reviews to evaluate the use of innovative tools have been performed. [7,11] However, in these studies, attention was focused on use of the tool by the target group of patients. No solid studies that deal with the use of e-communication tools by professionals in primary care have been found. Because this does not necessarily reflect whether providers use the tool in the care process, recently we reported on the use of an e-communication tool for professionals in

primary care in theNetherlands. [12] A multidisciplinary digital communication tool, Congredi (Fast Guide, Oud Gastel, the Netherlands), was implemented to improve communication about care among providers. It includes an interactive multidisciplinary care plan and a secure e-mailing channel. It was selected on the basis of jointly developed functional specifications. It was expected that the use of the tool would lead to reduced costs because fewer phone calls and travel time are needed and providers can work more effectively because they can communicate at a convenient time and place. A bottom-up approach was chosen to guide further development and implementation. [13,14] It seems a promising tool because professionals use it. In our study, it was used by a large group of professionals (N = 203) and deemed usable because they performed actions as expected, such as regularly adapting care goals, communicating by a secure communication channel, or inviting relevant professionals to link. [12] However, even with this outcome, little is said about the adequacy of use. Adequate use was defined as "whether the intensity of use of the tool is reflected in the use of Congredi." Therefore, in this study, the focus was on evaluating the use of the tool in a care context that differed in complexity.

THE STUDY

Aim

The aimof this study was to evaluate whether providers used the tool adequately, by measuring whether use differed between complex and less complex care situations. The assumption was that, if providers involved in the care of a specific patient group used Congredi adequately, changing levels of involvement among providers would be reflected in the use of Congredi. This led to the following expectations:

1. During less complex care, fewer providers are involved in Congredi patient records; during complex care, more providers are involved.
2. During less complex care, the level of care activity per patient is lower than during complex care.

To compare usage in the two subgroups, the following research questions were addressed:

1. How many and which providers are linked to the Congredi system for the less complex and complex groups?
2. How many and which actions are performed within the Congredi system in the less complex and complex groups?
3. Is there a difference in the number of actions per patient between the less complex and complex groups?
4. Is there a difference in the number of providers per patient between the less complex and complex groups?

Design

An observational, comparative study was performed across two subgroups of patients, one with less complex care needs and one with complex care needs. Data were gathered from the Congredi system over 42 weeks between March and December 2014. The research was submitted to the medical ethical committee; it was considered that no further review was necessary.

The Tool

Congredi is a communication tool for providers, and it was originally developed for primary care by a general practitioner. It consists of an option to share data in a care plan and asynchronous communication options using secure email. The included multidisciplinary care plan was based on the social, functional, mental, physical, and communication problem inventory domain model. [15] Providers received a practical instruction training session lasting 4 hours and demonstrating use of the Congredi tool. The patient had to give permission to begin a record and to invite providers to link. After patient permission was obtained, a provider opened a Congredi record for the patient and filled in a care plan. Other providers who were involved with the patient and had access to Congredi could be invited by link so that they could view the care plan and use it interactively. Provider actions were recorded in the system. The following are three main categories of actions: care actions (problem assessment, defining care goals, observing patients' health status, and adapting care goals), e-mailing, and inviting other providers to link. All providers had the ability to update the care plan and initiate actions; they received alerts when there were e-mails in their inboxes.

Participants

We first selected Congredi patient records with multiple healthcare providers and then investigated whether it was possible to distinguish subgroups according to care levels (ie, complex and less complex care). We chose records for patients with dementia. In the Netherlands, the case manager dementia (C) has a central role in the care for people with dementia. C is assigned to patients from the time that dementia is confirmed or suspected. [86] Case managers are primarily specially trained nurses whose goal is to guide the patient and informal carers in dealing with the disease and to coordinate care around the patient. [87] In this way, the case manager functions as a "safety net" around the patient and can communicate with or refer to other providers within primary care, such as the general practitioner and nurse. [18,19] At the beginning, the network of involved professionals consists of a case manager, a general practitioner, and, incidentally, a paramedic, such as a physiotherapist.

When physical needs increase and more care is required than can be provided by C, C is responsible for connecting with other providers, primarily a nurse (N). [16] The presence of a nurse in the care record can therefore be construed as an indication of a more complex care situation. Thus, on the basis of the presence of a nurse, we could distinguish between less

complex and complex care situations: the presence of a nurse in Congredi records indicates a complex care situation; the absence of a nurse indicates a less complex situation.[16]

Data collection

Data were retrieved from the Congredi system during 42 weeks in 2014. Providers could initiate Congredi records during the whole period.

The following variables were measured:

Characteristics of patients in Congredi

- Demographic data (age, sex)
- Diagnosis (dementia)

Providers linked to Congredi records

- Number and type of providers per record
- Combinations of providers in records
- Type of activities (care activities, e-mail messages, and inviting colleagues to link)
- Frequency of activities per record

Data analysis

The unit of analysis was the Congredi record. Analysis of variance was performed using IBM SPSS Statistics version 20 (IBM, Armonk, NY).

RESULTS

Ninety-six patients with more than one professional involved were selected (n = 96), as shown in Table 1. Within this group of patients with dementia, 43 were in the less complex group and 53 were in the complex group. Most patients were older than 80 years (68.7 %), and females were prevalent (58.3 %).

Table 1. Characteristics of low-complex and high-complex patients in Congredi

Variables	Categories	Low-complex n = 43 (%)	High-complex n = 53 (%)	Total patient records n = 96 (%)
Age				
	< 70	1 (2.3)	3 (5.8)	4 (4.2)
	71-80	11 (25.6)	15 (28.8)	26 (27.1)
	81-90	23 (53.5)	30 (57.7)	53 (55.2)
	> 90	8 (18.6)	4 (7.7)	12 (12.5)
	Missing		1	1
Gender				
	Male	16 (37.2)	18 (38.3)	34 (35.4)
	Female	27 (62.7)	29 (61.7)	56 (58.3)
	Missing		6	6

Table 2 shows the mean number of professionals active in patient records of patients with dementia (3.10). There was a significant difference in the number of professionals involved between less complex and complex patients (2.51 vs 3.58, P = .000). Nurses were present only in the complex group. The mean number of casemanagers dementia (C) was lower in the complex group (1.65 vs 1.19, P = .000). The mean number of general practitioners (G) and paramedical caregivers (P) was slightly but not significantly higher in the complex group.

Table 2. The number of professionals involved in Congredi

Professionals	Low-complex mean (SD) n = 43	High-complex mean (SD) n = 53	Total mean (SD) n = 96	p
C	1.65 (0.53)	1.19 (0.40)	1.40 (0.51)	.000
N	0.00 (0.00)	1.36 (0.62)	0.75 (0.82)	.000
G	0.72 (0.91)	0.77 (0.89)	0.75 (0.89)	.776
P	0.14 (0.35)	0.28 (0.57)	0.22 (0.49)	.151
Total	2.51 (0.70)	3.58 (1.67)	3.10 (1.43)	.000

Abbreviations: C, case manager dementia; G, general practitioner; N, nurse; P, paramedical caregiver.

In Table 3, the different combinations of providers linked to less complex and complex patient records were shown. In the less complex group, in 41.9 % of the records, there was only a combination of case managers dementia. A general practitioner was linked to 46.5 % of the records (CG and CGP); and paramedical caregivers, in 13.9 % (CGP and CP). In patients with complex care, the combination ofCN occurred most frequently (43.4 %). A combination with a general practitioner (CNG and CNGP) was found in 52.8 % of the records, and in 20.8 %, there was a combination with a paramedical caregiver (CNGP and CNP).

Table 3. Combinations of professionals in Congredi

Combinations of professionals in Congredi	Frequency n (%)
Low-complex (n = 43)	
CC	18 (41.9)
CG	19 (44.2)
CGP	1 (2.3)
CP	5 (11.6)
High-complex (n = 53)	
CN	23 (43.4)
CNG	19 (35.8)
CNGP	9 (17.0)
CNP	2 (3.8)
Total	96

Abbreviations: C, case manager dementia; G, general practitioner; N, nurse; P, paramedical caregiver.

Table 4 shows for which activities Congredi was used within the two groups. In the complex group, there was almost twice as much care activity (10.43 vs 5.61, P = .001). In addition, frequency of e-mailing (1.28 vs 0.25, P = .040) and the number of providers invited to link (2.20 vs 1.27, P = .000) were also significantly higher.

Table 4. Actions in Congredi

Actions in Congredi	Low-complex mean (SD) n = 43	High-complex mean (SD) n = 53	Total mean (SD)	p
Care activities				
problem inventory	1.05 (0.68)	1.30 (0.82)	1.19 (0.77)	.102
care action	0.93 (0.79)	1.83 (1.91)	1.42 (1.57)	.004
care action adaption	0.95 (0.89)	1.81 (1.85)	1.42 (1.57)	.006
observations	2.68 (1.64)	5.49 (4.80)	4.22 (3.96)	.000
Total care activities	5.61 (3.17)	10.43 (8.54)	8.25 (7.06)	.001
emails sent	0.25 (0.62)	1.28 (3.24)	0.81 (2.48)	.040
invite involved professionals to link	1.27 (0.82)	2.26 (1.60)	1.81 (1.39)	.000

DISCUSSION

The results of this study indicate that the providers adequately used the innovative electronic communication tool Congredi in their care for patients with dementia. The results were identified by comparing use for the less complex and complex groups of patients with dementia care.

A first indication for adequate use is that providers were technically able to use the tool. In this light, it was deemed a positive result that the providers used all elements of Congredi. Second, the results seem to indicate that Congredi was adequately used as a communication tool for providers involved in the care of patients with dementia, because use seemed to be adapted to each patient's situation. Use of Congredi for the complex group was more intense compared to that for the less complex group. A third indication of adequate use is that, in the less complex group, nearly half of the patients had two case managers linked to their record. This does not signal higher complexity because, apparently, no other professionals were needed; however, it could mean that the case manager needed backup from a colleague in case of absence or for collegial consultation. This could suggest that, for continuity of care, case managers find it advisable to have a colleague case manager linked to the patient record. [19] In the complex patient group, a second case manager was less necessary because there was always a nurse present beside the case manager to support the continuity of care. In approximately one-third of the cases, two nurses were involved.

Some findings concerning the pattern of provider involvement are interesting, for instance, the involvement of the general practitioner. In the Netherlands, the general practitioner has the role of gatekeeper of the care, and every patient has a general practitioner. To carry out this role, it is necessary that the general practitioners monitor the current status of the patient. One would therefore expect every patient with dementia to have his/her general practitioner linked to the Congredi patient record. However, the number of general practitioners involved was comparable in both groups at approximately 50 %, indicating that half of the patients did not have a general practitioner linked to their Congredi record. This fact is not surprising, because a patient generally does not have an increasing number of general practitioners when the situation deteriorates. However, the fact that a general practitioner was linked in only half of the Congredi records requires an explanation. Congredi is an innovation, and it could be that the level of implementation had not reached all general practitioners, and that they were not active in opening Congredi accounts so that they could be linked to patient records. On the other hand, one would expect the case manager and nurses to ensure that a general practitioner was linked to the patient record, because the general practitioner is necessary for many aspects of decision-making concerning patient care. It seems advisable not only to specifically instruct case managers to invite the general practitioner to link, but also to convince the general practitioner of the importance of taking initiative to become connected. For general practitioners, Congredi is an additional system, and it is a known barrier that they do not participate actively in additional eHealth systems if their own administrative system cannot interface with the additional adaption. This barrier should be overcome by policy changes at the supplier and payer level.

Another interesting pattern was the low, although increasing, involvement of paramedical caregivers. We did not find the low number unexpected, because we did not focus on the paramedical caregivers when creating the sample. The fact that their numbers increased for patients in complex care situations is promising.

The pattern of involvement of case managers shows that their number decreased in the complex group, but they remained present. This can be explained by the fact that coordinating tasks might be handed over to nurses if they have more regular contact with the patient system.

Concerning the number of activities in relation to adequate use, there were some interesting findings. In the care plans, activities that were relevant in multidisciplinary care were noted. The level of care activity varied between the two patient groups; there was twice as much activity for patients in the complex group. This is as expected and might indicate adequate use of the tool. On reflection, the question arises whether this is an average level of activity in multidisciplinary care; can this be perceived as a high or low level of activity? It was not clear in the literature what the usual level of multidisciplinary communication in primary care is for

patients with dementia.[21–23] It is therefore difficult to compare these results with "usual care" in electronic multidisciplinary communication.

The pattern of activities found in Congredi may also reflect adequate use of the tool by providers because all activities increased when the care situation became more complex. This distribution of the care activities reflects what professionals are trained to do: perform care methodically, which usually includes assessing problems, initiating actions, observing effects, and adapting their actions. In multidisciplinary care, Congredi is an advantage because providers will be able to communicate easily with each other during increased activity. [24]

Interestingly, besides the expected activities, there were some new activities taking place in Congredi. These activities deserve special attention because they increased significantly.

The reason could be that in Congredi, unlike in a paper file, providers receive an alert when there is new information in a patient record, and this may trigger additional activity. First, there is an increase in the activity "observations," which involves sharing notes on patients' care among providers. In the primary care setting, this is important because often the providers do not share a patient administration system or even a workplace. If this communication had taken place during a "live" meeting, it would have taken a lot of time. To share observations, providers are dependent on visits or telephone calls, which require travel and being available at the same time. Secure e-mailing is also an option, but this may occur without viewing the care plan and is therefore inconvenient because the receiving party must find the information in their own record system. This is in contrast to Congredi, in which the care plan and notes are both accessible. Second, there is an increase in the activity "invite involved professionals to link." This action enlarges the safety network around the patient. This is a necessary element when more professionals are involved in the care of the patient and more action takes place. When professionals are linked, fragmentation of care can be prevented. [25,26] In addition, there is a slight increase in secure e-mailing, although the absolute volume remains small. We expected a higher increase, but this may be lower because the need to use e-mail is less due to the shared information in the care plan.

At some point, it would be interesting to also invite patients to join the collaboration. When professionals use an e-communication tool adequately, the results become transparent in the e-care plan. Then, it would be possible to create adequate interaction between patients and professionals. [27] This has been shown to be effective by Gee et al [6] in the eHealth-enhanced CCM. [7] Further research could be performed to examine whether health outcomes and health behavior improve. [28]

CONCLUSION

This study indicates that healthcare providers involved in the multidisciplinary care of patients with dementia use the innovative e-communication tool Congredi adequately in the care process. The changing involvement of professional caregivers and the level of care activities during differing complexity of the care were reflected in the use of Congredi. Therefore, it is plausible that providers used the tool adequately. Further research can focus on whether the use of an e-communication tool, resulting in increased communication, leads to a better quality of care and patient outcomes.

4

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4

E-communication amongst patients and professionals

The challenge of involving elderly patients in primary care by using an electronic communication tool with their professionals: a mixed methods study

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ABSTRACT

Background: Elderly patients in primary care often have multiple health problems, with different healthcare professionals involved. For consistency in care it is required that communication amongst professionals and patient-systems (patient and informal-carers) be well tuned. Electronic-communication can make it easier for patient-system to be active in care.

Objective: To examine whether an e-communication tool (Congredi) designed for professionals, including a care plan and secure e-mail, is usable for patient-systems and what their experiences are.

Methods: In a multi-method study home-dwelling elderly patients with two or more professionals were invited to use Congredi; data were gathered from the system after 42 weeks. Also semi-structured interviews were undertaken with patient-systems.

Results: Data about actual use of the tool were gathered from 22 patients. Four profiles of Congredi-users were distinguished, varying in intensity of use. Data from interviews with members of patient-systems (n = 7) showed that they were motivated and able to use Congredi. Barriers in daily use were limited participation of professionals, unanswered e-mail and not being alerted about actions. Despite limitations patient-systems retained their motivation.

Conclusion: Congredi was usable for patient-systems. The barriers found seem not to be tool-related but primarily user-related. An important barrier for daily-use was limited active participation of involved professionals in a Complete Feedback Loop. Potential for future implementation was found, as patient-systems were intrinsically motivated for better feedback with the professionals, even though in this study it only partly met their expectations.

INTRODUCTION

Elderly patients in primary care often have multiple health problems, with different health care professionals involved. [1] For consistency in care it is required that communication amongst all be well tuned. [2] Much can be gained if patient-systems communicate productively with involved professionals. [3-7] This is underscored by the chronic care model (CCM), which states that an informed, active patient-system in interaction with a prepared, proactive practice team improves the quality of patients' outcomes. [7-9]

Evidence shows that eHealth technology, including electronic communication, can make it easier for the patient-system (patient and informal-carers) to be active in care. [10-16] With the advent of eHealth it is relevant to understand in which way e-communication tools can support patient-systems to become active. [14,17-19] From the literature it has become clear that successful eHealth interventions need to contain a Complete Feedback Loop (CFL). [16] According to Gee et al the CFL should consist of five stages of communication in which both professionals and patient-systems have an active role: (1) transmission of data and information about patients' health status, (2) interpretation of data and information using previously established knowledge and/or wisdom and use of evidence-based standards, (3) address the specific need of the individual patient, (4) timely feedback to the patient addressing their needs, and (5) regular repetition of the feedback loop. [16]

Besides promising outcomes, researchers have identified challenges that occur and need attention when implementing e-communication tools. [20-26] First, barriers concerning technical aspects of the tool have been identified: ease of use, perceived usefulness, efficiency of use, availability of support, comfort in use, and site location. [20] Second, patient characteristics such as low income, education, cognitive impairment, low computer literacy, as low social support and high illness burden have been shown to influence use of e-communication.[20,27] Third, professional characteristics influence use of the tools. For instance healthcare providers beliefs (is the tool useful for professionals and patient) [24,28,29] the fact that general practitioner adoption of email remains low even though it is easily available [26] professionals do not give equal priority to e-communication (nurses are more conscientious than physicians) [29] low computer literacy, insufficient basic formal training in health IT applications, physicians' concerns about more work; workflow issues; problems related to new system implementation, including concerns about confidentiality of patient information; depersonalization; incompatibility with current health care practices; lack of standardization; and problems with reimbursement.[20] Fourth, barriers to implementation can also be found at the institutional level. There are concerns about confidentiality and security[103] unclarity in the implementation process concerning decisions about roles, sufficient time and sufficient competence of professionals.[24,29]

The challenge in this study is to find out whether it is feasible to connect a newly developed professional tool, which has been shown to work, to patients. Given that e-communication

between professionals and patient-systems seems to be helpful, a prerequisite is that patient-systems are able and motivated to use the tools. [18] The aim of this study was to describe the use and experiences of patients with an e-communication tool (Congredi), which was selected by partners in primary care.[30]

METHODS

The following research question was addressed: is an e-communication tool for professionals (Congredi) usable for elderly patient-systems to participate in care?

