Designing information and communication technology to enable person-centred care in chronic disease management

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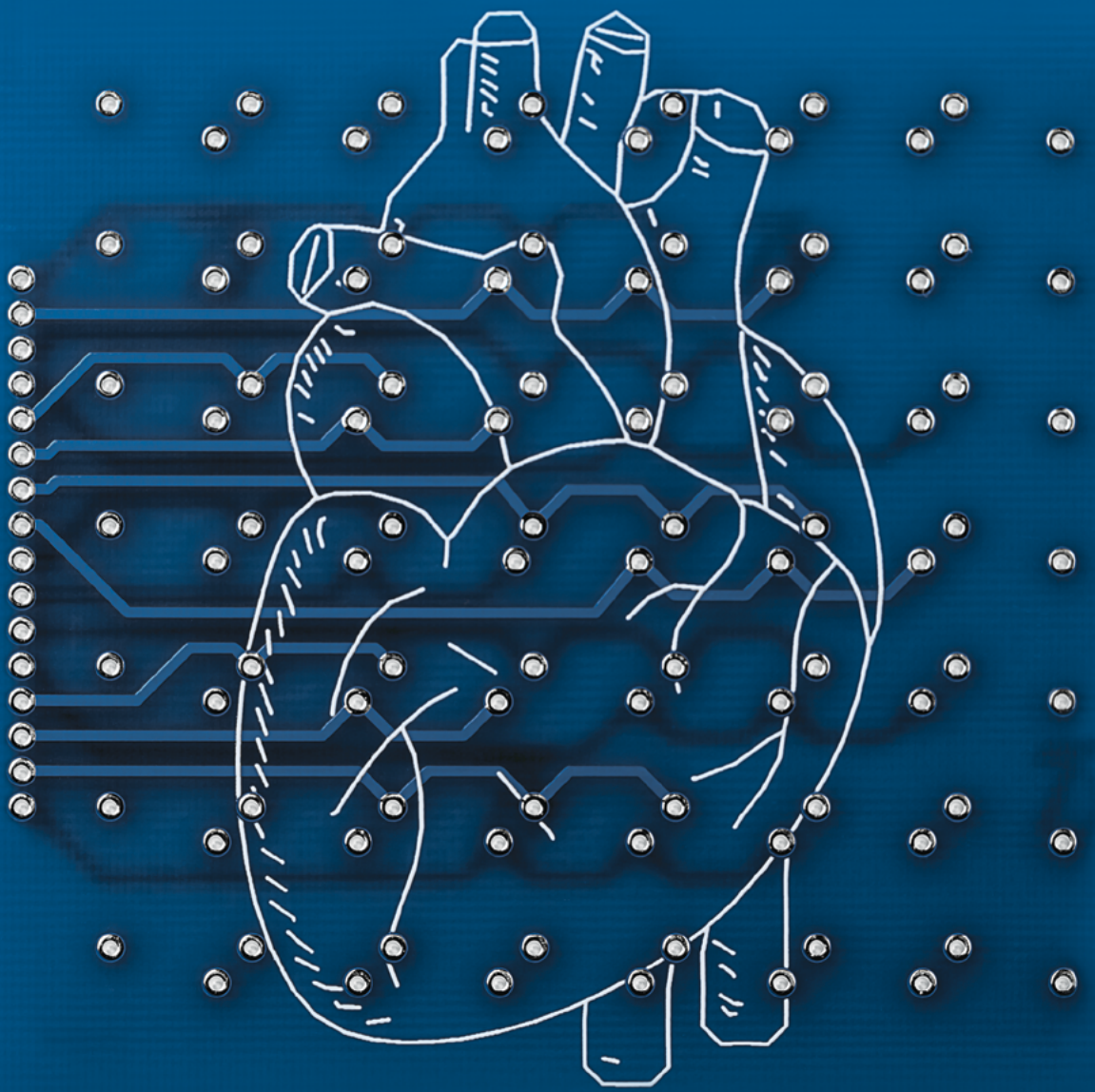

Sabine E. Wildevuur

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Colophon

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in het bijzonder mijn ouders Toet & Charles,
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Designing information and communication technology to enable person-centred care in chronic disease management

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Chapter 1
General introduction

1. Information and communication technology to support person-centred care

'The doctors used the iPads, but only once did they turn the screen around to show it to the patient. We interviewed the doctors afterwards and told them: "We gave you these tools and you said that shared decision-making is important. Not once did we see you show the patient the screen."' (researcher, Australia)

The above situation came up during one of the interviews for my study. When I asked a participant for a case involving Information and Communication Technology (ICT) that supported both the patient and the health care professional in health care practice, they described this one. Health care professionals were given a tablet during ward rounds to enable them to exchange information with patients and to stimulate shared decision-making, for instance by showing patient results and graphs pertaining to their health. However, in practice, the health care professional barely used the technology to interact with the patient.

'The clinicians said: "Ward rounds aren't the time for shared decision-making." So, maybe we observed during the wrong time. They said: "Shared decision-making happens in the clinic, in the office, but not on ward rounds because there are so many patients to go through and they are not well. [...] The focus is to get them out of hospital, not to talk to them about what they want." And you may or may not agree on that, but [those] were the responses we got. In a way, having the computer, having the opportunity to show them stuff, showing them graphs on how they are doing, showing them x-rays might be useful. But I haven't seen in practice that it really happened that way.' (researcher, Australia)

The researcher in Australia introduced the technology in a clinical setting as an enabler for person-centred care and, specifically, shared decision-making between the patient and the health care professional. All parties involved were in favour of enhancing shared decision-making, but, for several reasons, the technology was not used as the researchers had anticipated. Perhaps the wrong setting had been chosen, or the health care professional was not sufficiently motivated to apply technology. Whatever the reason might have been, ICT support did not work out.

Discrepancy between the potential and the implementation of ICT-PCC interventions

ICT offers ways to enable more personalised and accessible care for patients that is digitally supported, remote, and that improves the quality of care and clinical outcomes and shortens hospital stays (Talboom-Kamp et al., 2018; Wolf et al., 2012; Swedberg et al., 2011). However, twenty years' worth of information and communication technology projects in the health sector have shown that most ICT projects remain projects (Granja et al., 2018; Andreassen et al., 2015) and are never implemented in daily health care practice (De Bont and Bal, 2008).

Surprisingly few ICT interventions with the potential to support chronic disease management continue beyond the research and development phase (Ross et al., 2016; Obstfelder et al., 2007). Many promising ICT interventions in health and care are characterised by non-adoption or abandonment by their users (Greenhalgh et al., 2017). Careful attention should be given to socio-technical factors to maximise the successful implementation and adoption of such technologies (Black et al., 2011).

We argue that integrating principles of Person-Centred Care (PCC) into ICT interventions could maximise the potential of eHealth interventions. These principles are based on the PCC-approach that encourages and empowers patients to actively take part in their care process by building a collaborative partnership between the patient and the health care professional (Ulin et al., 2016; Ekman et al., 2012). ICT can help enable a person-centred approach that supports the patient-health care professional partnership, in which patients are involved and empowered to take an active part in their care and shared decision-making process. Vice versa, a person-centred approach to care might also benefit from ICT as an enabler to strengthen the patient-professional partnership over distance.

Since insight is lacking on how ICT enables a person-centred approach to care that supports both patients and health care professionals in disease management, our study connected the concepts of ICT and PCC, which we will refer to as Information and Communication Technology-enabled Person-Centred Care (ICT-PCC). To expand the knowledge on person-centred care and ICT, and specifically on how ICT supports the patient-health care professional partnership in chronic disease management, our study is guided by the question: *How does information and communication technology support patients and health care professionals in chronic disease management in a person-centred approach to care?*

We approach this question from a social-science perspective and state that a person-centred approach is ignored in (the design of) most eHealth interventions[1] and with it the patient-professional partnership. In this thesis, we use various studies to show how ICT supports a person-centred approach towards the management of chronic diseases. By doing so, we make an important contribution to the field of Information System Research (ISR) and Social Science and Medicine (SSM).

ISR seeks to analyse the impact of information technologies, explain how they are used by persons and organisations, and examine the influences of the design, management, use, and valuation of information technologies at various levels of analysis, while SSM focuses on social-science research on health. Accordingly, we connect the fields of ISR and SSM to better understand how ICT-PCC interventions influence the relationship between the patient and the health care professional with regard to chronic disease management in *practice*.

In this general introduction, we introduce the main concepts of **person-centred care** and **Information and Communication Technology** in more detail, in the context of **chronic disease management.** We then introduce the different chapters with their sub-research questions and explain how they are related to each other.

1) Although we use in this thesis the term "Information and Communication Technology for health", the terms "eHealth" and "digital health" may be used interchangeably, where appropriate.

2. The changing relationship between patient and health care professional

The relationship between the patient and the health care professional(s) is the foundation of modern medicine, as health care professionals interact with their patients in order to diagnose, predict, treat or even prevent diseases. The principles of the crucial patient-health care professional bond were already recorded centuries before Christ, by the Greek physician Hippocrates (c. 460 – c. 370 BC), who is considered to be one of the founders of modern Western medicine. He had his students swear the Hippocratic Oath, which physicians-to-be take to this day.

The Oath is a symbolic declaration to deliver care in the best interest of patients and serves as the foundation of the organisation of health care. The modern version of the Oath reads (Graham, 2000):

"[...] I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm to anyone. To please no one will I prescribe a deadly drug, nor give advice which may cause his death. Nor will I give a woman a pessary to procure abortion. But I will preserve the purity of my life and my art. I will not cut for stone, even for patients in whom the disease is manifest; I will leave this operation to be performed by practitioners (specialists in this art). In every house where I come I will enter only for the good of my patients, keeping myself far from all intentional ill-doing and all seduction, and especially from the pleasures of love with women or with men, be they free or slaves. All that may come to my knowledge in the exercise of my profession or outside of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal. [...]"

Over the years, the nature of the relationship between the patient and the health care professional shifted slowly. Instead of seeing the patient as a collection of symptoms, and the health care professional as the one offering biomedical knowledge, a more integral and personal approach to care was developed (Balint, 1955). The health care professional also had to examine the whole person in order to form an 'overall diagnosis', which was coined patient-centred medicine, indicating another approach to medical thinking (Balint, 1969).