Design

A mixed-methods design was chosen. [17,31,32] To examine the actual use of Congredi by patient-systems quantative data were retrieved from the Congredi data system during 42 weeks. Also data were gathered from individual interviews with members of patient-systems to examine their experiences, motivation and satisfaction with Congredi. The interviews were semi-structured and were scheduled to take 30 minutes. All interviews were audio-recorded and transcribed verbatim. Respondents were offered the choice of being interviewed face-to-face or by telephone.

Intervention

Congredi is a communication tool developed for professionals by professionals. [30] It consists of patient records with a care plan and a communication channel (secure e-mailing). Professionals use it to communicate about care of a mutual patient. For each patient a record is initiated, with a care plan based on the Social, Functional, Mental, Physical and Communication (SFMPC) domain model. [18] In the plan current care problems are assessed, involved professionals make observations and care actions are assigned. The secure e-mail channel can be used for sending and receiving e-mail to colleagues about the care plan. One professional is appointed as coordinator of the patient record and is responsible for linking other professionals. All professionals can update the care plan. To achieve optimal communication in a CFL about a mutual patient there are two conditions: first that all involved professionals link to the patient-record and second that they are active and react to communication of others.

The intervention consisted of giving patient-systems access to their Congredi record through a patient portal, enabling them to view their care plan and to communicate with the professionals. They could actively contribute by monitoring the care plan and communicating or giving feedback about their needs to their professionals. The intervention was limited to providing access to the communication tool for professionals; no specific adjustments for patients were made with respect to professional jargon or addition of specific paragraphs of special interest for the patient-system.

Inclusion in the sample

The study population consisted of the patient-systems (patient and informal-carers) of elderly patients with two or more professionals involved. A convenience sample was recruited. The professionals invited patient-systems with whom they already had good communication, using face-to-face contact, telephone or unsecure e-mail, and they expected they were capable of using Congredi. These patient-systems were invited to become a Congredi-user by the general practitioner or nurse. To enter Congredi patients had to give informed consent to start a patient-record and to link relevant healthcare professionals to it. Part of the approached population, namely those who became active users of Congredi, was invited for an interview by e-mail from their coordinating professional.

Variables and measures

Actual use was mapped quantitatively with variables from the system. First, the characteristics of the patients (age, gender) and discipline of the coordinating professional were retrieved. Second, data about the actual use of Congredi by the patient-system were gathered: duration, number of professionals involved per Congredi record, frequency of use and type of actions. Duration of active use was defined as the number of weeks within which patients were active in Congredi, starting from the first time they logged on and ending at the end of the measuring period or, if patients stopped prematurely, the date of the last action by the patient-system. The date of the last action was defined as the date followed by a period of at least 12 weeks in which no actions took place. Frequency of use included all actions that took place when the user logged on to Congredi. The types of action encompassed Congredi record views and e-mail communications (receiving, sending and reading). Last the number of prematurely stopping patients was retrieved.

From the interviews three types of variables about experiences with the use of Congredi were retrieved. First, the characteristics of the patient-system-member were gathered: role (patient or informal carer), gender, age, living situation, social activity, education level, computer competency, relation to patient, distance to patient, intensity of care. Second, the users' perception of usability of Congredi was assessed (technical problems, attractiveness, user-friendliness). Third, motivation, expectations, experiences and satisfaction with Congredi were discussed.

Analysis

Quantitative data were described using frequencies in SPSS 20. The data concerning the actual use of Congredi were analysed at patient-system level; the system did not have the option to distinguish between users of the patient-system, thus also not between patients and informal-carers. When more than one professional from the same profession was involved (for example several district nurses), one person represented the subgroup. Due to privacy considerations, we used only anonymous data from Congredi and therefore it was not possible to link the interviewees to a Congredi record.

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Data on motives and experiences, encouraging and impeding factors have been gathered through interviews. Semi-structured interviews were held, ensuring that all topics in the topic list (appendix 1) were discussed. The topic list was compiled from themes found in the literature. With regard to usability, a fairly strict structure was made in advance by carefully monitoring technology, user-friendliness and attractiveness. The other components (motives, experiences, satisfaction) were also structured. Each theme was launched with an open question to give the respondents the space to tell their own story. The interviews were scheduled to take 30 minutes. All interviews were audio-recorded and transcribed verbatim. Respondents were offered the choice of being interviewed face-to-face or by telephone. One researcher conducted all the interviews (CJ) and two researchers (CJ, WR) analysed the results independently. The themes were extracted together and discussed until consensus was reached.

RESULTS

Description patient-systems in Congredi

Forty-six patient-systems were offered the opportunity to log on to Congredi. Twenty-two patient-systems actually logged in (47.9 %) and thus had an active patient record in Congredi. The majority of the patients in the Congredi records was female and between the age of 80 and 90 years old (Table 1). In 20 of the 22 patient records, the coordinator was a nurse. The other two coordinators were general practitioner and elderly care consultant.

Table 1. Description patients in the Congredi records

Variables		Active pat n = 22 (%)
Age		
	< 70	3 (13,6)
	71-80	3 (13,6)
	81-90	13 (59,1)
	> 90	3 (13,6)
Gender		
	Male	8 (38,1)
	Female	13 (61,9)
	Missing	1

All patient-systems (n = 22) that had logged on to Congredi were invited for an interview. Seven members of a patient-system accepted the invitation; all were informal-carers and a child of the patient: three sons and four daughters (table 2). The majority was over 50 years of age, had followed post-secondary school education, did not live with the patient but their own family, had a (voluntary) job and felt they were highly competent computer users. Four lived

near to their parent (cycling distance). All reported that, within the patient-system, they had the task of monitoring Congredi.

Table 2. Description of members of the patient-system who gave an interview

In-formal carer	Sex	Age	Relation to patient	Education level	Distance to patient	Intensity informal care (visit + telephone)	Computer competency	Living situation	Social activity
A	F	> 65	Child	University	Far	Weekly	High	Partner	Retired
B	F	50-65	Child	University	Far	Weekly	High	Partner + children	Job
C	F	> 65	Child	Secondary	Far	Weekly	High	Solo	Volunteer
D	M	50-65	Child	University	Near	Daily	High	Partner	Job
E	M	50-65	Child	Vocational	Near	Daily	High	Partner	Job
F	M	50-65	Child	Vocational	Near	Weekly	High	Partner	Job
G	F	< 50	Child	University	Near	Weekly	High	Solo	Job

Actual use of Congredi by patient-systems

Results pertaining to the duration of use show that from the moment the 22 patient-systems had registered in Congredi, there were activities in their record from 1 to 38 weeks during the 42-week observation period (table 3). Fifteen were still active at the end of this period; seven stopped prematurely.

The number of professionals active in Congredi records was on average 3.82. This varied from one to nine professionals (1x1, 7x2, 4x3, 3x4, 2x5, 2x6, 2x7, 1x9). It was unclear whether this constituted all involved professionals.

Concerning frequency of use results showed that the total number of activities by patient-systems in their Congredi record varied from 1 to 179. Several activities were performed: 17 patient-systems viewed their records, varying from 1 to 124 times, sent e-mail to professionals varying from 1 to 33 times, received e-mail from professionals varying from 1 to 22 times, read e-mail varying from 1 to 22 times.

Four patient-system profiles were distilled from these results:
- *Collaborators:* five patient-systems (22,7 %) viewed the record more than five times and sent, received and read e-mail. All were still active at the end.
- *Consumers*: five patient-systems (22,7 %) viewed the record between two and five times, read all received e-mail, but hardly sent e-mail.
- *Casuals*: seven patient-systems (31,6 %) viewed the record once, read their e-mail irregularly and did not send any e-mail.
- *Non-Consumers:* five patient-systems (22,7 %) registered in Congredi but performed no further activities. They all received e-mail from their professionals, but did not read them. Four stopped prematurely.

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Table 3. Activities of patient-systems in Congredi

patients/ activities	non-consumers average (range)	casuals average (range)	consumers average (range)	collaborators average (range)	Total patients average (range)
active period (wks)	5 (1-14)	7 (1-27)	4,8 (2-8)	33,2 (27-38)	12,3 (1-38)
prematurely stopped	80%	11%	40%	0,00%	31,80%
professionals linked	6,2 (2-7)	2,1 (1-3)	4 (2-6)	5,6 (4-9)	3,8 (1-9)
dossier views	0,0	1 (0-1)	2,6 (2-3)	50,2 (11-124)	12,2 (0-124)
emails sent	0,0	0,0	0,2 (0-1)	15,2 (1-33)	3,5 (0-33)
emails read	0,0	0,7 (0-3)	0,4 (0-1)	10,6 (1-33)	2,7 (0-33)
tot.act. (dossier view, emails read and sent)	0,0	1,7 (1-4)	3,2 (2-5)	76 (13-179)	18,6 (0-179)
emails not read	3 (1-7)	0,6 (0-2)	0,0	0,0	0,9 (0-7)
emails received	3 (1-7)	1,3 (0-4)	0,4 (0-1)	10,6 (1-22)	3,6 (0-22)

Usability of Congredi experienced by patient-systems

The interviews yielded information concerning the usability of Congredi. The informal-carers did not experience technical problems: they were able to log on to Congredi, instructions were clear and technical support was not needed. They had some comments on the user-friendliness of Congredi. All mentioned that they would have appreciated an alert when they received e-mails. Professional jargon was not mentioned as a barrier. Some also commented that the care plan could have been more 'attractive' for them; in the layout it was not clear to them, which care actions had been agreed.

Motivation and expectations, experiences and satisfaction of the patient-systems

Motivation

The informal-carers had an intrinsic motivation for using Congredi: they wanted a better overview of the care for their parent, a check on appointments made and to be informed about incidents and to collaborate more effectively with all professionals involved. In most cases, the collaboration with the coordinating professional was already perceived as good before Congredi. This experience had built their trust and helped in their decision to try Congredi when their professional invited them.

> *"In my opinion, it seemed to me a good thing that there is a kind of central point where you can always find out what's going on"*

Expectations

The informal-carers expected that Congredi would be "a point where everything comes together", where an overview of the actual care plan and care actions could be obtained. It would be an easy way to communicate with relevant professionals about their opinions or issues. It would help them to take care of their parent because they could see updates on the care plan, feedback on the visits of professionals to their parents and to be informed about incidents. One informal caregiver expected that the amount of work would decrease because she could do more coordination from a distance when change in the care situation was needed.

> *"The agreement was actually that if there were reports about my mother, they would be entered in the system. So then I could see what conversations she had or whether something was going on with her. And I could also report something if I found something wrong or I could report if I was worried myself."*

Experiences and satisfaction

For some informal-carers Congredi lived up to their expectations. They checked Congredi as a regular activity and were satisfied with the communication with the professional. Others found routinely checking Congredi was taxing because there often was no new information. For some this was a reason to stop.

Informal-carers experienced a limitation because not all relevant professionals were linked to Congredi. Furthermore, some informal-carers reported that e-mails sent to professionals were not answered; this did not work as an incentive for further use of the tool. The amount of work for the informal caregivers did not decrease.

Informal-carers perceived it as supportive when professionals reacted to their e-mail about observations and worries. Some informal-carers felt more involved when using Congredi; they checked for messages regularly and felt it as their responsibility to respond and share their observations. They felt that they were making a contribution to the care process. Others went back to their old form of collaboration and involvement using telephone, face-to-face contact or unsecure e-mail, because Congredi did not add value for them. Informal-carers perceived only small effects on the care plan (observed malnutrition by informal carer led to dietary advice). They also experienced small improvements in collaboration with the professionals by the use of Congredi (using e-mail to give feedback felt as collaboration). In general patient-systems were satisfied with the actual execution of care. Use of Congredi did not make a difference on that count.

> *"Yes and this general practitioner …. I ask a question and there is no answer … yes, well I think just leave it."*

"That overview did not happen. E-mailing is the only way I get something into it … and then I don't get a response. And the particular GP, whom I specifically mailed with the neurologist's information, never saw it! And this was all-important informa-tion. So yes, that works very demotivating. I can tell you that."

"If I think my mother is not doing well then I'll send an e-mail about it: it may be sen-sible to visit my mom to see what you think of her yourself. The nurse then reports: I have visited your mother and talked to her … for example, her sister died recently and she finds this very hard, and then …. such a feedback. But what has been discussed between the GP and the nurse, you do not actually see that. Or actions that need to be taken. Too little."

"Yes, I would recommend it. It's because everything goes digital. And in this city, they obviously use Congredi so I would recommend them to use that, because that's how it works. It can certainly improve and then it's handy."

DISCUSSION AND CONCLUSION

General Findings

Ultimately, almost half of the patient-systems that logged in were hardly active. At a first glance this seems low. But, we were dealing with the implementation of a technological in-novation of which it is known that the adoption starts with a relatively small group. Rogers argues that the adoption of an innovation takes place in stages; it starts with a select group of innovators and early adopters and then proceeds to the early and late majority. [33] We therefore concluded that the extent of participation of those that logged in (a quarter of all patient-systems approached) is reasonable.

Amongst the group of users (50 %) four user-profiles (collaborators, consumers, casuals and non-consumers), based on the intensity of use of the e-communication tool, were found. Half was regularly active in Congredi (collaborators and consumers), some were occasionally active (casuals), but also one quarter was not active. [34] An explanation of this difference could be that Congredi was coordinated by professionals and ZWIP by patients.

The main users appeared to be the informal-carers. Those that gave an interview were all informal-carers. However, due to blinding, it is not known in which profile category the interviewed patient systems were active. However, it is plausible that they came from the collaborator and consumer group because, from the statements in the interviews, it can be deduced that the interviewees have at least looked at their Congredi records several times. So, it can be concluded that seven of the ten members of the collaborators and consumers were in-terviewed. It might be hypothesised that their characteristics provide a profile of collaborators

and consumers: sons or daughters, over 50 years, highly educated, competent in computer-use, socially active which seems in line with other findings. [34]

The fact remains, however, that quite a number is not participating. Technical issues were not found to be a barrier because all users logged in without problems and did not require helpdesk support. From the interviews we learned that instructions were sufficient. Because Congredi is a tool developed for professionals, it is quite conceivable that certain characteristics, such as professional jargon, would be experienced by patient systems as a barrier, but this was not the case; it was not mentioned as a barrier. However there was a need for a certain degree of tailoring because this was a trigger for several informal-carers to stop using Congredi. Some tailoring of the screens was named, as was also an alert when there was any form of action such as mutation in the care plan or e-mail.

A Complete Feedback Loop is important as a catalyst for effective eHealth technologies. [11,16] Congredi was found to be suitable for a Complete Feedback Loop (CFL) because all five stages of the CFL could be run through. [16] Although the Congredi system appears to meet the conditions for a CFL, patient-systems perceived the CFL to be limited. An explanation can be found in the way of use by the professionals. The records showed that on average 3.82 professionals were connected. That seems a realistic number considering the patient population, though the interviews showed that not all professionals were linked and not all were active because patient-systems did not receive reactions to their emails. Both were experienced as a barrier. In our research, as in others, it seems that the professionals who are using the tool could do this better; the new professional-patient communication patterns in the CFL needs attention[17,35-38]

Patient-related factors may play a role. Three components can be distinguished: (1) characteristics related to professional (amongst others netiquette), (2) characteristics of the patient (state of health, active role of the patient-system), (3) characteristics of the caregiver-patient relationship (trust, degree of insistence on using Congredi).
A relationship is found between poor health, multimorbidity, many doctor visits and high e-communication. [39] Because our patient-population partly meets these characteristics it can be assumed that this group is amenable to an e-communication tool, specifically when their situation worsens. [40] Another influencing factors on use of eHealth systems is trust. [41-44] The sample selection was based on trust between patient and professional, which may have lead to an active role as nearly half of the sample logged on to Congredi.

Issues on implementation of e-communication tools
The invitation for an interview was accepted in all cases by informal-carers. This was not unexpected, as they are known to play a crucial role in the care of these patients. [34,45] It is therefore presumed that informal-carers were quite active within the study population.

Continual support is important to them which may be why they were motivated to use Congredi. [45] Human support from the provider has been shown to increase compliance, but it was not examined how often the patient-systems were proactively urged to use Congredi. [41] In further implementation this aspect needs attention. It is also advisable to focus on the informal-carers. [32,46]

We noted that professional jargon was not named as a barrier for use by the informal-carers. An explanation may be that the informal-carers who were interviewed were mainly highly educated and that they were sufficiently trained in these matters as semi-experts in the disease status of their parent. [41,47] In this study a tool that had been shown to be feasible for professionals, was offered to patients without making many adjustments. Other studies show that modifying language is not necessary. [10,48] The benefits of having information surmount language problems; however tailoring of content is recommendable. In summary, it may therefore be possible to introduce e-communication technologies that have not yet been fully developed for patient-systems.

Limitations and future research

The number of active patient-systems was found to be a limitation in this study. Professional- and patient-related factors may play a role. Three components could be distinguished: (1) characteristics related to the professional (amongst others netiquette), (2) characteristics of the patient (state of health, active role of the patient-system), (3) characteristics of the caregiver-patient relationship (trust, degree of insistence on using Congredi).