The patient-professional relationship changed from a paternalistic biomedical tradition, in which the doctor was more prominent and the distance to the patient was large, to a more collaborative approach, in which the patient is no longer the passive target of a medical intervention but is involved actively in his or her own care (Naldemirci et al., 2018; Dudas et al., 2013). This change in the patient-health care professional relationship is particularly visible in the treatment of chronic diseases, which are on the rise.

In the beginning of the 20th century, the main reason to consult a doctor was an acute disease and our health care system was built on this. Starting from the second half of the 20th century, however, more and more patients required treatment for chronic diseases (Aiwan, 2011). Life expectancy has increased rapidly in recent decades due to improved medical care and the development of highly specialised health care, within an evolved health care structure and sys-

tem.[2] This does have a certain drawback; we may live longer, but an increasing number of people live with one or more chronic conditions that can adversely affect their health-related quality of life. In Western society, the majority of diseases are now chronic conditions, and this development is expected to continue as a result of an ageing society, putting pressure on the sustainability of our health care systems (WHO, 2018).

The shift from mainly acute diseases to an increase in chronic conditions is reflected in the patient-health care professional relationship. Chronic patients have become more actively involved in the care process as partners of the health care professional and experts on living with a chronic condition (Nolan et al., 2004; Bodenheimer, et al., 2002). In the case of chronic diseases, self-management of the condition has become important and even necessary, since only the patient can be responsible for his or her daily care (Holman & Lorig, 2004).

Chronic disease management builds on the relationship between the patient and the health care professional, with the patient becoming a partner in the process, contributing to almost every decision or at every action level (Lorig et al., 2006). Patients and health care professionals should work as partners, developing a relationship that gives patients the best chance to control their disease. As Lorig and Holman (2004) state about the necessity of patients with a chronic condition to manage their disease: 'One cannot not manage' (Lorig & Holman, 2003, p.1). So, both patients and health care professionals have to take responsibility in the management of a chronic condition.

3. Towards a person-centred approach to care

Person-centred care (PCC) has emerged in the light of the aforementioned developments. PCC can be considered a specific type of shared decision-making, which involves an interaction process established in the partnership between patients and health care professionals (Heckemann et al., 2016; Olsson et al., 2013). PCC emphasises the need to build patient-professional partnerships based on the personal, individual meaning that a (chronic) disease has in a person's life (WHO, 2011; Ekman et al., 2011).

There has been a shift towards using the term 'person-centred' instead of 'patient-centred' (Stewart, 1995), to embrace the entire body of a person's needs and preferences, rather than just their medical needs (Brummel-Smith et al., 2016). The aim of patient-centred clinical practice is care which: (a) explores the patient's main reason for the visit, concerns, and need for information; (b) seeks an integrated understanding of the patient's world—that is, their whole person, including their emotional need and life issues; (c) finds common ground on what the problem is and is based on a mutual agreement with regard to management; (d) enhances prevention and the promotion of health, and (e) enhances the continuing relationship between the patient and the doctor (Stewart, 2001, p. 444).

2) https://www.who.int/gho/mortality_burden_disease/life_tables/situation_trends_text/en/

Nowadays, more and more health care professionals, policy-makers and managers are convinced that patients could benefit from person-centred care, in which the patient is no longer the passive target of a medical intervention, but is involved actively in his or her care (Ekman et al., 2011). The term 'person-centred care' stems from the field of elderly care, where it referred to the development of integrated care for particularly frail and vulnerable people (Nies & Leichsenring, 2018).

Person-centred care is described as a systematic approach to disease management that encourages and empowers patients to actively take part in their care process by building a collaborative partnership between the patient (person expert) and the health care professional (care and treatment expert) (Ulin et al., 2016; Ekman et al., 2012). Research on person-centred care has in common that the partnership between patients and health care professionals is crucial to providing PCC (Olsson et al., 2013; Ekman et al., 2011).

We based our studies on the model developed at the University of Gothenburg's Centre for Person-Centred Care, which provides a structured approach to person-centred care. This PCC-model consists of three core components: *initiating* the partnership by eliciting a detailed patient narrative; *working* the partnership between patient and health care professional by implementing narratives in the care process through shared decision-making; and *safeguarding* the partnership by documenting the partnership in the patient record (Ekman et al., 2011). These components of the PCC build on each other and may be iterative.

We choose to follow Ekman's approach, in which the patient narrative takes centre stage in the patient-professional partnership. The patient's narrative is the person's personal account of his or her illness and symptoms, and their impact on life. It captures the person's suffering in an everyday context, in contrast to medical narratives that reflect the process of diagnosing and treating the disease (Ekman et al., 2013). We put the component of 'working the partnership' centre stage in our research, without losing sight of the other ones. This component is linked to the shared decision-making process between the patient and the health care professional.

Remarkably, hardly any use is made of Information and Communication Technology to support the several components of a person-centred approach to care (Heckemann et al., 2016). This is striking, since ICT has the potential to remotely connect patients and health care professionals (digitally) to improve the quality of care (Talboom-Kamp et al., 2018; Wolf et al., 2017; Swedberg et al., 2011). In addition, taking into account and incorporating components of person-centred care into a holistic approach of designing and developing eHealth interventions will improve the impact of the technology (Van Gemert-Pijnen et al., 2011). However, more research is needed to expand the knowledge on how ICT enables a person-centred approach to care.

4. Information and Communication Technology interventions to support person-centred care

Since the beginning of the 21st century, ICT applied for health care purposes – also known as eHealth (Pagliari et al., 2005; Eysenbach, 2001) – has grown strongly and is now increasingly being introduced in health systems and services worldwide (WHO, 2006). ICT is being used more and more, for example, to support the interaction between patients and health care professionals – also remotely – to enable the digital documentation and exchange health care information and monitor conditions.

All over the world, policies are introduced in favour of the wider application and implementation of ICT interventions to increase the quality, accessibility and affordability of health services. ICT is of particular added value when it comes to the management of chronic diseases that require long-term care. ICT interventions might support the management of chronic diseases by – among others – facilitating shared decision-making between patients and health care professionals, and allowing for remote monitoring of chronic conditions, remote consultations, or even remote treatment.

Consequences of introducing technology

By integrating the principles of person-centred care into ICT interventions, the potential of ICT can be maximised, enabling persons with a chronic condition to manage their lives more independently (Heckemann et al., 2016). Leaving aside the existing studies on the introduction and implementation of ICT in health care settings, research on how ICT enables the patient-health care professional relationship is scarce (Black et al., 2011; Dedding et al., 2011). In our studies, we researched ICT-enabled PCC by connecting ICT and PCC in order to find ways how technology supports managing diseases for persons with a chronic condition and their health care professional(s).

To do so, we consider the consequences of introducing ICT in the social setting of chronic disease management.

'Technology is not neutral. We're inside of what we make, and it's inside of us. We're living in a world of connections — and it matters which ones get made and unmade.' (Haraway, 1991)

Technology is not a fixed entity that moves from invention through diffusion into routine use (Obstfelder et al., 2007). The implementation of technology is an interplay between technical issues and social factors, which produces a certain outcome. In our study, we focused on the changing roles and patterns of (social) interaction that are connected with the introduction of ICT in health care organisations (Sergeeva et al., 2017; Leonardi & Vaast, 2016; Majchrzak et al., 2016; Faraj & Azad, 2012).

In doing so, we build upon knowledge in the field of Information System Research. Within ISR, we broaden the field of design science research, a particular perspective within IS research, by adding knowledge and understanding

on how ICT supports person-centred care. We also explain how technology has influenced the patient-professional relationship in health care practice, thereby offering an empirical example of an important social context. By relating research findings to the academic literature on ICT and person-centred care, we expand the understanding of the role played by ICT in supporting person-centred care.

5. Design ICT-PCC for health care practice

The aim of this thesis can be divided into two parts. In **Part I** – based on **literature** research – we investigate which ICT interventions have been used to support patients and health care professionals in PCC management of the 'big five' chronic diseases, based upon the question: *What are the **preconditions** for ICT-enabled PCC in chronic disease management?* We will explain how these questions relate to the overall research question in more detail below.

Part II examines the theory on ICT-PCC interventions for chronic disease management in the empirical setting of health care **practice**, answering the research question: *How does ICT-PCC **afford** and **enable** the partnership between patients and health care professionals with regard to chronic disease management in practice?*

Aim of the chapters

We will answer the above questions in four different chapters (see: table 1.1). We started by focusing on the extent to which ICT-enabled PCC already exists and has proven to be effective in terms of medical and organisational outcomes (Chapter 2). The outcome is an overview of the extent, range and nature of ICT-PCC interventions. We found, among other things, that the patient-professional partnership was hardly supported with ICT.

To better understand what is necessary to support patients and health care professionals with ICT in a person-centred approach towards chronic disease management, we distilled the preconditions for or 'building blocks' of ICT-PCC (Chapter 3). Based on an analysis of thirteen studies, we identified four preconditions for ICT-enabled person-centred care. Building on our analysis, we explained how ICT can be better tailored towards the management of chronic conditions by including these preconditions. However, we also detected a misfit between ICT and how the technology supported the partnership **in practice**.

Accordingly, we analysed the fit of Information and Communication Technology-enabled Person-Centred Care (ICT-PCC) and how it supported the patient-health care professional partnership **in practice** by distinguishing the affordances of ICT-PCC (Chapter 4). We found that though there were some obvious constraints, such as personal, financial, organisational and technological barriers, which stood in the way of implementation, an important additional factor was that the *patient-professional partnership* was not taken into account in the design and development of ICT-PCC interventions.