In our research, as in others, it seemed that the professionals who were using an e-communication tool could do this better; the new professional-patient communication patterns in the Complete Feedback Loop (CFL) need attention. (17,26-29) A CFL is important as a catalyst for effective eHealth technologies. (11,16) Congredi was found to be suitable for a CFL because all five stages of the CFL could be run through. (16) However, although the Congredi system appears to meet the conditions for a CFL, patient-systems perceived the CFL to be limited. An explanation could be found in the way of use by the professionals. The records showed that on average 3.82 professionals were connected. That seems a realistic number considering the patient population, though the interviews showed that not all professionals were linked and not all were active because patient-systems did not receive reactions to their emails. Both were experienced as a barrier.

Concerning the patient-related factors, research shows a relationship between poor health, multimorbidity, many doctor visits and high e-communication. (30) Because our patient-population partly met these characteristics it could be assumed that this group was amenable to an e-communication tool, specifically when their situation worsens. (31) Another influencing factors on use of eHealth systems is trust. (32-35) The sample selection was based on trust

between patient and professional, which may have lead to an active role as nearly half of the sample logged on to Congredi.

We did not perform sophisticated qualitative analyses; we focused primarily on the topics that were known from the literature, and in the interviews no other topics were raised, even if explicitly asked.

Conclusion

Congredi, an e-communication tool developed for professionals, was usable for patient-systems but an alert was wanted when professionals had performed action in the Congredi record. The barriers found seem not to be tool-related but primarily user-related. Limited active participation of involved professionals in a Complete Feedback Loop was an important barrier. Potential for future implementation was found, because patient-systems were intrinsically motivated for better feedback with the professionals, even though in this study it only partly met their expectations.

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APPENDIX 1: INTERVIEW SCHEDULE CONGREDI WITH TOPIC LIST

Context Question:
- Can you tell me about your illness and the reason why you receiving care?
- What kind of care are you receiving?
- How is your living situation?
- How are your contacts with the caregivers?

Personal characteristics
- Are you patient OR informal carer?
- Relationship to patient
- Year of birth
- Education
- Living situation i.r.t. (informal) care
- Computer skills
- Role of internet in daily life (how often, what)
- Informal carer: degree of involvement in care
- Informal carer: family situation
- Informal carer: job or other obligation

Initial Question: Did you use Congredi?
- Log on
- Your data
- Questionnaires and care plan
- Messages.
  (Ask per functionality whether they have used it, and if so, how they experienced this, and if not, why not?)

Then let the interviewee talk as much as possible and submit subjects.
In any case, the following topics must be considered (possibly by the researcher through open questions. Order random)

Use
- How were you connected, How was it offered to you? Did you receive explanation about use?
- What did you use it for? (Together with family / carer, keep control over my care with carers, check if the appointments made are listed and performed, check data, email with my carers)

- Readability of the healthcare provider's texts
- Support when using Congredi: granddaughter or case manager, or else
- Ease of use Congredi: slow, difficult, attractive

Motivation use of Congredi
- Why did you want to use Congredi?
- What was the reason you wanted to be connected?
- What were your expectations of Congredi?
- Have they come out?
- Has your care changed compared to when you were not connected to Congredi?

Use experiences
- How did you perceive the use of Congredi?
- Did you gain anything by using Congredi? Example?
- Did it help?
  - See Care Plan
  - E-mail contact
  - See data
- What does Congredi mean for your (chronic) disease?
- Has the use of Congredi changed how you experience your health; Do you feel fitter, for example, are you more optimistic or do you feel more depressed? Example?

Collaboration with caregivers
- Has using Congredi changed your contact with your healthcare providers?
  - What matters have changed? Example? (experienced as a partner, direct contact with my healthcare providers, quick answer to my questions, answers were helpful, so healthcare providers will contact me if necessary, my data was in order).
- Has it helped you to improve collaboration with the healthcare provider?

Involvement in your care process:
- Do you feel that, by using Congredi, you can control and guide your cared and influence it?
  - What has changed? Example? (Frequency of care, amount of face-to-face contacts less, digital contacts more. What are your feelings about this? Did you feel that you should not telephone anymore)?

Execution of care
- Did using Congredi help you to carry out your care as intended? How? Example? (E.g. you can read it in the care plan, exact instructions)

Finishing

- Can you name positive experiences with Congredi?
- Can you name negative experiences with Congredi?
- Is there anything else you want to say about your experiences with Congredi / care?
- If you would advise someone, would you recommend Congredi?
- If I have additional questions, may I call you again?

End interview

1. Thank your respondent for the interview

Indicate that you can still talk about everything if you want to. Leave email address.

5

Exploring the effects of patients taking a vigilant role in collaborating on their e-medication administration record

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ABSTRACT

Objective: Errors in the electronic medication administration record (eMAR) occur in 25.6 % of cases, mainly due to communication errors. The aim of this study is to investigate whether the quality of the eMAR improves when patients play a vigilant role by checking their medication using a patient communication tool linked to their eMAR (eMAR-PCT) to communicate asynchronously with the pharmacist about errors. Effects on health outcomes and self-care are also explored.

Methods: In this quasi-experimental study, polypharmacy patients using five or more medications were randomly selected and invited to use their eMAR-PCTs. Participants also received two digital questionnaires assessing health and self-care (week 0 and 26). Statistical analyses were performed on two subgroups: eMAR-PCT users and non-users.

Results: An inclusion rate of 43.5 % (n = 152) was achieved. Women were more prevalent than men among the users group (56.4 % vs. 43.6 %). Among the eMAR-PCT users, 75 % logged in more than once, and 17.9 % communicated asynchronously with the pharmacist. The content of the e-mails shows that eMAR-PCT was used as intended. No improvement in the quality of the eMAR was found. The self-care variables self-efficacy (p = .006) and collaboration with the pharmacist (p = .021) showed significant improvement in the users group.

Conclusion and discussion: The results showed no effect on eMAR quality and a modest improvement in self-care. Active digital patient participation to improve the quality of eMAR merits further investigation as, in line with other research, tentatively positive results are shown on self-care. Possibilities for implementation are promising as half of the patients who pledged to use eMAR-PCT actually did, and used it as intended.

BACKGROUND AND SIGNIFICANCE

In the Netherlands pharmacists keep an electronic medication administration record (eMAR) for the patients in primary care who use medication [1,2]. The eMAR is important because medication care is a complex process, and errors are common (25.6 % median rate of error) [1,3]. These errors are an important cause of hospital readmission, morbidity and even mortality [4,5] and are often the result of inaccurate communication [6]. Improving the quality of eMARs is therefore of prime importance.

Medication care is complex, and although the patient has a responsibility for adhering to the prescription, a range of professionals also has a shared responsibility in making the right medication available to the right patient at the right time. In the Netherlands, guidelines have been developed to improve the medication reconciliation process. They describe the respective roles of patients, doctors, nurses, nurse practitioners and pharmacists [2,7]. The role of the doctor is to consult the updated eMAR before a new prescription is written. The patients' role is to produce an updated eMAR when the doctor is visited. The role of the pharmacist is to keep an accurate overview of the patient's current medication in the eMAR [2]. This involves a changing role for pharmacists. Initially, his or her primary task was limited to dispensing medication. Gradually, the pharmacist has also become a caregiver in the medication reconciliation process. They now perform medication care tasks such as periodic comprehensive medication therapy reviews of the eMAR with patients and monitoring changes in the eMAR, so that it is always up to date [8–10]. Therefore, he or she is the patient's primary partner for an accurate eMAR. These periodic medication reviews take place during face-to-face contacts between patient and pharmacist, but not at every encounter. Communication tools using Internet could complement the process for medication reconciliation by enabling the patients to correct errors in eMAR and to add self-help medications in between the regular periodic reviews and thus may contribute to adequate adherence.

Several options are available to improve the quality of the eMAR. Some actions target the pharmacists' role. Examples include developing practice guidelines (including agreements about communication and data exchange among professionals) and direct involvement in maintaining the quality of eMARs by initiating periodic checks of their accuracy [11–13].

Other actions are directed at the patient's role in avoiding medication errors [12,14]. Initially, patient involvement was instigated by professionals, but it is increasingly prompted by the patients themselves [15]. Patient involvement is viewed as an aspect of self-care; that is deliberate and self-initiated actions that patients can take to enhance their health [1,16]. A potential self-care role that needs to be explored is for patients to be 'vigilant', that is: keeping a watchful eye on the eMAR, always being alert to potential errors and communicating about the errors with professionals [17]. Patients have been shown to play an effective role as 'vigilants' when they are able to access their own eMAR [18,19]. One way this can be realized is by providing digital access to eMARs and enabling patients to make corrections in the eMAR at any convenient time. In non-acute situations, asynchronous communication (such as e-mail)

between patient and pharmacist has been shown to be a user-friendly option [12,20–22]. Such communication methods enable both parties to communicate about the eMAR at the time and place of their choice.

It is as yet unclear in the literature whether patient access to the eMAR and asynchronous communication about errors are effective strategies for increasing accuracy because little specific research has been undertaken. In other fields of care, results have been obtained using digital multi-component interventions, including asynchronous communication between patient and care- giver. Systematic reviews have shown that such interventions do not affect health outcomes [16,17]. Significant results have been shown for such aspects of self-care as empowerment, self-efficacy and improved collaboration between patient and caregiver [23,24]. These findings justify more detailed research into effective strategies for helping primary care patients collaborate with their pharmacists to improve the accuracy of eMARs through electronic access and asynchronous communication. This focus is also sup- ported by earlier research that suggests that patients are interested in digital communication with their health care providers [25,26].

OBJECTIVE

The aim of this study is to investigate the effects of patient participation in the medication reconciliation process through the use of a patient communication tool (eMAR-PCT) linked to their eMAR. The primary research question is whether the use of the eMAR-PCT is feasible and secondly whether the use of eMAR-PCT increases the accuracy of the eMAR. We also explored whether the use of the eMAR-PCT affects health outcomes and self-care-related variables (i.e., the patient's perception of medication adherence, patient's self-efficacy and the collaborative relationship between patient and pharmacist)?

MATERIALS AND METHODS

The design of this study is quasi-experimental. The patients were invited to use the intervention (eMAR-PCT) and data were gathered during 26 weeks. At the start of the study and after 26 weeks, the participants also completed digital questionnaires that assessed health and self-care variables. The patients' experiences with the eMAR-PCT were evaluated via digital questionnaires after eight weeks. The study took place between July 2012 and January 2014. Permission to perform the study was granted by the Medical Ethics Committee of the University of Utrecht.

Intervention

The eMAR-PCT is a module on the pharmacist's website with a personal patient login. The eMAR-PCT offers the patient the possibility of looking at the prescribed use (method, dose and frequency) of medications at any time and allows easy communication with their pharmacists about errors or changes and adding self-help medication, for instance, by facilitating questions via email.

Patients were invited to check their eMAR after every change in prescription and to notify their pharmacists when corrections needed to be made. They were also asked to report any use of self- help medications and to pose questions they had about medication use.

Patient population and recruitment procedure

In this project, the use of the eMAR-PCT was evaluated in home dwelling polypharmacy patients who use five or more different medications [2]. These patients were not only complex due to the polypharmacy; also multimorbidity and the fact that they were home dwelling inhibited medication reconciliation. Patients from two pharmacies in The Netherlands were recruited. Two inclusion criteria were applied: the use of five or more medications and access to a computer with an Internet connection and a mobile telephone, which is needed for verification purposes to log on to the eMAR- PCT.

The recruitment procedure was as follows: pharmacist's composed a list of patients who used five or more medications. A randomized and stratified selection was made of the entire population of eligible patients to assure a weighted sample of four subgroups (male/female, 65+/65-years), using the SPSS randomization procedure. The patients were invited by telephone to participate in this study. Patients who showed interest were invited for an initial consultation, during which the pharmacist explained the purpose of the study and the login procedure and asked for permission to share the eMAR with the researcher for the purpose of this study. After receiving informed consent from the patient, the pharmacist provided the researcher with the patient's email address. The researcher sent the participating patients a link to the first digital questionnaire via e-mail. The researcher checked for a response to the questionnaire on a weekly basis and, if necessary, sent a reminder to the patient, with a maximum of four reminders.

Variables and measures

To answer the research questions, the following variables were measured:
Actual use of the eMAR-PCT was registered in the system.
- The number of patient logins to the eMAR-PCT.
- The number of emails sent by the patient.
- The content of the patient's emails.
- The number of emails sent by the pharmacist.
- The content of the pharmacist's emails.

The effect of eMAR-PCT use was measured in terms of the quality of the eMAR and the patient's quality of life and self-care.

The quality of the eMAR was measured by registering the corrections made to the eMAR during verification consultations between the pharmacist and the patient at week 0 and at week 26. During the verification consultations, the pharmacist presented the patient with the eMAR and asked him/her to verify the correctness of it. Corrections were assessed within the following activities: starting a new medication, stopping a medication, changing the timing of administration, and changing the medication's dosage. In the analysis, all of the corrections were considered together.

Quality of life was measured digitally at week 0 and at week 26 using the 12-Item Short Form Health Survey (SF-12) [27]. This widely used questionnaire consists of eight domains (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health), which are summarized in two subscales: the mental components (MCS) and physical components (PCS) of health. Both scales have a mini- mum score of 0 (low quality of life) and a maximum score of 100 (high quality of life). The responses to the SF-12 are based on the patient's perceptions.

Self-care-related outcomes were also measured digitally at week 0 and week 26. The mea- surement of these outcomes focused on three parameters:

- Therapy adherence patient-perceived adherence to medication prescriptions was measured using two items from the Cardio Vascular Risk Management questionnaire [27] adapted to this target group. The questions, with five-point scales, asked after the frequency of adherence to medication and patient's expectations of their adherence. The sum score varied from two (high adherence) to ten (low adherence)
- Self-efficacy (confidence in one's own abilities) in relation to therapy adherence was measured with an adapted version of the Diabetes Management Self-efficacy Scale [28]. The original Diabetes Management Self-efficacy Scale consisted of 20 items, which in factor analysis showed two factors regarding general situations and difficult situa- tions. In this study we used a shortened and adapted version of four items referring to difficult situations. The focus was changed from diabetes to medication management. The questions focused on self-efficacy in medication management in difficult situations such as parties or holidays, integrating new medications in the daily routine and asking questions about medication dispensed by the pharmacist. Five-point scales were ap- plied and the sum score varied from four (low self efficacy) to 20 (high self efficacy). The reliability of the modified scale, using Cronbach's alpha, was reasonable at .67
- Collaborative relationship with the pharmacist was measured using a self-developed questionnaire consisting of six 5-point scale items (e.g., In the previous half year, I have experienced my pharmacist acting as a partner in keeping my eMAR up to date and My pharmacist's answers have been helpful for me). Scores were minimally 6 (good

collaborative relationship) to maxi- mum of 30 (less collaborative relationship). Content validity was tested by a panel of chronically ill patients, and also discussed with pharmacists. The questionnaire was shown to be reliable (Cronbach's alpha = .86). The patients were also asked to provide an overall rating of their collaborations with the pharmacist using a 10-point scale.

Patients' characteristics were measured at week 0 using a digital questionnaire that queried the following information:
- Date of birth.
- Sex.
- Socioeconomic status (SES), derived from the postal code using standard algorithm [28].
- Highest level of education.
- Health status (number of chronic illnesses).
- Internet skills.

Statistical analyses

Two subgroups of patients were identified: users (those who logged in to the eMAR-PCT at least once) and non-users (those who never logged into the eMAR-PCT). The differences between these two groups were analysed in terms of mean scores with standard deviation or frequencies and percentages using Student's T test resp. Chi-square tests. The analyses were performed with SPSS version 20. The results were considered significant if p ≤ .05; p-values between .05 and .10 were regarded as a trend toward significance.

RESULTS

Sample characteristics

Starting with the pharmacists' patient records, 517 people met the inclusion criterion of using five or more medications. Contact was established with 349 people; 164 did not have access to the Internet and a mobile phone or chose not to participate. The main reasons for non-participation were lack of interest, illness or language issues. The remaining 185 patients met with their pharmacist for the initial consultation, after which 33 withdrew from the study. Ultimately, a total of 152 out of 349 people entered the project, resulting in an inclusion rate of 43.5%.

Of those included in the sample (n = 152), some never logged into their eMAR-PCT (n = 74, 49%), and some logged into their eMAR-PCT at least once (n = 78, 51%). The first group constitutes the non-users in this study, and the last group constitutes the users.

The first questionnaire was returned by 105 participants; 115 returned the second questionnaire. The patients who returned the questionnaires were compared with those who did not. A significant difference (p = .000) in returning the questionnaires was shown between the

users (76.9 %) and the non-users (37.8 %). There was also a significant difference in gender (p = .003), with women more prevalent among the responders. Age, SES, and computer and Internet skills did not differ between the two groups.

The sample characteristics are shown in Table 1. Approximately 90 % of the participants reported having chronic conditions; 30 % reported having two or more chronic conditions. The majority of the participants completed secondary education or higher; 10 % reported elementary education as their highest level. The majority met the average SES for the Netherlands, 10 % had a lower SES, and 25 % had higher a SES. Three out of four participants used the Internet on a daily basis; 2 % rarely used it. The majority of the sample (70 %) assessed their Internet skills as average or good.

A comparison of the users and non-users showed no significant differences between the two groups except for gender: women were overrepresented in the user group.

Actual eMAR-PCT use

An analysis of the actual use of the eMAR-PCT showed that 78 patients used the eMAR-PCT, with the following results:

Number of logins to the eMAR-PCT

Nineteen patients (24.4 %) logged into their eMAR-PCT once. Thirty-two (40 %) viewed it two to five times during the six-month period. The remaining users viewed their eMAR-PCT six to ten times (n = 13, 16.7 %), eleven to twenty times (n = 10, 12.8 %), or more than twenty times (n = 4, 5.1 %).

E-mails

All users were offered the opportunity to send e-mails to their pharmacist through the eMAR-PCT. Fourteen users (17.9 %) actually did so. These fourteen were compared with the non-e-mailers in terms of gender, age, education, SES, chronic diseases and Inter- net skills. A significantly larger portion of the users group used the Internet daily (p = .035); on average, they logged in fifteen times and sent a total of 37 emails. The majority sent one email during the six-month study period (n = 8; 53 %). Six users who sent emails did so between two and six times; one sent thirteen emails.