So, we studied the dynamics of the introduction of an ICT-PCC interven-

Table 1.1 *Overview of the parts and the chapters on ICT-PCC*

CHAPTER	RESEARCH QUESTION	RESEARCH SETTING	METHODS	DATA	MAIN RESULT
PART I, RESEARCH BASED ON LITERATURE					
2	Which ICT-interventions have been used to support patients and healthcare professionals in PCC - management of the 'big five' chronic diseases?	Determine the extent, range and nature of existing ICT-PCC interventions	Scoping review	350 studies included, 60 relevant studies	Overview of the research field of ICT-PCC for chronic disease management. Identification of the research gaps in the existing evidence base of ICT-PCC interventions for the 'big five' chronic conditions.
Wildevuur, S.E., Simonse, L.W.L. Information and Communication Technology-Enabled Person-Centered Care for the "Big Five" Chronic Conditions: Scoping Review. Journal of Medical Internet Research 2015;17(3):e77. doi:10.2196/jmir.3687					
3	What are the preconditions of ICT-enabled PCC in chronic disease management?	Comparative analysis of 13 scientific studies on ICT-enabled PCC-interventions for cancer treatment	Gioia methodology for interpreta-tive coding	13 cases of ICT-enabled person-centred cancer care	New concept and theory development on ICT-PCC, leading to the determination of the preconditions of ICT-PCC interven-tions for chronic disease management.
Wildevuur S, Thomese F, Ferguson J, Klink A. Information and Communication Technologies to Support Chronic Disease Self-Management: Preconditions for Enhancing the Partnership in Person-Centered Care. Journal of Participatory Medicine 2017;9(1):e14. doi:10.2196/jopm.8846					
PART II, RESEARCH BASED ON PRACTICE					
4	How does ICT-PCC afford the partnership in healthcare practice between patients and healthcare professionals towards chronic disease management?	Experiences in practice with ICT-enabled PCC to support the patient-professional partnership towards chronic disease management, in both Australia and the Netherlands	In-depth qualitative analysis	17 interviews	Distinction of ICT-PCC-related affordances.
Submitted: Health Policy					
5	How does ICT enable the partnership between healthcare professional(s) and the patient in chronic disease management in healthcare practice?	Case study of an ICT-PCC-intervention, namely an Artificial Pancreas system	Inductive case study and interviews	Case study and 12 interviews	Building a CT-PCC framework, based on inductive case study.
Wildevuur SE, Simonse LW, Groenewegen P, Klink A. Information and communication technology enabling partnership in person-centred diabetes management: building a theoretical framework from an inductive case study in The Netherlands. BMJ Open 2019;9:e025930. doi: 10.1136/bmjopen-2018-025930					

tion in health care practice to support the patient-health care professional partnership towards the management of Diabetes Type 1 (Chapter 5). Based on the results, we built a new conceptual framework for ICT-enabled person-centred care.

The chapters are described in more detail below. We explain how the chapters relate to each other, what the main results are, and how the chapters contribute to answering the overall research question of this thesis: *How does information and communication technology support patients and health care professionals in chronic disease management in a person-centred approach to care?*

PART I - Literature-based research: review of ICT-PCC interventions and their preconditions

In chapter 2 *Information and Communication Technology-Enabled Person–Centred Care for the "Big Five" Chronic Conditions: Scoping Review* we conducted a scoping review to map and provided an overview of ICT-PCC interventions that are applied in chronic disease management to enable patients to play an active part in their care and decision-making process. We explained the central concepts of this thesis in more depth, namely **Information and Communication Technology** and **Person-Centred Care**. These concepts are described in the context of **chronic disease management**. Furthermore, this chapter elaborates on the social and scientific relevance that underlies our study on ICT-enabled PCC.

The chapter provides a review of the literature on ICT-enabled PCC and scopes the field by answering the sub-research questions: *Which ICT interventions have been used to support patients and health care professionals in PCC management of the 'big five' chronic diseases?* and: *What is the impact of these interventions, such as on Health-Related Quality of Life and cost efficiency?* The aim of the scoping review is to investigate the extent, range and nature of research in the field of ICT-PCC.

We identified research gaps in the existing evidence base of health studies regarding the 'big five' chronic disease (diabetes mellitus, cardiovascular and chronic respiratory diseases, cancer and stroke). This was important, since such a general overview of the extent and nature of published research involving ICT interventions in PCC for chronic disease management did not exist before this study.

One of the conclusions of the scoping review read that hardly any of the studied ICT-PCC interventions could be regarded as fully person-centred. Also, we discovered that research on how ICT supported the patient-professional partnership in chronic disease management is scarce.

Chapter 3 *Information and Communication Technologies to Support Chronic Disease Self-Management: Preconditions for Enhancing the Partnership in Person-Centred Care* is based on the insights gained and the research gaps identified in chapter 2, finding a mismatch between the intended use of ICT-PCC interven-

tions and the actual outcomes in health care practice. The research question central to this chapter was: *What are the preconditions of ICT-enabled PCC in chronic disease management?* We used ICTP-PCC cases found during the scoping study, which was described in the previous chapter. Based on the cases from literature studies, we distilled the preconditions for ICT-PCC. Our dataset consisted of thirteen cases of ICT-PCC interventions that were used for the management of cancer, which was the largest category in the scoping review. Based on the analysis of the cancer studies, we identified four preconditions for ICT-enabled person-centred care.

Identifying preconditions for ICT-enabled chronic disease management was an important step in improving the support enjoyed both by the patient and the health care professionals. We now have a better understanding of what is necessary to support patients and health care professionals with ICT in a person-centred approach towards chronic disease management.

Building on our analysis, we explained how ICT can be better tailored towards the management of chronic conditions by including these preconditions. Moreover, the study also revealed a discrepancy between *intended* and reported *actual* outcomes in terms of realising person-centred care through ICT. In the next chapter, we studied whether and how these preconditions afford a person-centred approach towards chronic disease management in *practice*.

PART II - Research based on practice

Since we revealed a discrepancy between *intended* and *actual* outcomes in the previous chapters of Part I), we decided to take a next step in Part II) from gaining theoretical insights based on literature review, to gaining insights based on practice in chapters 4 and 5.

The previous chapter revealed a discrepancy between *intended* and reported *actual* outcomes in terms of supporting both patients and health care professionals in a person-centred approach to chronic disease management. By preventing this mismatch in the future, we argue that the patient-professional partnership within ICT-enabled PCC might be strengthened.

In chapter 4 *Technology supporting the partnership between patients and healthcare professionals towards chronic disease management: Practices in Australia and The Netherlands*, we focused on how ICT affords the partnership between patients and health care professionals in practice.

We included participants in our study who were familiar with the use of ICT-PCC interventions. We conducted an in-depth qualitative analysis of their experiences with these interventions to study how ICT afforded the partnership between patients and health care professionals. We did so through semi-structured interviews that were held as a means to gather information on ICT-enabled person-centred care. Our focus was not so much on the technology itself, but on how ICT afforded a person-centred approach to care by supporting the professional-patient partnership.

We included a wide range of users as interviewees to get an overview from different angles. Besides the primary users (patients and health care professionals), we involved secondary users (such as developers of ICT-enabled PCC, policy-makers, and researchers) to better understand how ICT is used in practice to support the patient-professional partnership. This chapter sought to answer the research question: *How does ICT-PCC afford the partnership in health care practice between patients and health care professionals towards chronic disease management?*

In the previous chapter, we identified affordances of ICT-enabled person-centred care. In chapter 5 *Information and Communication Technology enabling partnership in person-centred diabetes management: building a theoretical framework from an inductive case study in The Netherlands*, we elaborated on these ICT-PCC-affordances by investigating how exactly ICT enabled the partnership between patients and health care professionals towards chronic disease management in practice. This phenomenon is not fully understood, and insights are lacking on how this partnership is influenced and transformed by ICT. To address this gap, we selected a case study involving an innovative ICT intervention that was developed to support diabetes management in a person-centred approach to care. Our core research question was as follows: *How does ICT enable the partnership between health care professional(s) and the patient in chronic disease management in health care practice?*

We chose to employ an inductive case study to focus on the dynamics present within a single setting of an ICT intervention used in practice for the management of type 1 diabetes, namely an Artificial Pancreas system. We interviewed persons with type 1 diabetes, health care professionals and a policy advisor. When introducing ICT in a health care context, the technology could be studied as part of a dynamic and networked health care environment. We concluded that this should include a focus on the patient-professional partnership and how it is reshaped by the introduction of ICT.

The case study led to the construction of a framework for ICT-enabled person-centred chronic disease management. This new conceptual framework provides insight into the dynamics of the partnership between health care professionals and persons with a chronic disease and how it is enabled by ICT in chronic disease management of diabetes.

Chapter 6 *General discussion and conclusion* returns to the overarching research question: *How does information and communication technology support patients and health care professionals in chronic disease management in a person-centred approach to care?* We summarise the principal findings, and discuss these findings in terms of practical and managerial implications, the limitations of the conducted research, and suggest further research.

Research methods

Knowledge on how ICT enables a person-centred approach towards chronic disease management is scarce. In order to get an up-close and in-depth understanding of how ICT-PCC is used in practice, we opted for an inductive research method. We looked at practical situations to boost our insight into the field of

PCC and ICT. Through inductive theory development, we were able to develop insights on the relatively unknown phenomenon of enabling PCC through ICT, understand how the process of introducing ICT enabled PCC in the organisation of a health care setting unfolded, and explain the occurrence of surprising events (Edmondson & Mcmanus, 2007).

Different research methods, such as a scoping review, in-depth interviews, and an inductive case study, were combined. We started with the scoping review method in chapter 2 (Levac et al., 2010). This is an appropriate method to systematically scan and evaluate which studies fall inside or outside the scope of the research area that is explored for evidence (Arksey, 2005). We emphasised the scoping technique to identify gaps in the evidence base.

In chapter 3, we analysed thirteen cases of ICT-enabled cancer care as a case study, by following the initial steps for structuring qualitative data in new concept and theory development (Gioia et al., 2013). The Gioia methodology is a systematic approach using interpretative coding, which was useful for our aim of distilling the preconditions of ICT-enabled PCC based on evidence derived from the selected cases.

The research conducted in chapter 4 consisted of semi-structured interviews as a means to gather information on ICT-enabled person-centred care and to identify ICT-PCC affordances. Besides the primary users (patients and health care professionals), we involved secondary users, such as ICT developers, researchers and policy-makers.

The research method used in chapter 5 was an inductive case study (Eisenhardt et al., 2007), for which we held in-depth interviews with both health care professionals and patients on the practical use of an ICT-PCC-intervention for persons with Type 1 Diabetes. The method was applied to study the dynamics of the professional-patient partnership and to develop a theoretical framework of ICT-PCC for chronic disease management.

Further details on the research methods are described in the methods section of the various chapters.

Because little is known of ICT-enabled PCC, rich and detailed data from practice are needed to shed light on the phenomenon. More grounded, practice-based insights can help in the quest to design care models in which new ways of interacting and deciding between patients and health care professionals improve the quality and effectiveness of chronic disease management.