Most emails from the patients to their pharmacist addressed substantive matters related to the nature of their medication care:
- Accuracy of eMAR-PCT (n = 21), corrections and additions.
- Questions about medication (n = 3).
- Technical matters (n = 8): the functional use of the eMAR-PCT (e.g., 'Can my partner also log into his eMAR-PCT?'), technical problems relating to the eMAR-PCT.
- Service questions (n = 3): home delivery of medication and the respective roles of the physician and pharmacist (e.g., 'Whom do I need to contact for a repeat prescription?').
- Cancelling eMAR-PCT use (n = 2) because it did not meet the patient's expectations.

Table 1. Characteristics of the eMAR-PCT users and non-users.

Variables	Categories	Total n = 152 (%)	Users n = 78 (%)	Non-users n = 74 (%)	p
Sex					.036
	Male	51.3%	43.6%	59.5%	
	Female	48.7%	56.4%	40.5%	
Age					.745
	0-65 years	53.3%	55.1%	51.4%	
	66-100 years	46.7%	44.9%	48.6%	
Education					.142
	Elementary	9.7%	8.8%	11.1%	
	Secondary	51.6%	59.6%	38.9%	
	Higher	38.7%	31.6%	50.0%	
SES					.968
	1	11.8%	11.5%	12.2%	
	2	61.8%	62.8%	60.8%	
	3	26.3%	25.6%	27.0%	
Pharmacist					.468
	1	15.8%	16.7%	14.9%	
	2	84.2%	83.3%	85.1%	
Chronic conditions					
	Yes	88.8%	90.3%	86.8%	.370
	Number of chronic conditions reported				.138
	0	19.7%	12.8%	27.0%	
	1	50.7%	55.1%	45.9%	
	2	19.1%	21.8%	16.2%	
	3	6.6%	7.7%	5.4%	
	4	3.3%	1.3%	5.4%	
	5	.7%	1.3%	.0%	
Internet use					
	Intensity of use				.513
	(Almost) daily	78.4%	82.4%	72.9%	
	Multiple times per week	12.1%	10.3%	14.6%	
	A few times per week	6.9%	4.4%	10.4%	
	Rarely	2.6%	2.9%	2.1%	
	Self-assessed computer skills				.318
	Moderate	21.6%	16.2%	29.2%	
	Average	40.5%	45.6%	33.3%	
	Good	30.2%	29.4%	31.2%	
	Very good	7.8%	8.8%	6.2%	

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The pharmacists' emails to their patients (n = 22) were in reply to the patients' e-mails (n = 15) or alerts to the patients about the possibilities provided by the eMAR-PCT (n = 7). The reply e-mails were about the accuracy of the eMAR (n = 9), technical questions (n = 4) and services (n = 2).

Effects of eMAR-PCT use

The quality of eMAR is shown in Table 2. At the second verification consultation, corrections were necessary for approximately 20 % of the eMARs. There was no significant difference in the number of corrections between the users and the non-users.

The participants did not perceive a significant change in their health (quality of life) during the six-month study period.

Table 2. Effects of the eMAR-PCT: outcome variables.

Variables		Sample	N	Week 0	Week 26	Difference	P
Quality of the eMAR				Mean (SD)	Mean (SD)		.169
	Number of eMARs with corrections	Users	70		16 (22,9 %)		
		Non-users	44		8 (18,2 %)		
	Number of corrections	Users	70		0.5 (1.2)		
		Non-users	44		0.4 (0.9)		
Quality of life							
	Physical	Users	53	57.5 (26.5)	59.1 (27.6)	1.7	.445
		Non-users	24	54.7 (24.1)	52.9 (23.9)	-1.8	.238
	Mental	Users	53	75.0 (22.7)	71.3 (24.3)	-3.6	.194
		Non-users	25	76.5 (13.1)	72.5 (19.9)	-4.0	.587
	Health rating on a 10-point scale	Users	54	7.0 (1.4)	7.0 (1.8)	0	.832
		Non-users	24	7.0 (1.3)	7.0 (1.2)	0	.833
Therapy adherence							
		Users	55	9.5 (0.9)	9.6 (0.7)	0.2	.168
		Non-users	25	9.4 (0.7)	9.4 (0.9)	0	.852
Confidence in one's own abilities							
		Users	53	18.7 (2.1)	19.3 (1.6)	0.6	.006
		Non-users	24	18.0 (2.3)	18.5 (2.7)	0.5	.433
Collaborative relationship with pharmacist							
	Aspects of collaboration	Users	50	14.4 (4.1)	15.7 (4.4)	1.3	.021
		Non-users	22	15.8 (4.9)	16.2 (4.4)	0.4	.588
	Rating on a 10-point scale	Users	55	7.6 (1.3)	7.5 (1.4)	0	.830
		Non-users	25	7.4 (1.4)	7.1 (1.7)	-.3	.448

DISCUSSION

This study aimed to evaluate the effects of patients' use of an eMAR-PCT on the accuracy of the eMAR. Regarding the primary out- come, no significant difference was found in the number of eMAR corrections between users and non-users of eMAR-PCT. A significant increase in the secondary outcome of self-care, specifically in the areas of self-efficacy and collaboration with the pharmacist, was identified for the eMAR-PCT users. The health outcomes (quality of life) did not differ significantly between the two groups.

Substantive findings

The number of errors found in the eMAR did not differ greatly from the mean rate of errors reported in other studies, though 20 % is lower than the 26 % in the literature and is a relatively good result for the participating pharmacists [1]. However, because 80 % of the eMARs did not contain errors, the likelihood of realizing improvements is small. Moreover, a half-year follow-up period may be too short for many changes in medications, and thus errors, to occur.

In the small group (n = 14) of patients who communicated asynchronously and participated in both verification consultations, no eMAR corrections were needed. The e-mailers were active users, and all of the e-mails were relevant. No significant differences were found between the e-mailers and the rest of the users. This result may indicate that active use of the eMAR and communicating errors is effective in realizing accuracy.

The fact that the patients' quality of life was minimally influenced was not surprising be-cause the sample consisted of patients with chronic conditions. Substantial changes in their health were not to be expected during the relatively short study period. Quality of life depends on multiple factors in addition to medication use. Pecina et al. found similar outcomes concern-ing eHealth among older patients with comorbidities [29].

Regarding self-care, the users group showed a significant increase in self-efficacy regarding medication use, and they reported an improvement in their collaboration with the pharmacist. However, these improvements in collaboration did not result in a higher general rating of the pharmacist, as such ratings might also be influenced by the physical environment or the general service level, among other factors. Therapy adherence did not differ among the groups.

Our findings are in line with recent systematic reviews of the effects of web-based interventions on patient empowerment, which show that eHealth has a tentatively positive effect on self- care elements such as self-efficacy [30,31]. This merits further investigation because these changes may support a more active vigilant role of the patient in monitoring the eMAR in the future.

Methodological issues

The study sample successfully attained equal representation among the groups of patients who used eMAR-PCT and those who did not. It is interesting to note that apart from gender, no distinguishing characteristics were identified between the questionnaire responders and non-responders. This result is consistent with the findings of Kontos et al. in a large study examining

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the predictors of eHealth usage. They found that being female was a predictor of all types of eHealth use, including sharing medical records and communicating about them [36]. Age and SES did not influence eMAR- PCT use. To minimize the risk of bias the differences in technology adoption were assessed but no differences in intensity of computer use and perceived computer competency were found. This was also the case for the variables 'adherence' and 'self-efficacy'. The groups were found to be quite comparable which suggests that there is no reason not to generalize the results of this study.

A methodological issue that merits some attention is the inclusion of patients in innovative eHealth studies. The inclusion rate of patients in this digital form of patient participation in medication care was quite high (approximately 43.5 %). An explanation could be that the sample was selected from the group of polypharmacy patients who probably had experience with errors in the eMAR and who were approached by their own pharmacists to communicate about these errors. In comparison to a large study in England in which people were invited by letter to activate digital access to their health record, one-third took the first steps to enter the study and a quarter actually activated the patient portal [32]. In the first phase of innovation, it can be helpful to take into account several factors, particularly how patients perceive the innovation, the characteristics of potential adopters, and organizational aspects [33]. These characteristics have not been well studied [34,35]. In this study, the only characteristics that seemed to be relevant for the adoption of eMAR-PCT use were being female and, in the case of e-mail use, being a daily user of the Internet. SES seemed irrelevant, as did age and education level.

Feasibility issues at the intervention level

A precondition for obtaining any results with healthcare innovations such as eMAR-PCT is that patient's use it as intended. Because the eMAR-PCT was used by more than half of the patients in the sample, we concluded that it seemed usable. One in five eMAR- PCT users not only looked at their record but also corresponded about what they saw with their pharmacist via e-mail. These e- mailers were active users who logged in fifteen times on average. The content of the e-mails indicate that the eMAR-PCT was used as intended. We found no indications that the user group had specific characteristics.

In this study the main focus was on feasibility of the intervention. The eMAR-PCT seems to work and might therefore be a valuable additional tool in the medication reconciliation process to keep the eMAR up to date. The added value of eMAR-PCT is that patients' monitoring of the eMAR is enabled in a user-friendly way; they can perform the monitoring at their own convenience. This could increase the chance of the much-needed patient participation in the medication reconciliation process. From the viewpoint of Rogers' theory on diffusion of intervention [37], the rate of adoption is actually relatively high as 43.5 % is close to the tipping point of 50 %, when the intervention will be broadly diffused. Specifically as the eMAR and eMAR-PCT were only introduced two years before the study and many innovations take over ten years to be implemented [38].

An important question, however, remains unanswered: why did non-users not use the system? This is an important but difficult question for further implementation, as already described by Rogers [37]. All the participants in the study, users and non-users, had initially promised their pharmacist that they would use the eMAR-PCT and about half became non-users. A search for characteristics of early adopters did not show up significant items. Patients are at the decision-stage of implementing an innovation and many individual aspects (such as personal traits, motivation and meaning of the innovation) have influence, as a result empirical evidence is difficult to find [37,39]. It remains unclear at this point why a motivated group did enter the study and did not use eMAR-PCT. Further (qualitative) research needs to be performed.

Feasibility issues at the organizational level

A considerable investment by the pharmacists was needed to enrol patients in this study in a primary care setting. In a Dutch study on eHealth, health care professionals confirmed that they do not always recognize the potential of eHealth solutions such as eMAR-PCT for self-management and prevention [40]. Professionals might also question whether eHealth consultations required more effort than expected; consequently, the number of corrections in the eMAR was not known for all of the users because not all of them attended both consultations. Additionally, there was a relatively low response to the questionnaires among the non-users, although the users and non-users did not differ in Internet skills or use. Apparently, the non-users did not feel the need to communicate digitally about their medications. The fact that they did not use eMAR-PCT may have also been a factor in their failure to return the second questionnaire.

Lessons learned

The use of eMAR-PCT by patients seems a promising intervention, even though we could not determine whether it lead to a significant increase in the accuracy of the eMAR. This is in line with a study in the United States within the VA, where it is concluded that it is certainly feasible to improve medication safety by enabling patients to interact through a web portal [19]. This is a promising expansion.

Perhaps this study was performed too early in the adoption of this intervention. We tried to implement a new innovation broadly, whereas by starting with a group of enthusiasts we would certainly have required less recruitment time.

We have learned that the use of eMAR-PCT was associated with two significant improvements in self-care: First, an increase in self-efficacy for medication-use was shown because the patients' confidence about making the right decisions about medication- use in different situations increased. Second, the collaborative relationship between the patients and the pharmacists increased significantly. This improved collaboration is a start for the type of participation that is envisioned in modern health care policy; that is, the patient plays a vigilant role and shares the responsibility for checking the eMAR with the pharmacist. A comprehensive approach is needed, although the effect is limited. These are elements that can help increase

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patient self-care in health care, and they are consistent with the findings in a Cochrane review on this subject [12]. It is also promising to find that the active users who both looked at their eMAR regularly and e-mailed the pharmacist about what they saw did not need to correct eMARs.

CONCLUSION

Active patient participation in checking the quality of medication records through the eMAR-PCT is an innovation that merits further investigation. Half of the patients who pledged to use the module actually did. A significant characteristic of these early adopters of the innovation was that they were female. Patient emails showed that the users understood the purpose of the eMAR-PCT. No effect on eMAR quality was found. The modest improvement in the area of self-care may be expected to positively support active self-care behaviour. Further research with a longer study period is needed to test whether active digital communication by chronically ill patients in medication reconciliation has effects on clinical outcomes.

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General discussion and conclusion

The studies described in this thesis concern the implementation of innovative e-communication tools in the field of primary healthcare, a relatively new and challenging area of research. [1,2] In this chapter the main findings and methodological reflections will be discussed and conclusions presented. As an impetus to expand knowledge in this area, this thesis focuses on the evaluation of the use of two e-communication tools in primary healthcare. The central question is: 'How is e-communication used in the practice of primary healthcare and what are stimulating and impeding factors for its use?' Answers were sought about the use of the tools between professionals and between patient and professional.

In this study, e-communication was operationalized as the sharing of data about healthcare problems and care actions, accessible for inspection by all parties involved in the care process and combined with a secure communication environment by using electronic tools (chapter 1). This operationalization is based on the eCCM. [3,4] The use of two e-communication tools is evaluated. The tool Congredi enables healthcare providers and patients/informal carers (children and partners) to look at the care action plan and realize coordinated care through communication. [5] The second tool, eMAR-PCT, is used by pharmacists and patients and enables patients to access their own medication file, to communicate about errors and ask questions about the use of the medication. [6] The e-communication between professionals was evaluated in two studies with Congredi (chapter 3 and 4). The e-communication between patient and professional has been studied for both Congredi and eMAR-PCT (chapter 5 respectively chapter 6).

To describe the actual use of the e-communication tools the following sub-questions were addressed.
1. Are relevant professionals and patients/informal carers connected?
   a. How many of them are connected?
   b. What are the characteristics of the connected professionals and patients/informal carers?
   c. Which impeding and stimulating factors do the users experience (technology, user-friendliness, motivation)?
2. Do involved parties make data available
   a. Are shared problems and changes recorded?
   b. What are the patterns of recorded healthcare data
3. Do involved parties respond to the input of others?
   a. What is the extent of use?
   b. How do patients/informal carers experience the use of the tool with professionals?

The research question is socially relevant due to the growing number of home-dwelling elderly with multimorbidity. [7-10] In effect, the group of involved formal and informal carers also grows, which increases the necessity for communication and coordination. [8-10] The cur-

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rent evidence shows that e-communication could be a possible solution for current barriers in communication.[14-20]

MAIN FINDINGS

The studies were consecutively aimed at: examining the state of the art concerning e-communication (chapter 2); investigating how professionals in general use the digital communication tool Congredi (chapter 3); attempting to answer the question whether the tool was used adequately by studying care situations with different levels of complexity (chapter 4); focusing on patients' experiences with the tool Congredi in a mixed-methods study (chapter 5); examining patients' use of the tool eMAR-PCT to monitor their medication record (chapter 6). The following results emerged from the different studies.

Literature study (chapter 2)

In a literature review [21], fifteen studies were retrieved to answer the following research questions:

1. Do patients and providers use asynchronous communication within internet-based interventions and do they find it usable?
2. Does the use of asynchronous communication within internet-based interventions affect health behaviour and health outcomes?

We concluded that (i) patients use the asynchronous communication options and that patients are interested in using email. Patients are willing to participate and are taking the initiative to discuss health issues with their healthcare providers. (ii) The effect of asynchronous communication on health outcomes and on health behaviour was not shown unequivocally in these studies.

E-communication between professionals (chapter 3 and 4)

Professionals' use of the e-communication tool Congredi was evaluated in two studies. In the first study (Chapter 3), the following research questions were addressed [22]:

1. How many and which professionals are linked to Congredi records?
2. How many and which actions are performed by the professionals in Congredi records?
3. Is there a relationship between the combination of professionals in the care-plan and the performed actions?

Data, concerning a broad sample of home-dwelling elderly, were gathered from the Congredi system over a period of 10 months (42 weeks) and analysed. The results showed an inclusion rate of 21.4 % (n = 203); nearly half were nurses. During the study, professionals were active in 448 patient records. Three types of actions (care activities such as assessment of the current problems, care actions, observations/evaluation and care action adaption; sending, reading, answering emailing; process activities such as becoming a coordinator and inviting

involved professionals to link) were registered in the patient records. Three types of patient records were detected: multidisciplinary records (45%) in which professionals from different disciplines were active, monodisciplinary records (14%) in which several professionals from the same discipline were active and solo records (41%) in which only one professional was active. Most activities occurred in the multidisciplinary records. The most active combination of professionals was the combination of GPs and nurses.

In the second study (chapter 4) on adequate use of the tool, two hypotheses were tested. [23] The assumption was that if professionals involved with patients in care situations of differing complexity use Congredi adequately, the changing involvement of caregivers must be reflected in differences in the use of Congredi. This means that:

a. During low-complex care, fewer professionals are involved in Congredi,
b. During low-complex care, the level of care activity per patient is lower than during high-complex care when there is more care activity per patient.

Patients with dementia were entered in the subgroups low-complex care (n = 43) and high-complex care (n = 53). Results showed that the mean number of care activities in the low-complex group was significantly lower than in the high-complex group. The number of professionals involved with low-complex care versus high-complex care differed. The most frequent combination in the low-complex group was of different case managers dementia (41.9%). The fact that different case managers were involved ensured continuity of care despite part-time appointments and holidays. In the high-complex group, the most frequent combination was of case managers and nurses (43.4%).

E-communication between patients and professionals (chapter 5 and 6)

The aim in the first study focusing on patients (Chapter 5) was to examine whether an e-communication tool (Congredi) designed for professionals, including a care plan and secure email, was usable for patients and their informal carers and what their experiences were. [24] For this multi-method study, 46 patients were approached, 22 of which have become active on Congredi. As a result of this study four profiles of Congredi-users could be distinguished, varying in intensity of use: *collaborators* viewed the record frequently (more than five times) and sent, received and read email, all were still active at the end; *consumers* viewed the record less frequently (between two and five times), read all received email, but hardly sent email; *casuals* viewed the record once, read their email irregularly and did not send any email; *non-consumers* registered in Congredi but performed no further activities, even though they all received emails from their professionals.

Data from interviews with informal carers of the patients using Congredi (n = 7) showed that they were motivated and able to use Congredi. In general technique and usability were not a problem, although some informal carers found it annoying not being alerted about actions. Barriers in daily use were primarily related to use by professionals: the limited number of participating professionals and the limited activity of professionals in unanswered email. A small

part of the informal carers continued using Congredi, but a larger part stopped due to these barriers. The informal carers nevertheless recognized the benefits of a digital communication tool, provided that the healthcare providers used the tool adequately.

In the second study into the use of an e-communication tool for patients and professionals (chapter 6), the aim was to investigate whether the quality of the eMAR improves when polypharmacy patients play a vigilant role. [25] They could check their medication using a patient communication tool linked to their eMAR (eMAR-PCT) to communicate asynchronously with the pharmacist about errors. The use by patients was evaluated, and effects on health outcomes and self-care were also explored.

The results showed an inclusion rate of 43.5 % (n = 152). One hundred and fifty two were willing to participate in the study and join eMAR. We found that half of the 152 participants showed no activity in eMAR (non-users) and the other half showed at least some activity (users). Among the eMAR-PCT users, 75 % logged in more than once, and 17.9 % communicated asynchronously with the pharmacist. The content of the emails showed that eMAR-PCT was used as intended. Regarding the effects on self-care, it was found that self-efficacy (p=.006) and collaboration with the pharmacist (p=.021) showed significant improvement in the user group. A significant improvement in the quality of the eMAR was not found.

Based on these findings, we concluded that the researched e-communication tools were used on a small scale. Results showed that users were able to link to the tool, they were able to use it adequately and they were able to react to the communication. The professionals and patients who actively used the tools used them as intended, which was visible in the use-pattern. Also, in chapter 4, we hypothesized that the complexity of care would be reflected in the intensity of use, and this was confirmed.

Concerning the professionals in Congredi, nurses were the largest group of users; the most active combination of professionals was the combination of GPs and nurses. Characteristics of active patient-users of Congredi included being an informal carer and a child of the patient. Regarding technical aspects, such as user-friendliness and clarity, respondents did not report impeding factors, but there were points of improvement. The most important impeding factor was the limited use of the tool by the professionals involved.

The active professionals who used eMAR-PCT were all pharmacists, but that was not surprising, because they were the only professionals involved. The eMAR-PCT study showed that patients and professionals responded to each other's input.

STRENGTHS AND LIMITATIONS

In the region, there was an administrative need to be innovative concerning the application of e-communication tools, aimed at solving problems in multidisciplinary communication and preventing mistakes in the medication administration record. The regional administrative platform decided to implement a digital communication tool (Congredi) to promote communication between health care providers in primary healthcare. Important elements of this decision were that there were high and promising expectations, although there was no convincing evidence of effectiveness and that the tool was developed from the perspective of care practice; this had consequences for which data were registered, how they were registered and the way in which privacy was handled.

The development of the tool was done systematically and with care in good alignment with the users. Our research therefore took place in an already deployed innovative practice, with agreements between tool developer and care providers about which data were registered and with privacy protection of paramount importance. Our research started when a larger-scale implementation was to be deployed, after two pilot projects were carried out in different neighbourhoods and the results were processed. During the pilots we were hesitant with additional research because there was a great reluctance to burden employees with extra work, because working with Congredi was already seen as taxing, because it concerned a new practice.

An intervention tool had also been developed for the prevention of errors in the medication administration record (eMAR), including the determination of the type of data recorded about the use and the manner in which the registered data were stored, including privacy regulations. But in the eMAR study there were more opportunities to shape the research as a researcher: there were fewer stakeholders involved and shorter lines with the implementers.

Limitations of this innovation-research

Specific limitations from a scientific perspective were perceived in our studies of the e-communication tools. Some limitations are inherent to research in general, but some limitations gain a special dynamic in innovation-related research. We will reflect on these limitations in general and in relation to our findings.

1. Little evidence is available about the implementation of e-communication; therefore it is implemented based on expectations and not on evidence.
2. Lead-time for innovative technological interventions is short, much shorter than needed for research.
3. The dynamics of the needs of the practice (rapid introduction of new better care) is at odds with rigorous research.

1. Little evidence is available about the implementation of e-communication
Innovating on basis of expectations and not evidence

Many e-health innovations are introduced and implemented without a proper evalua-tion of whether such eHealth innovation is proven to be effective. In general innovations are based on evidence, but due to the innovativeness of eHealth little evidence is available. The decision to implement something new is often made administratively on the basis of, more or less thoroughly substantiated, theoretical expectations (these expectations are divers, such as care-related, efficiency or cost-related but legitimate considerations). Often design and evalu-ation goes hand in hand, but exploreassessment of these tools remains difficult because an increasing number of tools are available which still need to be described. [26,27] An overview of the evidence is also impeded because key criteria for predicting success, specifically in telec-are, are not being assessed. [28] Increasingly it seems relevant for implementation in practice that eHealth research should be more contextual. [29] It is however tempting to introduce e-communication. An example is introducing it for economic reasons because it seems conve-nient and modern and may therefore result in more clients for the healthcare organization, or because time is saved by the professionals or the patient with digital communication instead of face-to-face, or monitoring instead of visiting the practitioner. It is also tempting in terms of content because the expectation is that patient's self-management will be promoted, that it yields better information than retrospective self-reporting by the patient and that coordination of the care will be improved.[30]

When the innovation is initiated and the expectations are not in practice, the innovation is stopped, not always after a thorough evaluation, and often because there is a new novelty. This results in a waste of money and time, and the process starts again with a different technology. An important motivation for this doctoral thesis is to better support the innovation process with evaluation from the practice.

Comparison difficult

The lack of factual data about the current communication between professionals and pro-fessionals with patients was a limitation in making a comparison with 'usual care'. [31] Ideally we needed to collect data ourselves about usual care, for instance with a control group outside the region that did not use Congredi. This was, however, not feasible. Finding a good control group takes time, and that would cause unwanted delays with the pace of implementation. Our best option to perform the Congredi study was to latch onto existing developments in the field and perform a field study of this innovative instrument that had already shown to be usable by a multi-method approach in foregoing stages in the development. Therefore, we chose to use a prospective design directed at understanding how the use of the innovation works. It was an option to conduct retrospective research through individual interviews and / or focus groups. However, because professionals who used Congredi in the preliminary phase had already been interviewed, we did not repeat this. Looking back this was regrettable. In Congredi patient users we did this because there was no preliminary stage and this provided meaningful infor-mation. In the study of Congredi-use by patients, we did use a multi-method approach because

it was for the first time that patients were connected. This provided meaningful information and useful recommendations for improvement of the Congredi tool.

In the less complex setting of the eMAR study (6) we aimed at having a control group. However, we suffered from the fact that during the recruitment process the economic situation of pharmacists changed, as a result of which several pharmacists could no longer participate and it was therefore no longer feasible to set up a control group as the study had already been planned. In the eMAR study, which was the first study we performed, we explored determinants for use by comparing groups of users and non-users on several variables but did not find significant differences. However, there was no question of a pure control group here because the users and non-users could also differ on motivational or psychosocial variables that were not measured, but these factors could have been of influence. It was therefore impossible to draw firm conclusions about the effects of use on health outcomes (quality of the patient file and self-management) and that is why it was limited to an exploration.

2. Lead time for innovative technological interventions is shorter than time needed for research, therefore RCT's generally study out-dated care

Another limitation is that the lead-time of an innovative eHealth intervention is very short in comparison to other interventions. [32] Particularly in digital innovations this is often because another version or technique is already available. An extreme example of this is a robust study of the effectiveness of a digital training for communication skills of oncologists. [33] The speed of application of the technology was made dependent on the robustness of the research. The study took four years and showed good results, but for the practice it was hardly relevant. The course was developed with image plate technology, but when the study was completed the image plate technology was out of date and was no longer used.

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Figure 1. **Based** on Rogers, E. (1962) Diffusion of innovations. Free Press, London, NY, USA. Public Domain, https://commons.wikimedia.org/w/index.php?curid = 18525407
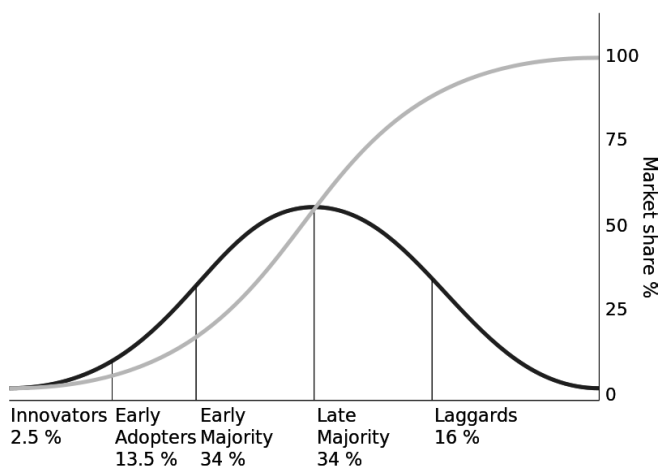
Focus on implementation and acceptance by the users

Referring to the context, this is an implementation process of a relatively large innovation. Every effort has been made to implement the tool. The emphasis was on interested users who had the intention to use the tool. This is also in line with the insights of Rogers, who posits that a successful implementation takes a long time and that success starts with the acceptance of the intervention by a limited group of health care providers (the innovators) and then the early adopters (also a small group). To promote implementation within the given boundaries of time and money, focussing on the users is therefore justified. This is at the same time a limitation because we did not study the barriers and facilitators for non-users. The tool seems useable for the professionals, but we realize that we studied a specific group that was interested in innovation and was also motivated to make extra efforts. This does not mean that the same applies to employees that are less motivated by innovation. The fact that behavioural changes require time, feedback and repeated incentive is also a limitation. This study was limited between 21 and 42 weeks.[34]

3. The dynamics of the needs of practice (rapid introduction of new better care) is at odds with rigorous research

Rigorous research tends to have a delaying and therefore demotivating effect on practice, causing the innovation to wither. This creates a dilemma for all forms of research in practice, but due to the short lead-time the dilemma is even greater in eHealth research. When innovating with eHealth, performing rigorous research (such as RCT's) is disadvantageous for the implementation process. However, not performing research also has disadvantages for the implementation process. It is therefore important to match the question to the appropriate research method. [35] In this case the innovation did not add a risk for patients or professionals but the research question *How is e-communication used in the practice of primary healthcare and what are stimulating and impeding factors for its use* was considered relevant for large-scale financial investments for the healthcare providers.

Low response

A consequence was that in the Congredi study we had no influence on the way the intervention was introduced because the implementation was already under way. In the eMAR study, where the researcher led the study and was able to decide if and when reminders were sent this may have been of influence because 43.5 % were found willing to participate (though only half of this group became active users).

In the studies in this thesis, the response was 20-25 %. At first glance, this is low for scientific research and raises questions about generalizability. [36] However, in this thesis innovations were examined, which have their own patterns. For recently introduced innovations, participation rates are often relatively low. [37,38] Rogers' theory about the diffusion of innovations could offer an explanation for the low response rates among both professionals and patients. [138] In his theory, Rogers focuses on the life cycle of innovations, in which he distinguishes

five stages with five groups of users (innovators (2.5 %), early adopters (13.5 %), early majority (34 %), late majority (34 %) and laggards (16 %)). According to Rogers' theory, it was to be expected that the participants in the studies in this thesis mainly consisted of innovators and early adopters. [34,39] Seen from this perspective, a 20-25 % response rate is rather successful.

In view of the theory of Rogers and in reflection on our results, it could be advisable for the introduction of innovative practices not to aim primarily for generalizability and involving large groups in the study. Particularly in the early stages of innovation, it is important to investigate whether an innovation meets the needs of interested parties, innovators and early adopters, according to Rogers. Only when that is the case, is it possible to include the 'majorities' and achieve sample sizes to make statements in the context of generalizability.[34]

No insight in medical data

The studies were designed in a pragmatic/natural situation. Therefore the available log data were used. The researcher had no influence on what was registered in the log files of the innovations, which had already been fixed previously by the supplier based on feedback from practice and privacy issues. The process of changing the content of eHealth technology takes time and was therefore not feasible within the study. This made that part of the data was less accessible. This is specific for innovation-related research when using existing eHealth tools.

A consequence was that the researcher was bound by agreements with participating care organizations about privacy and there was no insight into the medical data, resulting in the following limitations.

- No control on the level of disease burden, which has been known to influence use (chapter 3 and 4)
- No control on the number of carers involved per patient because there was no opportunity to get an overview of the patient's network because we did not know the names of the professionals or patients involved; thus we did not know who was NOT connected (chapter 3 and 4)
- It was not possible to trace the individual healthcare provider (chapter 5)

In the analysis it was not possible to check thoroughly for specific care and disease-related characteristics, therefore patient selection was difficult. The research was not leading, but the care was leading.

Strengths of this innovation-research

After listing the above limitations, the question actually arises whether it has been meaningful that we conducted this thesis.

In our view, the answer is affirmative because the research has yielded various relevant insights.

The strength of this innovative research lies in the following.

1. Pragmatic research makes it of value for many contexts

2. Power can be created by using small research cycles with comparable variables
3. Benefits of the research can be identified, despite the fact that the research only partly meets the classic standard

1. *Pragmatic research makes it of value for many contexts*

Because the study was performed in natural circumstances the results would be of value for implementation in comparable natural circumstances. This thesis has shown that it is possible to include several aspects of innovation, when studying an e-communication tool, in the practice of primary care. Innovation deals with the first application of a new practice, in which as much as possible should be learned about all aspects that play a role. Implementation can take place when an innovation has been applied successfully elsewhere. [40] According to the literature, it is advisable to take several aspects of innovation into account during the innovation process, not only the design of the tool, but also administrative and financial aspects. [41,42] Kadu et al show that assessing organizational capacity and needs and incorporating the health care providers' perspective before introducing the innovation will strengthen the chances of successful implementation, as we have also experienced in our study. [43] Besides, such innovations take a long time and require leadership. [42] It is advisable to carry out research into eHealth innovations in a well-prepared practice, rather than in an artificial (a laboratory) setting.

Model helpful

The knowledge incorporated in the eCCM, and the underlying CCM, has been underscored by evidence. [43-46] For us the model proved a helpful tool in mapping the steps made concerning (i) providing administrative support and agreement with the partners (the organizational cluster Community - Health System - eCommunity - eHealth System), (ii) developing the requirements for a tool in consultation with the users (Self-management Support, Delivery Systems Design, Clinical Decision Support, Clinical Information Systems), (iii) testing and refining the tools with the users in practice with focus on these requirements and on ingredients for a training course (eHealth Education). In this way it was possible to realize an e-communication tool that meets the contextual and tool related conditions for a Complete Feedback Loop (CFL). The CFL refers to desirable interaction between professionals and patients to enhance self-management. It requires that all relevant participants (patients, informal carers, professionals) are linked and adequately communicate (e.g. reading new information, answering e-mails). By studying the actions within the CFL, we could see whether the design of the intervention had to be adjusted.

Context helpful

Within the context of the regional, administrative platform, two studies (Congredi and eMAR) were carried out which increased the chances of dissemination of the tools and a high response. [34,47] It was a stimulating factor that commitment had already been acquired on an administrative level for the simultaneous execution of multidisciplinary innovation. The results

show that the innovation process was apparently satisfactory, in terms of response, approach and usability.

The Congredi study was a challenge because the focus was wide; many healthcare professionals, several healthcare providers and their patients could, in principle, participate. Through the regional platform it was possible to jointly formulate the functional specifications for the design of the technology and make administrative agreements in preparation of the performance of the study (eCCM clusters of e-Health Community and e-Health Systems). Despite these agreements the study yielded that the largest barrier for a working CFL was the limited use of Congredi by professionals. Literature research shows the complexity of making regional agreements about collaboration within primary care. [11] It is advisable to revise these agreements when such limited engagement is observed and to further concretize commitment to the collaboration in a subsequent phase of innovation.[11]

Within the eMAR study, of which the scope was limited to the polypharmacy patients and their pharmacist, the context of the regional platform seemed sufficient. The study yielded a CFL that worked. The next phase of innovation could be for the regional platform to agree that all pharmacists use a similar system, thereby increasing the group of users and enabling research into health outcomes.

2. *Power can be created by using small research cycles with comparable variables*

Measuring the same independent variable in all four studies creates power: amount and kind of users, amount and kind of use, dynamic of use. In study 6 patients were randomized by age and gender. We looked at the use of the technology from different angles (interprofessional use, high and low complex contexts, patient use), which benefit the reliability of certain findings (triangulation).

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The PDSA approach was usable

In the foregoing stages of the development of the e-communication tools the Plan-Do-Study-Act approach (PDSA) was chosen. Our results confirm that the PDSA approach can be used for innovation research. [48] The value of PDSA was in change management; the improvement cycles were perused, as it were, with all parties involved in a defined context. Starting points comprised problems in the field with pilots, so that, with each developmental step, we could learn from users (professionals) how further development of e-communication should be designed. For the use of Congredi, the wishes of users were taken into consideration for further development in co-creation, which has proved a suitable approach. [49,50] On the other hand, limited involvement of the end-users of new tools during the design phase makes it harder to realize a high adoption rate. [49,51] However, it is important that the PDSA is systematically performed and documented so that results are comparable with other studies. [48,52,53] Literature research also shows that it is advisable to use a roadmap for the development of

e-Health. [49,50] This roadmap should include an integration of technology, development, people orientation and context.