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Chapter 2

Information and Communication Technology-Enabled Person-Centred Care for the “Big Five” Chronic Conditions: Scoping Review

This chapter is based on the following article:
Sabine E Wildevuur, Lianne WL Simonse. Information and Communication Technology-Enabled Person-Centered Care for the “Big Five” Chronic Conditions: Scoping Review. *Journal of Medical Internet Research* 2015;17(3):e77. doi:10.2196/jmir.3687[1]

1) The published article was accepted by a journal with a preference for US English. Therefore, the title to which we refer to is in US English, whereas the body of the text was adapted to UK English, which is the base of this thesis.

Abstract

Background: Person-centred information and communication technology (ICT) could encourage patients to take an active part in their health care and decision-making process, and make it possible for patients to interact directly with health care providers and services about their personal health concerns. Yet, little is known about which ICT interventions dedicated to person-centred care (PCC) and connected-care interactions have been studied, especially for shared care management of chronic diseases. The aim of this research is to investigate the extent, range, and nature of these research activities and identify research gaps in the evidence base of health studies regarding the "big five" chronic diseases: diabetes mellitus, cardiovascular disease, chronic respiratory disease, cancer, and stroke.

Objective: The objective of this paper was to review the literature and to scope the field with respect to two questions: (1) *Which ICT interventions have been used to support patients and health care professionals in PCC management of the big five chronic diseases?* and (2) *What is the impact of these interventions, such as on health-related quality of life and cost efficiency?*

Methods: This research adopted a scoping review method. Three electronic medical databases were accessed: PubMed, EMBASE, and Cochrane Library. The research reviewed studies published between January 1989 and December 2013. In five stages of systematic scanning and reviewing, relevant studies were identified, selected, and charted. Then we collated, summarised, and reported the results.

Results: From the initial 9380 search results, we identified 350 studies that qualified for inclusion: diabetes mellitus (n=103), cardiovascular disease (n=89), chronic respiratory disease (n=73), cancer (n=67), and stroke (n=18). Persons with one of these chronic conditions used ICT primarily for self-measurement of the body, when interacting with health care providers, with the highest rates of use seen in chronic respiratory (63%, 46/73) and cardiovascular (53%, 47/89) diseases. We found 60 relevant studies (17.1%, 60/350) on person-centred shared management ICT, primarily using telemedicine systems as personalised ICT. The highest impact measured related to the increase in empowerment (15.4%, 54/350). Health-related quality of life accounted for 8%. The highest impact connected to health professionals was an increase in clinical outcome (11.7%, 41/350). The impacts on organisation outcomes were decrease in hospitalisation (12.3%, 43/350) and increase of cost efficiency (10.9%, 38/350).

Conclusions: This scoping review outlined ICT-enabled PCC in chronic disease management. Persons with a chronic disease could benefit from an ICT-enabled PCC approach, but ICT-PCC also yields organisational paybacks. It could lead to an increase in health care usage, as reported in some studies. Few interventions could be regarded as "fully" addressing PCC. This review will be especially helpful to those deciding on areas where further development of research or implementation of ICT-enabled PCC may be warranted.

Information and Communication Technology-Enabled Person-Centred Care for the "Big Five" Chronic Conditions: Scoping Review

Introduction

Information and communication technology (ICT) offers a means to support the self-management of chronic diseases and "empowerment" of patients, primarily through the Internet. Chronic diseases—also known as noncommunicable diseases—generally progress slowly over a long time. According to the World Health Organization (WHO), the "big five" chronic diseases are diabetes mellitus, cardiovascular and chronic respiratory diseases, cancer, and stroke (1). In Western society, chronic diseases make up the largest proportion of diseases and this is expected to grow further as a result of an aging society putting pressure on the sustainability of the health care system.

By successfully adapting to a chronic illness and self-managing the disease, people are able to handle their life with some degree of independence despite their medical condition and are capable of participating in social activities including work and feel healthy despite their limitations (2,3). For "connected" home health care during disease management, patients are expected to increasingly use eHealth services in codecision with their health care providers and thus play an active role in managing their own disease.

eHealth offers a promising way to connect chronic patients and their health care providers, thereby ensuring that both are more involved in the long-term care needed for chronic diseases. In-depth research has been conducted to show that patients use health-related virtual communities and electronic support groups to keep themselves informed on treatment decisions and to manage their health (4,5). However, these ICT applications focus on situations in which a health care professional is not necessarily engaged. Moreover, the impact of these types of ICT and person-centred care (PCC) interventions on (health-related) quality of life is unknown.

In our study, we explored the extent to which ICT applications have been used to support self-management of one of the five chronic diseases—in situations where both a health care professional and patient are involved—and determine their impact.

Because health systems and services have become overly biometrics-oriented, disease-focused, technology-driven, and doctor-dominated, WHO advocates putting patients at the centre of health care addressing PCC as a key dimension of health care quality (6). The 21st century is envisaged as the century of PCC, especially in the care of the chronically ill (3).

The term PCC was initially used in the field of elderly care, where practitioners sought to provide better services to particularly frail and vulnerable people. Nowadays, more and more health care professionals, policy makers, and managers envision that patients could benefit from a person-centred approach to care in which the patient is no longer the passive target of a medical intervention, but is instead actively involved in his or her care (7).

Ekman (7) distinguished three routines of PCC activities:

1. Initiating the partnership: patient narratives;
2. Working the partnership: shared decision making, and;
3. Safeguarding the partnership: documenting the narrative.