3. *Benefits of the research can be identified, despite the fact that the research only partly meets the classic standard*
    The following insights were gained:
    a. Technology is used, and used as intended
    b. Professional factors inhibited the implementation, not system factors
    c. Characteristics of professional-users play a role
    d. Characteristics of patient-users: mainly influenced by illness-related factors, and to a lesser extent by socio-demographic factors

    a.   Technology is used, and used as intended
    After studying the technology and the user-friendliness of the tool successively, the fit between users and the system seems to be adequate and relevant barriers did not appear to be tool-related. We could conclude this because the participants in the Congredi study as well as in the eMAR study hardly made use of the help desk option. In interviews, patients indicated that the technology was not complicated.

    We observed no impeding factors for professionals and patients to use the tools as intended. Even use of professional language does not have to be a reason to postpone implementation with patients because the patients find 'being connected' and able to communicate more important. We attempted to see whether the tool was adequately used in work processes by comparing user patterns with the expected patterns in regular healthcare. [54] In Congredi, problems, care actions, care action mutations and observations were recorded according to the expected steps of methodical work (chapter 3 and 4). The number of times new problems were recorded remained relatively low, as could be expected in primary healthcare. If there are many problems, patients are usually hospitalized. However, the number of observations did increase when the situation of the dementia patient became more complex: this is relevant for multidisciplinary coordination (chapter 4). We noticed that the professionals who used Congredi used the possibility to link other professionals to patients, thus strengthening the network around the patient (chapter 3 and 4). This was especially the case when care became complex, as we witnessed in people with dementia. Overall, the results show that the total amount of activity in the shared care action plan increased when the care situation becomes more complex (chapter 4).

    For patients, it is important that users experience the tool as attractive to use and that their experiences are integrated into the development process of the tool. [38,45] Informal carers indicated one point of improvement for Congredi: users should be alerted to new messages. Because this was not the case, they sometimes did not see emails from healthcare providers

or saw them too late. Partly because of this, the use of the tool had not yet been integrated into their daily routine. Professionals did get notifications about new email messages, but this was not included for the patient system. The involved informal carers who used Congredi expected the tool to be usable because they dealt with many different healthcare providers; they wanted a better overview of the care of their parents and better access to relevant healthcare providers. The interviews showed that this goal was only partly reached as not all relevant professionals linked and were active, which made the tool less usable. During the recruitment period, participants in the eMAR study declared their motivation to be actively involved in their own care stemmed from previous experiences with errors in the medication chain and they expected the tool to be usable for this purpose. For those who used the tool, this was so. In both studies, patients were unable to add their own data; they could only look at the existing data in the file. However, they were able to send a secure email or get in touch in a different way with the professionals, and part of the patients also did this within the tools. This procedure enabled the professionals to adjust the files. We do not know to what degree this also happened offline, outside of the tools.

b.   Professional factors inhibited the implementation, not system factors

The main barrier to increasing the use is the fact that professionals are not sufficiently connected to the technology. In primary care the level of use of e-communication technology is low and it is not integrated in the care standard and daily work processes. [38] Therefore some of the professionals were not familiar with using e-communication technology during their work (chapter 3 and 4). This may been of influence on the limited use by professionals and also have created a barrier to inviting patients to start a record and could therefore have influenced the response level. Schifferdecker et al found that training providers in primary healthcare settings improves the management of information. [55] Gee et al added an eHealth education field in the eCCM, which emphasises the need for attention to all aspects of training providers and patients in the use of eHealth. [3] From the results of our study we find it advisable that, to improve implementation of e-communication amongst professionals, there should be attention for eHealth education and agreements at an administrative level.

c.   Characteristics of professional-users

Half of all professional Congredi users were nurses. The most frequently occurring multidisciplinary combination was, as expected, that of nurses and GPs. In the literature we mainly found clear results concerning provider-patient communication for the two professions separately but not about e-communication within this combination. The literature does show indications that e-communication tools are useful for nurses in supporting self-management of specific patient groups. For instance, a nurse-administered internet-based patient-provider communication tool has been shown to reduce depression in breast-cancer patients. [56] With another tool the number of outpatient visits and hospital admissions for patients with inflammatory bowel disease were reduced. [18] This shows willingness and motivation for using e-tools. On the other hand,

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GPs increasingly use electronic patient records and offer their patients the option of requesting prescriptions and asking questions online. [57] They have concerns about the innovation process and the safety of communication with other professionals regarding the management of patients with complex care needs. [10,38,57] In our study of patients in low- and high-complex situations we also found that only in half the Congredi records GP's were active (chapter 4). Though we did not investigate the reasons for this, it could be explained by the fact that Congredi is an additional system for the GP. The use of a system that is not theirs might not promote trust in security. However, about multidisciplinary communication, hardly anything is known. Only Barr et al performed a systematic review about the impact of ICT on multidisciplinary collaboration and found three themes to focus on to enhance the impact of ICT: absence of professional conflict, collective engagement and continuous learning. [47] These factors can be regarded as contextual factors in the eCCM. [3] The finding that both nurses and GPs have a positive attitude towards innovation with eHealth in primary care is important for innovation.[57]

d.   Characteristics of patient-users

All studies in this thesis were of primary healthcare patients with a significant need for care. For eMAR-PCT, polypharmacy patients were included who used five or more medicines and for Congredi, patients were included who were home-dwelling elderly with two or more involved professionals.

There are specific patient-characteristics, which are predictors of use of an e-communication tool. Makai et al, found that patients use e-communication tools when an informal caregiver is involved, activities of daily living are problematic and also a large number of care providers are involved. [58] Another predictor is the degree of instability in the illness and/or care need of the patient. Having a diagnosis and showing active health behaviour is associated with the use of digital tools. [59] People with cancer who have little social support and suffer a lot from the disease, seek email contact and digital self-management advice. [60] Informal carers around patients are known to use e-communication tools. For instance, informal carers of stroke patients are reported to mainly use emails to discuss themes such as 'asking for advice, seeking support and looking for information'[61]. These characteristics were confirmed in our study of Congredi, where similar aims were reported in the interviews with informal carers. Due to the situation of their vulnerable parent, they wanted to have an overview of care by the different professionals so that they would be able to fulfil their tasks as informal carers effectively. Also, their individual examples of active e-communication dealt with changes in illness or care of their parent. It seems that if the illness becomes worse or the situation becomes less stable, patient systems have more motivation to use the tools.

The literature is not clear on the influence of socio-demographic variables. In a study performed among low-income, uninsured, and vulnerable populations low health literacy formed a barrier for use. [62] Wimble finds in a large study that being younger and having a higher

education level is a predictor of use. [59] In this study we were able to compare users and non-users of the e-communication tool eMAR (chapter 6). We did not observe a relation with socio-demographic characteristics (age, educational level, SES), but this could be explained because we selected participants who already had, and used, a computer with an Internet connection.

The conclusion is that the scope of use of e-communication tools is mainly influenced by illness-related factors, and to a lesser extent by socio-demographic factors. For future research into the implementation of new tools, it is recommended to look at groups in which the illness and/or care need is less stable, since this group is probably motivated to communicate and to use the tools.

FINAL REFLECTIONS

1. *The extent of the problem requires action*

The problem of seamlessly integrating care is increasing due to the number of home-dwelling patients with multimorbidity, and involved disciplines. E-communication offers opportunities to improve communication between professionals, and to involve the patients so that they can play a role in the realization of integrated care. But, as with so many new technologies, it takes a long time to develop a usable and effective tool. It goes step by step. The e-transfer from A to B has now been implemented on some scale, but, for patients with a chronic disease, a continuous exchange of information is needed to be able to monitor the quality of care. New platforms and apps can help, but it is problematic that there is no collective decision-making at national level about suitable instruments. The fact that healthcare parties now often build their own platforms or introduce apps is an answer but not a guarantee for integrated care.

2. *Do research in a learning environment*

This thesis shows that learning about digital care in practice yields relevant knowledge. Therefore creating a learning environment is a promising way to develop digital care. Though practice proves difficult to control, making research difficult, in the PDSA we have found a form to scientifically substantiate development steps. That is of added value. The eCCM model has proven to be relevant; it requires collaboration and learning because it focuses on 'improved outcomes'.

3. *Instrument development and implementation in co-creation*

This thesis shows that when developing and implementing an e-communication tool in co-creation, all parties have meaningful input to make the instrument usable. The supplier, the professional and the patient have relevant input in the PDSA cycle at all stages. In case of failure, it is relevant to make an analysis in co-creation in order to be able to take the right follow-up steps.

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4. Create collaboration at an administrative level

It was possible to set up this thesis through regional agreements and a vision on joint learning. Collaboration is a prerequisite for a learning environment, which in turn is a prerequisite for implementation and research. Collaboration is necessary to make an e-communication tool, because it creates mutual trust and manages expectations. The willingness to learn is needed at the regional level. That is why responsibility needs to be taken by administrators to create collaboration in a region, with clear interprofessional agreements across the boundaries of professional groups. Also periodical evaluation is advisable to make substantiated adjustments to the long-term regional collaboration on e-communication.

CONCLUSION

In this thesis the use of e-communication tools in primary care has been studied. In answer to the question whether these tools work it was found that small but specific groups of professionals and patients, namely so-called innovators and early adopters, used the e-communication tools Congredi and eMAR-PCT. The active professionals were mainly nurses; the most active combination of professionals was that of GPs and nurses. With regards to technology, the respondents did not indicate impeding factors, but the limited (active) involvement of professionals was perceived as impeding.

E-communication worked for these groups. The tools were used adequately because the patterns of activity were comparable to regular care. In the Congredi study communication activity increased with the multidisciplinarity of the involved team and with the increasing complexity of care. In the eMAR study the content of the e-mails showed adequate e-communication. The professionals and patients who used the tools actively used them as intended in a Complete Feedback Loop.

The results can be explained using the theoretical eCCM, with its differing requirements for good (e-)care to lead to improved outcomes, and with Rogers' theory of *Diffusion of Innovations*. Both theories were helpful in the thesis.

Further study is recommended into the effects of the use of e-communication tools: do these tools help and save costs?

For successful development of regional e-communication, a focus on the goal and execution of the collaboration between professionals and with the patient is recommended, under the following conditions:

1. The extent of the problem requires action
2. Do research in a learning environment
3. Instrument development and implementation in co-creation
4. Create collaboration at an administrative level.

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Summary

SUMMARY

The primary care patient population is changing; it is getting older and chronic disease and multimorbidity is increasing among the population. Therefore the number of actors involved in their care increases. Along with the change in the population, roles are changing in primary care: patients/informal carers are increasingly acquiring a steering role and the role of the professional shifts towards that of information provider and coach. Involved professionals now need to ensure that their primary healthcare patients/informal carers receive sufficient support in their active role. Due to the increasing number of actors and the changing roles, aligning care becomes more complicated and continuity of care is at risk. These factors underscore the necessity for adequate mutual communication between professionals and between patients/ informal carers and professionals. E-communication technology, which has been introduced widely in society for different services, can facilitate communication in care, but has not been broadly adopted.

The objective of this thesis is to contribute to knowledge about the implementation of e-communication in primary healthcare by assessing the use of two e-communication tools in practice. E-communication was operationalized as the sharing of data about healthcare problems and care actions, accessible for inspection by all parties involved in the care process and combined with a secure communication environment by using electronic tools. This operationalization is based on the eHealth enhanced Chronic Care Model (eCCM). The main question of this thesis is: *How is e-communication used in the practice of primary healthcare and what are stimulating and impeding factors for its use; between professionals, and between patients and professionals?* The first tool, Congredi, enables healthcare providers, patients (home-dwelling elderly) and informal carers (children and partners) to view the care action plan and realize coordinated care through communication. [54] [54] [54] [54] The second tool, eMAR-PCT, was aimed at helping pharmacists to involve polypharmacy patients in their digital medication record by enabling them to access their medication record and to communicate securely about errors and ask questions about the use of the medication. The following characteristics were studied in both groups regarding the use of the e-communication tools: (i) Are relevant professionals and patients/informal carers connected (how many of them are connected, what are the characteristics of the connected professionals and patients/informal carers, which impeding and stimulating factors do the users experience (technology, user-friendliness, motivation)); (ii) do involved parties make data available (are shared problems and changes recorded, what are the patterns of recorded healthcare data); (iii) do involved parties respond to the input of others (what is the extent of use, how do patients/informal carers experience the use of the tool with professionals)?

Chapter 2 describes the results of a systematic review of the use and usability of patient-provider asynchronous communication for chronically ill patients and the effects of such

communication on health behaviour, health outcomes, and patient satisfaction. A search was performed using PubMed and Embase. The quality of the articles was appraised according to the National Institute for Health and Clinical Excellence (NICE) criteria. The analysis was focussed on use and usability of asynchronous communication by examining the frequency of use and the number of users of the interventions with asynchronous communication, as well as of separate electronic messaging. The analysis of the effectiveness of asynchronous communication took place by examining effects on health behaviour, health outcomes, and patient satisfaction.

Fifteen studies met the inclusion criteria. The results pointed out that patients' knowledge concerning their chronic condition increased and they seemed to appreciate being able to communicate asynchronously with their providers. They not only had specific questions but also wanted to communicate about feeling ill. A decrease in visits to the physician was shown in two studies. Increases in self-management/self-efficacy for patients with back pain, dyspnoea, and heart failure were found. Positive health outcomes were shown in twelve studies, where the clinical outcomes for diabetic patients (HbA1c level) and for asthmatic patients (forced expiratory volume [FEV]) improved. Physical symptoms improved in five studies. Five studies generated a variety of positive psychosocial outcomes. It was concluded that (i) the use of asynchronous communication showed that patients are interested in using email. Patients are willing to participate and are taking the initiative to discuss health issues with their providers. (ii) The effect of asynchronous communication on health and health behaviour was not shown unequivocally in these studies.

Chapter 3 reports how professionals use Congredi in the care of home-dwelling elderly patients. The research group was recruited through general practices and homecare organizations. Professionals opened Congredi records for elderly patients who had two or more professionals involved. The records were the unit of analysis. Data were gathered from the Congredi system over a period of 42 weeks.

The results described an inclusion rate of 21.4 % (203/950); nearly half of the participating professionals were nurses. During the study, professionals were active in 448 patient records; female professionals were prevalent. In 201 records, several professionals from different disciplines were connected (multidisciplinary records), in 63 records multiple professionals of the same disciples (monodisciplinary records) and in 184 records only one professional was connected (solo records). In the patient records, three types of actions were registered: care activities (problem assessment, care actions, observation/evaluation, care action adaption), emailing (sending, reading, answering), and process activities (becoming a coordinator, inviting involved professionals to link). Most activities occurred in the multidisciplinary records (mean 12.2), which had twice the number of activities of monodisciplinary records (6.35), and solo records had a mean of 3.43 activities. Most activities were care activities (mean 9.14), emailing had a mean of 0.89 activities, and process activities had a mean of 0.29. It was concluded that Congredi was used and usable for multidisciplinary communication among professionals.

The content of the tool provided an active communication practice, with significant increases observed in the actions that must be shared for the effective coordination of care.

Chapter 4 describes a further study of the use of Congredi by professionals: whether use is adequate in care situations of differing complexity. Ninety-six Congredi records of patients with dementia could be divided in the subgroups low-complex care (n = 43) and high-complex care (n = 53). If Congredi is an adequate communication tool for professionals, the changing involvement of caregivers must also be reflected within the two subgroups. We hypothesised that use would be more intensive in the high-complex group in comparison to the low-complex group. Data were gathered during 42 weeks.

Findings showed that the mean number of care activities in the high-complex group was higher than in the low-complex group (10.43 versus, 5.61 p=.001). The number of professionals involved with high-complex care (3.58) was higher compared to low-complex care (2.51) (p = .000). The most frequent combination in the high-complex group was case managers and nurses (43.4 %) and in the low-complex group was several case managers (41.9 %). It was concluded that professionals used Congredi adequately in the multidisciplinary care of patients with dementia because the changing involvement of caregivers and the level of care activities were reflected in the use of Congredi.

Chapter 5 presents findings from a mixed method study on e-communication between patient-systems and professionals. It is examined whether Congredi, a tool designed for professionals, is usable for patient-systems (patient/informal carer) and what their experiences are. Elderly patients with two or more professional care providers were invited to use Congredi. Data were gathered after 42 weeks. Semi-structured interviews were performed between patient-systems and professionals.

An inclusion rate of 47.9 % was observed. Four user profiles, varying in intensity of use, were distinguished: (i) *Collaborators* viewed the record more than five times and sent, received and read e-mail. All were still active at the end; (ii) *Consumers* viewed the record between two and five times, read all received e-mail, but hardly sent e-mail; (iii) *Casuals* viewed the record once, read their e-mail irregularly and did not send any e-mail; (iv) *Non-Consumers* registered in Congredi but performed no further activities. They all received e-mail from their professionals, but did not read them. Four stopped prematurely. Patients/informal carers were motivated and able to use Congredi. Barriers in daily use were the limited active participation of professionals, unanswered e-mail and a lack of e-mail alerts. Despite limitations patients/ informal carers remained motivated. Patients wanted a satisfactory feedback loop (CFL) with professionals. The CFL refers to satisfactory interaction between professionals and patients. It requires that all relevant participants (patients, informal carers, professionals) are linked and adequately communicate (e.g. reading new information, answering e-mails). It was concluded that Congredi (a tool designed for professionals) is usable for patients and could support a Complete Feedback Loop in care.

Chapter 6 also reports on e-communication between patients and professionals. A study was performed to investigate whether the quality of the electronic medication administration record (eMAR) improves when patients play a vigilant role, by checking their medication using a patient communication tool linked to their eMAR (eMAR-PCT) to communicate asynchronously with the pharmacist about errors. Effects on health outcomes and self-care are also explored. In this quasi-experimental study, polypharmacy patients using five or more medications were randomly selected and invited to use their eMAR-PCT. Participants also received two digital questionnaires assessing health and self-care (week 0 and 26). Statistical analyses were performed on two subgroups: eMAR-PCT users and non-users.

The results show an inclusion rate of 43.5 % (n = 152). Women were more prevalent than men among the users group (56.4 % vs. 43.6 %). Among the eMAR-PCT users, 75 % logged in more than once, and 17.9 % communicated asynchronously with the pharmacist. The content of the e-mails shows that eMAR-PCT was used as intended. Effects on quality of eMAR and self-care were explored. No improvement in the quality of the eMAR was found. The self-care variables self-efficacy (p = .006) and collaboration with the pharmacist (p = .021) showed significant improvement in the users group. In conclusion the results showed no effect on eMAR quality and a modest improvement in self-care. Active digital patient participation to improve the quality of eMAR merits further investigation as, in line with other research, tentatively positive results are shown on self-care. Possibilities for implementation are promising as half of the patients who pledged to use eMAR-PCT actually did, and used it as intended.

Chapter 7 integrates and discusses the findings in the previous chapters in relation to the literature.

We found a relatively low number of users in all studies; the response rate was about 25 %. However, when viewed from the perspective of Rogers' theory on diffusion of innovations, we found this result to be satisfactory and self-evident for innovation research. In his theory, Rogers focuses on the life cycle of innovations, in which he distinguishes five stages with five groups of users (innovators (2.5 %), early adopters (13.5 %), early majority (34 %), late majority (34 %) and laggards (16 %)) (figure 1). According to Rogers' theory, it was to be expected that the participants in the studies in this thesis mainly consisted of innovators and early adopters. [85,138] Seen from this perspective, a 20-25 % response rate is satisfactory.

The active professionals who used eMAR-PCT were pharmacists, while Congredi was mostly used by nurses; the most active combination of professionals was the combination of GPs and nurses.

The approach with the Plan-Do-Study-Act cycles (PDSA) and mixed methods in development and application of the tools was successful. The value of PDSA lay in change management; the improvement cycles were perused, as it were, with all parties involved in a defined context. Starting points comprised problems in the field with pilots, so that, with each developmental step, we could learn from users (professionals) how further development of e-communication

should be designed. It is advisable to use a roadmap for the development and implementation of e-Health. [37]Such a roadmap should include an integration of technology, development, people orientation and context.

Applying the eCCM model was helpful. We built on knowledge incorporated in the eCCM. The model proved a helpful tool in mapping the steps made concerning (i) providing administrative support and agreement with the partners (the organizational clusters Community-Health Systems and eCommunity-eHealth), (ii) developing the requirements for a tool in consultation with the users (Self-management Support, Delivery Systems Design, Clinical Decision Support, Clinical Information Systems), (iii) testing and refining the tools with the users in practice with focus on these requirements and on ingredients for a training course (eHealth Education). In this way it was possible to realize an e-communication tool that meets the contextual and tool related conditions for a Complete Feedback Loop (CFL). By studying the actions within the CFL, we could see whether the design of the intervention had to be adjusted.

The usability of the tools is good. The fit between users (professionals and patients) and the system seems to be adequate and relevant barriers did not appear to be tool-related. Moreover, we observed no impeding factors for professionals and patients to use the tools as intended. We attempted to see whether the tool was adequately used in work processes by comparing user patterns with the expected patterns in regular healthcare. We noticed that the professionals who used Congredi used the possibility to link other professionals to patients, thus strengthening the network around the patient. This was especially the case when care became complex, as we witnessed in people with dementia. Overall, the results show that the total amount of activity in the shared care action plan increased when the care situation becomes more complex.

For patients, it is important that users experience the tool as attractive to use, and that their experiences are integrated into the development process of the tool.

The limited participation in the tool by professionals in the Congredi study was experienced as a problem. The involved informal carers who used Congredi expected the tool to be usable because they dealt with many different healthcare providers; they wanted a better overview of the care of their parents and better access to relevant healthcare providers. The interviews showed that this goal was only partly reached as not all relevant professionals linked and were active, which made the tool less usable. It seems advisable to specifically instruct nurses and case managers in their training to invite the general practitioner to link, but also to convince the general practitioner of the importance of taking initiative to become connected. For general practitioners Congredi is an additional system. It is a known barrier that GP's do not participate actively in additional eHealth systems if their own administrative system cannot save the additions. Policy of supplier and payer of these tools should focus on the overcoming of this barrier.

In conclusion, small but specific groups, namely so-called innovators and early adopters, used the studied e-communication tools Congredi and eMAR-PCT. E-communication worked for these groups. This is shown in the Congredi study because communication activity increased with the multidisciplinarity of the involved team and with the increasing complexity of care, and the patterns of activity were comparable to regular care. With regards to technology, the respondents did not indicate impeding factors, but the limited (active) involvement of professionals was perceived as impeding. The active professionals were mainly nurses; the most active combination of professionals was that of GPs and nurses. In the eMAR study e-communication was shown to work in the content of the e-mails. The professionals and patients (internet users with polypharmacy or with two or more healthcare providers) who used the tools actively used them as intended in a Complete Feedback Loop.

The results can be explained using the theoretical eCCM, with its different requirements for good (e)care leading to improved outcomes, and with Rogers' theory of Diffusion of Innovations. Both theories were helpful to our research.

For implementation, a focus on the goal and execution of the collaboration between professionals and with the patient is recommended. We have seen that, even if the technical aspects are well organized, one cannot be sure that the tool is well used.

For successful development and implementation of regional e-communication, the following conditions are recommended:

1.   The extent of the problem requires action
2.   Do research in a learning environment
3.   Instrument development and implementation in co-creation
4.   Create collaboration at an administrative level.

Samenvatting

SAMENVATTING

De patiëntenpopulatie in de eerstelijns gezondheidszorg verandert; men wordt ouder en onder de bevolking nemen chronische ziekte en multimorbiditeit toe. Daardoor stijgt het aantal actoren dat betrokken is bij hun zorg. Naast de verandering in de patiëntenpopulatie, veranderen rollen in de eerstelijns gezondheidszorg: patiënten / informele verzorgers krijgen steeds meer een sturende rol en de rol van de professional verschuift naar die van de informatieverstrekker en coach. Betrokken professionals moeten er nu voor zorgen dat hun eerstelijns gezondheidszorgpatiënten / informele verzorgers voldoende steun krijgen in hun actieve rol. Door het toenemend aantal actoren en de veranderende rollen wordt het afstemmen van de zorg ingewikkelder en komt de continuïteit van zorg in gevaar. Deze factoren onderstrepen de noodzaak voor adequate onderlinge communicatie tussen professionals en tussen patiënten / informele verzorgers en professionals. E-communicatietechnologie, die in de samenleving op grote schaal is geïntroduceerd voor diverse diensten, kan ook de communicatie in de zorg vergemakkelijken, maar wordt in de zorg niet breed aanvaard.

Doel van dit proefschrift was het bijdragen aan kennis over de implementatie van e-communicatie in de eerstelijns gezondheidszorg, door het gebruik van twee e-communicatie-instrumenten in de praktijk te evalueren. E-communicatie werd als volgt geoperationaliseerd: door middel van elektronische hulpmiddelen, delen van gegevens over gezondheidsproblemen en zorgactiviteiten met alle partijen die betrokken zijn bij het zorgproces, in combinatie met een veilig communicatiekanaal. Deze operationalisatie was gebaseerd op het eHealth-enhanced Chronic Care Model (eCCM). De hoofdvraag van dit proefschrift was: *hoe wordt e-communicatie gebruikt in de praktijk van de eerstelijns gezondheidszorg en wat zijn stimulerende en belemmerende factoren voor het gebruik ervan; tussen professionals en tussen patiënten en professionals?* Het eerste instrument, Congredi, stelt zorgverleners, patiënten (ouderen thuis) en informele verzorgers (kinderen en partners) in staat om het zorgactieplan te bekijken en gecoördineerde zorg door middel van communicatie te realiseren. Het tweede instrument, eMAR-PCT, heeft als doel apothekers te faciliteren om polyfarmaciepatiënten te betrekken bij hun eigen digitale medicatieoverzicht door hen in staat te stellen hun medicatieoverzicht te openen, veilig te communiceren over fouten en vragen te stellen over het gebruik van de medicatie. De volgende vragen werden in beide groepen onderzocht in verband met het gebruik van de e-communicatie instrumenten: *(i) Zijn relevante professionals en patiënten / informele verzorgers verbonden (hoeveel van hen zijn aangesloten, wat zijn de kenmerken van de aangesloten professionals en patiënten / informele verzorgers, welke belemmerende en stimulerende factoren ervaren de gebruikers (technologie, gebruiksvriendelijkheid, motivatie)); (ii) maken betrokken partijen gegevens beschikbaar (gedeelde problemen en geregistreerde veranderingen, wat zijn de patronen van geregistreerde gezondheidszorggegevens); (iii) reageren partijen op de input van anderen (wat is de mate van gebruik, hoe ervaren patiënten / informele verzorgers het gebruik van het instrument met professionals)?*

Hoofdstuk 2 beschrijft de resultaten van een systematisch literatuuronderzoek naar het gebruik en de bruikbaarheid van asynchrone communicatie tussen patiënten en professionals over chronisch zieke patiënten en de effecten van dergelijke communicatie op gezondheidsgedrag, gezondheidsresultaten en patiënttevredenheid. Het onderzoek werd uitgevoerd met behulp van PubMed en Embase. De kwaliteit van de studies werd beoordeeld volgens de criteria van het National Institute for Health and Clinical Excellence (NICE). De analyse was gericht op het gebruik en de bruikbaarheid van asynchrone communicatie door de frequentie van gebruik en het aantal gebruikers van de interventies met asynchrone communicatie, alsmede van afzonderlijke elektronische berichten te onderzoeken. De analyse van de effectiviteit van asynchrone communicatie vond plaats door de effecten op gezondheidsgedrag, gezondheidsresultaten en patiënttevredenheid te onderzoeken.

Vijftien studies voldeden aan de inclusiecriteria. De resultaten wezen erop dat de kennis van patiënten over hun chronische aandoening toegenomen was en ze leken te waarderen dat ze asynchroon met hun aanbieders konden communiceren. Ze hadden niet alleen specifieke vragen, maar wilden ook communiceren over zich ziek-voelen. In twee studies werd een afname van de bezoeken aan de arts gevonden. Bij patiënten met rugpijn, dyspneu en hartfalen werd een toename in zelfmanagement / self-efficacy gevonden. In twaalf studies werden positieve gezondheidsresultaten gevonden, waarbij de klinische uitkomsten verbeterd bleken voor diabetes patiënten (HbA1c-niveau) en voor astma patiënten (forced expiratory volume [FEV]). Fysieke symptomen verbeterden in vijf studies. Een verscheidenheid aan positieve psychosociale uitkomsten werd in vijf studies gegenereerd. Er werd geconcludeerd dat (i) het gebruik van asynchrone communicatie aantoonde dat patiënten geïnteresseerd waren in het gebruik van e-mail. Patiënten waren bereid deel te nemen en nemen het initiatief om gezondheidsproblemen met hun aanbieders te bespreken. (ii) Het effect van asynchrone communicatie op gezondheids- en gezondheidsgedrag werd in deze studies niet ondubbelzinnig getoond.

Hoofdstuk 3 geeft aan hoe professionals gebruik maken van Congredi in de zorg voor oudere patiënten thuis. De onderzoeksgroep werd geworven via huisartspraktijken en thuiszorg organisaties. Professionals hebben Congredi-records geopend voor oudere patiënten met twee of meer betrokken professionals. De records waren de analyse eenheid. Gegevens werden gedurende een periode van 42 weken verzameld uit het Congredi-systeem.

De resultaten beschreven een inclusiepercentage van 21,4 % (203/950); bijna de helft van de deelnemende professionals was verpleegkundige. Tijdens de studie waren professionals actief in 448 patiënten records; vrouwelijke professionals waren in de meerderheid. In 201 records waren meerdere professionals uit verschillende disciplines aangesloten (multidisciplinaire records), in 63 records waren meerdere professionals van dezelfde discipline aangesloten (monodisciplinaire records) en in 184 records was slechts één professional aangesloten (solo records). In de patiëntrecords werden drie soorten acties geregistreerd: zorgactiviteiten (probleembeoordeling, zorgacties, observatie / evaluatie, aanpassing van de zorgactie), e-mailen (verzenden, lezen, beantwoorden) en proces-activiteiten (coördinator worden, betrokken

professionals uitnodigen te linken). In de multidisciplinaire records kwamen de meeste activiteiten voor (gemiddelde 12,2), dit was tweemaal zoveel als de monodisciplinaire records (6.35); solo records vertoonden een gemiddelde van 3,43 activiteiten. De meeste activiteiten waren zorgactiviteiten (gemiddeld 9,14), e-mailen had gemiddeld 0,89 activiteiten en procesactiviteiten hadden een gemiddelde van 0,29. Geconcludeerd werd dat Congredi gebruikt werd en bruikbaar was voor multidisciplinaire communicatie onder professionals. De inhoud van het instrument liet een actieve communicatiepraktijk zien, waarbij significante toenames werden waargenomen van acties die bijdragen aan effectieve coördinatie van de zorg.

Hoofdstuk 4 beschrijft een studie met als vraag of het gebruik van Congredi door professionals adequaat is in zorgsituaties van verschillende complexiteit. Zes-en-negentig Congredi-records van patiënten met dementie konden worden verdeeld in twee subgroepen met laag-complexe zorg (n = 43) en hoog-complexe zorg (n = 53). Als Congredi een adequaat communicatie instrument voor professionals was, zou de veranderende betrokkenheid van zorgverleners binnen de twee subgroepen worden weerspiegeld. Verondersteld werd dat het gebruik in de hoog-complexe groep meer intensief zou zijn in vergelijking met de laag-complexe groep. Gegevens werden verzameld gedurende 42 weken.

Het onderzoek liet zien dat het gemiddelde aantal zorgactiviteiten in de hoog-complexe groep hoger was dan in de laag-complexe groep (10,43 versus 5,61 p = 0,001). Het aantal professionals betrokken bij de hoog-complexe zorg (3.58) was hoger dan bij de laag-complexe zorg (2.51) (p = .000). Case managers en verpleegkundigen (43,4 %) waren de meest voorkomende combinatie in de hoog-complexe groep en in de laag-complexe groep was dat meerdere case managers (41,9 %). Er werd geconcludeerd dat professionals Congredi adequaat gebruikten in de multidisciplinaire zorg van patiënten met dementie omdat de veranderende betrokkenheid van zorgverleners en het niveau van zorgactiviteiten weerspiegeld werden in het gebruik van Congredi.

Hoofdstuk 5 presenteert bevindingen uit een mixed-method studie over e-communicatie tussen patiëntsystemen (patiënt / informele verzorger) en professionals. Onderzocht werd of Congredi, een instrument ontworpen voor professionals, bruikbaar was voor patiëntsystemen en wat hun ervaringen zijn. Oudere patiënten met twee of meer professionele zorgverleners werden uitgenodigd Congredi te gebruiken. Gegevens werden verzameld gedurende 42 weken. Semigestructureerde interviews met patiëntsystemen werden uitgevoerd.

Een inclusiegraad van 47,9 % werd waargenomen. Vier gebruikersprofielen, variërend in intensiteit van gebruik, werden onderscheiden: (i) *Collaborators* bekeken het record meer dan vijf keer en verzonden, ontvingen en lazen e-mail. Allen waren nog steeds actief aan het einde van de onderzoeksperiode; (ii) *Consumers* bekeken het record tussen twee en vijf keer, lazen alle ontvangen e-mail, maar verzonden nauwelijks e-mail; (iii) *Casuals* bekeken het record eenmaal, lazen hun e-mail onregelmatig en verzonden geen e-mail; (iv) *Non-Consumers* registreerden

zich in Congredi, maar verrichten geen verdere activiteiten. Ze ontvingen allemaal e-mail van hun professionals, maar hebben deze niet gelezen. Vier stopten voortijdig.

Patiëntsystemen waren gemotiveerd en in staat Congredi te gebruiken. Barrières in dagelijks gebruik waren de beperkte actieve deelname van professionals, onbeantwoorde e-mail en een gebrek aan e-mailmeldingen. Ondanks de beperkingen bleven de patiëntsystemen gemotiveerd. Patienten wilden een bevredigende feedback lus (CFL) met professionals. Het CFL verwijst naar een bevredigende interactie tussen professionals en patiënten en vereist dat alle relevante deelnemers (patiënten, informele verzorgers, professionals) gekoppeld zijn en adequaat communiceren (bijvoorbeeld het lezen van nieuwe informatie, het beantwoorden van e-mails). Geconcludeerd werd dat Congredi geschikt is voor patiënten en een complete feedback lus in de zorg kan ondersteunen.

Hoofdstuk 6 rapporteert over e-communicatie tussen patiënten en professionals. Onderzocht werd of de kwaliteit van het elektronisch medicatieoverzicht (eMAR) toeneemt wanneer patiënten een waakzame rol spelen door hun medicatieoverzicht te controleren met behulp van een communicatieprogramma voor patiënten gekoppeld aan hun eMAR (eMAR-PCT) waardoor ze asynchroon met de apotheker kunnen communiceren over fouten en vragen. Effecten op gezondheidsresultaten en zelfzorg werden ook onderzocht. In deze quasi-experimentele studie werden polyfarmaciepatiënten die vijf of meer medicijnen gebruikten, willekeurig geselecteerd en uitgenodigd om hun eMAR-PCT te gebruiken. Deelnemers ontvingen twee digitale vragenlijsten om hun gezondheid en zelfzorg te beoordelen (week 0 en 26). Statistische analyses werden uitgevoerd op twee subgroepen: eMAR-PCT gebruikers en niet-gebruikers.

De resultaten tonen een inclusiepercentage van 43,5 % (n = 152). In de gebruikersgroep kwamen meer vrouwen voor dan mannen (56,4 % versus 43,6 %). Van de eMAR-PCT gebruikers, logden 75 % meer dan één keer in en 17,9 % communiceerde asynchroon met de apotheker. Uit de inhoud van de e-mails bleek dat eMAR-PCT gebruikt werd zoals bedoeld. Er werd geen verbetering gevonden in de kwaliteit van de eMAR. De zelfzorgvariabelen self-efficacy (p = .006) en samenwerking met de apotheker (p = .021) lieten een significante verbetering zien in de gebruikersgroep. Concluderend werd er geen effect aangetoond op de kwaliteit van eMAR en werd er een bescheiden verbetering aangetoond bij zelfzorgvariabelen. Het is aan te bevelen nader onderzoek te doen naar actieve digitale patiëntenparticipatie om de kwaliteit van eMAR te verbeteren, aangezien tentatief positieve resultaten werden getoond op zelfzorg, in lijn met ander onderzoek. Mogelijkheden voor implementatie zijn veelbelovend omdat de helft van de patiënten die beloofden om eMAR-PCT te gebruiken dit ook deed en het gebruikte zoals bedoeld.

Hoofdstuk 7 integreert en bespreekt de bevindingen uit de vorige hoofdstukken in relatie tot de literatuur.

In alle studies werd een relatief laag aantal gebruikers gevonden; de respons was ongeveer 25 %. Echter, gezien vanuit het perspectief van Rogers' theorie over verspreiding van inno-

vaties, werd dit resultaat voor innovatieonderzoek redelijk bevredigend en vanzelfsprekend bevonden. In zijn theorie richt Rogers zich op de levenscyclus van innovaties, waarin hij vijf fasen onderscheidt van vijf groepen gebruikers (innovatoren (2,5 %), vroege adopters (13,5 %), vroege meerderheid (34 %), latere meerderheid (34 %) en achterblijvers (16 %)) (figuur 1). Volgens Rogers' theorie was het te verwachten dat de deelnemers aan deze studies voornamelijk uit innovatoren en vroege adopters zou bestaan. Gezien vanuit dit perspectief is een 20-25 % respons vrij succesvol.

Apothekers waren de actieve professionals die eMAR-PCT gebruikten, terwijl Congredi voornamelijk door verpleegkundigen werd gebruikt; de meest actieve combinatie van professionals was de combinatie van huisarts en verpleegkundige.

Bij de ontwikkeling en toepassing van de instrumenten was de aanpak met de Plan-Do-Study-Act cycli (PDSA) en mixed-methods onderzoek succesvol. De waarde van PDSA lag in change management; de verbetercycli werden onderzocht, met alle betrokkenen die in een gedefinieerde context actief waren. Problemen in het veld die uit pilotstudies naar voren kwamen vormden het uitgangspunt, zodat we bij elke ontwikkelstap van gebruikers (professionals) konden leren hoe de ontwikkeling van e-communicatie verder te ontwerpen. Het is raadzaam om een routekaart te gebruiken voor de ontwikkeling en implementatie van eHealth. Een dergelijke routekaart zou een integratie van technologie, ontwikkeling, mensgerichtheid en context moeten bevatten.

Het toepassen van het eCCM-model was behulpzaam doordat er gebouwd kon worden op kennis reeds opgenomen in het eCCM. Het model was een nuttig hulpmiddel bij het in kaart brengen van de stappen die zijn gemaakt met betrekking tot (i) bestuurlijke ondersteuning en afspraken met de partners (de organisatorische clusters Community-Health Systems en eCommunity-eHealth), ii) het ontwikkelen van de eisen voor een tool in overleg met de gebruikers (Self-management Support, Delivery Systems Design, Clinical Decision Support, Clinical Information Systems), (iii) de instrumenten met de gebruikers in de praktijk testen en verfijnen met inachtneming van deze eisen en ingrediënten voor een opleiding destilleren (eHealth Education). Op deze manier was het mogelijk om een e-communicatie instrument te realiseren dat voldoet aan de contextuele en gereedschap gerelateerde voorwaarden voor een complete feedback lus (CFL). Door de acties in de CFL te bestuderen, konden we zien of het ontwerp van de interventie moest worden aangepast.

De bruikbaarheid van de instrumenten was bevredigend. De fit tussen gebruikers (professionals en patiënten) en het systeem leek adequaat te zijn en relevante barrières leken niet instrument-gerelateerd te zijn. Bovendien zijn er voor professionals en patiënten geen belemmerende factoren waargenomen om de instrumenten te gebruiken zoals bedoeld. Of de instrumenten adequaat in werkprocessen werden gebruikt is onderzocht door gebruikerspatronen te vergelijken met de verwachte patronen in de reguliere gezondheidszorg. De professionals die Congredi gebruikten, pasten de functionaliteit om andere professionals te koppelen aan

patiënten toe, waardoor het netwerk rond de patiënt versterkt werd. Dit deed zich vooral voor bij hoog-complexe zorg, zoals bij mensen met dementie. In het algemeen bleek uit de resultaten een toename van het totale aantal activiteiten in het zorgactieplan als de zorgsituatie complexer wordt. Voor patiënten-gebruikers was het belangrijk dat het instrument werd ervaren als aantrekkelijk om te gebruiken en dat hun ervaringen geïntegreerd werden in het ontwikkelingsproces van het instrument.

De beperkte deelname aan het instrument door professionals in de Congredi-studie werd door de betrokken informele verzorgers ervaren als een probleem. Ze hadden verwacht dat het instrument bruikbaar was omdat ze met veel verschillende zorgverleners te maken hadden; ze wilden een beter overzicht van de zorg van hun ouders en betere toegang tot relevante zorgverleners. Uit de interviews bleek dat dit doel slechts gedeeltelijk werd bereikt omdat niet alle relevante professionals verbonden waren en actief waren, waardoor het instrument minder bruikbaar was. Het lijkt raadzaam om verpleegkundigen en case managers in hun opleiding specifiek te instrueren om de huisarts uit te nodigen om te koppelen, maar ook om de huisarts te overtuigen van het belang van het nemen van initiatieven om te worden verbonden. Voor huisartsen is Congredi een extra systeem. Het is een bekende barrière dat de huisartsen niet actief deelnemen aan aanvullende eHealth-systemen als hun eigen administratieve systeem de toevoegingen niet kan opslaan. Beleid van leverancier en betaler van deze instrumenten moet zich richten op het overwinnen van deze barrière.

Concluderend werden de bestudeerde e-communicatie-instrumenten Congredi en eMAR-PCT gebruikt door kleine maar specifieke groepen, namelijk zogenaamde innovatoren en vroege adopters. E-communicatie werkte voor deze groepen. Dit blijkt uit de Congredi-studie, omdat de communicatieactiviteit toenam met de multidisciplinaire aard van het betrokken team en met de toenemende complexiteit van de zorg en de patronen van de activiteit vergelijkbaar waren met de reguliere zorg. Wat de technologie betreft, hebben de respondenten geen belemmerende factoren genoemd, maar de beperkte (actieve) betrokkenheid van professionals werd beschouwd als belemmering. De actieve professionals waren vooral verpleegkundigen; de meest actieve combinatie van professionals was die van huisarts en verpleegkundige. In de eMAR-studie bleek uit de inhoud van de e-mails dat e-communicatie werkte. De professionals en patiënten (internetgebruikers met polyfarmacie of met twee of meer zorgverleners) die de instrumenten gebruikt hebben, hebben ze actief gebruikt zoals bedoeld in een complete feedback lus. De resultaten kunnen uitgelegd worden met behulp van de theoretische eCCM, met zijn verschillende eisen voor goede (e-)zorg, en met Rogers' theorie van *Diffusion of Innovations*. Beide theorieën waren nuttig voor ons onderzoek.

Voor implementatie wordt een focus op het doel en de uitvoering van de samenwerking tussen professionals en met de patiënt aanbevolen. We hebben gezien dat, zelfs als de technische aspecten goed zijn georganiseerd, men er niet zeker van kan zijn dat de tool goed wordt

gebruikt. Voor een succesvolle ontwikkeling en implementatie van regionale e-communicatie wordt aanbevolen:

1. De omvang van het probleem vereist actie
2. Doe onderzoek in een leeromgeving
3. Instrumentontwikkeling en -implementatie in co-creatie
4. Creëer samenwerking op bestuurlijk niveau.

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Op deze plek wil ik een aantal personen bedanken die mij tijdens mijn opleidingen door hun visie op het vak verpleegkunde hebben geïnspireerd als rolmodel. Allereerst Ageeth Schippers, mijn stagebegeleider in de wijk. Zij heeft mij lang geleden laten zien dat verplegen betekent dat je patiënten met hun beperkingen ondersteunt om zoveel mogelijk te floreren. Later gaf Mieke

Grypdonck, emeritus hoogleraar Verplegingswetenschap, hier woorden aan in haar oratie "Het leven boven de ziekte uittillen". Nog later, in "Verpleegkunde en Presentie" inspireerde zij mij ook tot het gebruik van eHealth in de zorg, een andere manier van 'er zijn' voor de patiënt. Tijdens mijn Masteropleiding en later ook als onderzoeker heeft Jaap van der Bijl het concept 'self-efficacy' toegevoegd aan mijn bagage: de therapie kan pas werken als de patiënt vertrouwen heeft in eigen kunnen. Cruciaal om mee te nemen in dit type onderzoek. En natuurlijk bedank ik ook de leider van de Masteropleiding Francis Mensink, die steeds benadrukte naar mij en anderen hoe belangrijk het is om behalve in het ziekenhuis ook in de eerstelijn onderzoek te doen. De jarenlange persoonlijke steun die je mij hebt gegeven in dit traject was heel helpend om mij op het 'promotie pad' te brengen.

In mijn werk vormde de periode bij Meavita de inspirerende bakermat voor dit proefschrift. Vanaf 2003 hebben we daar een van de eerste beeldverbindingen met patiënten - Tvfoon - ontwikkeld. We wilden zo dicht mogelijk bij de patiënt zijn, om zorg op maat te kunnen leveren. Met eHealth was dit mogelijk geworden. Wat we zagen was dat patiënten de mogelijkheden van de nieuwe technologie op prijs stelden maar dat implementatie niet mee viel. Hier wil ik Frank Vijg bedanken voor zijn lef om innoveren op een nieuwe 'sociale' manier de ruimte te geven en daarnaast Ria Hofstede voor haar praktische en energieke leiderschap in dit proces. Vervolgens heb ik de opgedane kennis over eHealth toepassingen door verpleegkundigen, mogen uitbreiden in een project bij STG-HMF met het vertrouwen en de steun van Annemiek Goris, directeur, en van het ministerie van VWS waar ik met name Peter Kruithof als supporter van transmurale zorg en verpleegkunde wil noemen. Veertien inspirerende praktijken in het veld lieten zien dat er veel mogelijkheden liggen in het gebruik van eHealth, maar dat er wel actie (van professionals en managers) nodig is om te begrijpen wat er gebeurt als eHealth wordt toegepast en dit op een goede manier te implementeren in de organisatorische context en de werkprocessen. Voor de stap naar het daadwerkelijk uitvoeren van mijn promotieonderzoek heb ik veel steun ervaren van Mia van Leeuwen, voormalig directeur van de Stichting Transmurale Zorg Den Haag e.o. Zowel inhoudelijk, bij het ontwikkelen van het onderwerp, als bij het verwerven van fondsen voor het onderzoek was jij, Mia, een creatief denker en gesprekspartner. Dank ook voor jouw steun en inspiratie bij het behalen van de eindstreep. Ik ben blij dat jij mijn paranimf wilt zijn. En natuurlijk wil ik ook al mijn collega's bedanken voor de steun en de ruimte om dit proefschrift te kunnen afronden. De sponsoring van de evaluaties door CZ, Menzis en NutsOhra was letterlijk inspirerend; zonder hun financiering hadden we deze proefprojecten niet kunnen uitvoeren. Daarbij het is ook bemoedigend dat juist de zorgverzekeraar geïnteresseerd is in e-communicatie als mogelijkheid tussen professionals en patiënten. Dank aan alle regionale bestuurders en stakeholders die hun energie in hebben gezet om innovaties in de praktijk te implementeren en ook dank aan alle professionals in apotheken, ziekenhuizen en eerste lijn die de ruimte gaven om te onderzoeken hoe het werken met eHealth daadwerkelijk ging en wat nodig was om dit beter te doen. En dank aan alle patiënten die bereid waren met ons dit experiment aan te gaan.

Ook wil ik de Denktank bedanken, Will Mastbergen en Margriet Torny, voor de gepassioneerde gesprekken over het vak die we hebben gevoerd vanaf de tijd dat we samen in de wijk werkten; natuurlijk begeleid door heerlijke maaltijden. Op wat grotere schaal heeft de Honor Society of Nursing, Rho Chi, met al zijn inspirerende collega's mij gesterkt in de weg om ervaringen wetenschappelijk te onderzoeken en zo beschikbaar te maken voor anderen.

Dan zijn er nog de vele familieleden, vrienden en kennissen die onvermoeibaar en belangstellend bleven informeren naar mijn onderzoek en het proces van promoveren. Jullie betrokkenheid heeft mij steeds gemotiveerd om door te gaan. *And of course I would like to thank Ro and Mickey Quicke for supporting me from the UK and for all the interesting discussions we had on the subject.*

Tot slot wil ik mijn ouders bedanken voor de kansen en inspiratie die ze mij hebben gegeven. Pap, jij bent voor mij een bron van inspiratie met je energie en belangstelling voor vernieuwing, altijd open voor avontuur, "zeg nooit nee", "geef je ervaringen door zodat anderen er wat aan hebben". Het langdurige ziekteproces van Mam heeft mij veel geleerd over het belang van communicatie tussen allen in de zorg, en was daardoor ook een inspiratie. De steun vanuit mijn eigen gezin was een warm bad. Marije, Eline, Aletta en inmiddels ook Jochem en Jordy, bedankt voor alle gezellige uitjes en gesprekken die hielpen om weer door te gaan. En de kleine Norah die mij veel vreugde en afwisseling bracht in de slotfase. Bedankt, Marije, dat jij namens allen mijn paranimf wilt zijn.

En tot slot dank aan Henk, mijn partner op alle fronten. Op onze eigen wijze hebben wij dit traject samen gelopen. Dank voor al je steun op praktisch en ander vlak. Nu hoop ik samen met jou te gaan oogsten.

Curriculum Vitae

ABOUT THE AUTHOR

After enjoying primary and secondary education in various countries, I received my VWO diploma in the Netherlands. The most enriching thing I learned from that was that life is different everywhere, that there is something to be said for all ways of life and that you ultimately create the opportunity to live your own life the way you want it. This insight contributed to my motivation to choose nursing as a profession so that I could contribute to other people living their life as they wanted it, regardless of their disability. My focus has always been on implementing effective innovations that could make it easier for people to take care of themselves and thereby have the best possible life.

After a short period as the first HBOV-employee in the Wilhelmina Gasthuis (now AMC), I started working as a district nurse because I felt that in that position all aspects of nursing were applicable in my relationship with patients and in the team of professionals. In the anarchistic Amsterdam - Bos en Lommer - in the 1980s, it was the aim to organize healthcare within the neighborhood itself; that what was needed for the neighborhood was organized in and by the neighborhood. Thanks to this decentralized approach, patients received a more central place in the organization of care. Internet was in it's early stages and it was my vision was that this was an opportunity to provide people with customized, up-to-date and helpful information about their health in a 'store' near their home. In my thesis, for the Voortgezette Opleiding Beroepsinnovatie (1988), I discussed the possibilities of an 'Informationshop about healthcare' in the neighborhood.

As a regional nurse the insulin pen, as an innovative opportunity for patients, inspired me. I recognized that this was technology that turned diabetes patients from 'patients' into 'people with an interesting pen' which looked nice and which they could use for instance in the train to inject themselves through their shirts. The technique helped them to a more positive and equal position in life. My role was to facilitate nurses to take on their new role as patient coach, through awareness and training and the preparation of protocols.

In those years, as one of the first, I also set up joint office hours in the hospital with specialists and specialized nurses from the primary setting, so that patients received medical information and guidance in managing the disease in their lives. Chronic illnesses posed an ever increasing challenge for citizens and health care. In my experience, nursing was a core science in this, in addition to medical science. After all, nursing was aimed at "raising life above the disease" (inaugural lecturer Mieke Grypdonck), which in addition to healing contributes greatly to the quality of life of patients. In many ways I have worked to position the nursing profession in the professional associations and by teaching. In 1999 I obtained a Master of Science degree in Nursing in Cardiff (UK) with research into self-management of patients with rheumatism. After that, I researched the effects of self-management programs on special groups in a state of the

art study, and concluded that the programs only help if the user himself is convinced that he can handle the program.

In 2002, the time of 'creating business in health care', I became head of the innovation department of Meavita Thuiszorg. In the context of finding ways to get in touch with the patient and his needs even better, we then developed one of the first live-video connections with patients and learned a lot from this. What particularly impressed us was that patients experienced the connection via the internet with professionals, for 'just in case', as very important. Moreover, we offered programs to monitor their illness and also fun programmes. But health care was not yet ready for this concept.

After my experiences at Meavita, I was interested whether nurses also saw effects of this new technology in their work. In 2010, I interviewed and drew up a report from nurses who worked with eHealth techniques via Stichting Toekomstscenario's Gezondheidszorg (STG / HMF). Across the entire width of the field I saw that the possibilities for nurses to support their patients better were increased by the use of technology. However, this insight was not yet widely supported so that no structural adjustments to work processes were made. Only if managers were convinced in advance that it would be cheaper in this way did implementation take place. There was also a great deal of interest from abroad in our eHealth approach. In the context of, among other things EU programs, I was able to share our experiences on various international platforms.

From 2010 I started work at Stichting Transmurale Zorg Den Haag e.o. because this region was interested in working together towards the future. The task of the local administrators was: 'bring coherence in care'. My programme line was aimed at developing opportunities that would facilitate professionals and patients / citizens in taking their role in their care by using modern technologies that support them. This then unique place was the base for conducting this PhD research. I found it important to use my years of experience, in this 'primal age of a new era', to conduct descriptive research from practice, to help design evidence-based solutions for the healthcare of the future, with equal roles for patient and caregiver.