A narrative is defined as a spoken or written account of connected events. Modern medicine is generally disease-oriented and evidence-based; PCC starts with the person's subjective experience of his or her illness and its impact on daily life (8). Ekman et al (7) stated that the narrative is the starting point for building a collaborative, equalitarian partnership between the provider (care and treatment expert) and the patient (person expert) that encourages and empowers patients to actively take part in finding solutions to their problems.

Initial studies on PCC are promising and suggest that an implemented PCC approach shortens hospital stays and improves quality of care (9,10). Given the growing interest in the topic of PCC (11), the term is slowly entering the scholarly discussions around ICT interventions. eHealth—supported by ICT—could encourage patients to take an active part in their health care and the decision-making process, "empower" them, and support a person-centred approach (7).

Connecting patients and health care professionals would not only improve the (technical) system of communicating, but also trigger social innovations of care models in which new ways of interacting and deciding improve the quality and efficiency of the organisation (12). However, we do not know to what extent ICT-enabled PCC exists, has been studied, and proved to be effective in terms of medical and organisational outcomes, such as cost efficiency. In this study, we focused on identifying the gaps in this field.

With the introduction of the Internet, Web-based technology has been applied to health-related ICT systems, with an initial focus on fields such as telemedicine and telemonitoring, and more recently in Medicine 2.0 approaches apply-

ing Web 2.0 technologies (13). Telemedicine is defined in the Medical Subject Heading (MeSH) from 1993 as follows: "Telemedicine is the delivery of health services via remote telecommunications. This includes interactive consultative and diagnostic services." Telemonitoring represents a patient management approach combining various information technologies for monitoring patients at a distance (14). These advances have led to reviews on the specific technology of mHealth and eHealth (15,16). With respect to PCC, scoping reviews on care management have been conducted within the fields of reproductive medicine and chronic heart failure (9,17). However, no such studies on the combination of ICT and PCC management have been found.

We studied ICT interventions concerning the whole range of Internet technologies introduced since the inception of the Internet in 1989, from telemedicine to the new semantic and Web-based technologies of Health 2.0 and Medicine 2.0 technologies, including the recent evolution to smartphone communication with app technologies, and how these eHealth technologies are linked to PCC and with what impact. Through shared decision making, clinicians can help patients understand the importance of the information, measurements, and preferences in making the decisions that are best for them (18). The innovations in ICT could support PCC routines, self-management and empowerment, and enable persons to codecide about their medical treatments (19).

Given the lack of a general overview of the extent and nature of published research involving the subset of ICT interventions in PCC for chronic conditions, the aim of this study was to contribute by exploring existing studies and to draw conclusions regarding the overall state of research activities and discover research gaps.

The objective of this paper is to provide a review of the literature and to scope the field with respect to two research questions. Firstly, which ICT interventions have been used to support patients and health care professionals in PCC management of the big five chronic diseases? Secondly, what is the impact of these interventions, such as on health-related quality of life and cost efficiency?

This paper addresses the methods of the scoping review and its five different stages. Results provides overviews of the primary studies on PCC-ICT with participation of persons with a chronic condition of diabetes mellitus, cardiovascular and chronic respiratory diseases, cancer, or stroke. The state of knowledge in the health care domain is reported in terms of volume and nature and in relation to the outcomes reported. In Discussion, the review results are interpreted and compared with prior work. In addition, theoretical and practitioner implications of the study are described.

Methods

Scoping Review Study

Overview

We employed a rigorous literature review procedure by adopting the scoping review method. This is an appropriate method to systematically scan and evaluate which studies are within or out of the scope of the research area that is explored for evidence (20,21). We considered other types of literature review methods, such as systematic review, meta-analysis, and structured reviews, which share similar activities such as the collection, evaluation, and presentation of available research evidence in a systematic manner.

However, we chose to carry out a scoping review study because it best fit our research purpose with the emphasis placed on the scoping technique to "map" relevant literature in the field of interest rather than collecting similar evidence for a highly focused research question. The method is effective in identifying gaps in the evidence base where no research has been conducted and identifying emerging results in new fields of research; the methodological framework of Arksey and O'Malley was followed (22). Five stages of scoping and review were carried out: (1) identify the research question, (2) identify relevant studies, (3) select studies, (4) chart the data, and (5) collate, summarise, and report the results.

Stage 1: Identifying the Research Question

The research question was conceived from people's high expectations regarding the potential impact of ICT innovations on heavily overburdened health care organisations, specifically in combination with an increase in self-management of diseases of long duration such as chronic diseases. We postulated that ICT could help persons with chronic conditions to interact directly with their health care providers about their personal health concerns and thereby empower them in the self-management of their personal health (information) and care plan.

To search for evidence that might support our postulate, we formulated the following questions:

1. Which ICT interventions have been used to support chronic care providers in PCC?
2. What is the impact of these interventions on health-related quality of life, and cost efficiency?
3. What other relevant study outcomes have been reported?

In the context of this paper, patients are defined as "individuals who are interacting directly with health care providers and services about personal health concerns" (23). Starting from the point of view of ICT-enabled self-care and seeing "empowerment" as a possible outcome of applying this to the field of management of chronic diseases, we chose the definition of person-centred care coined by Ekman (7).

We consider eHealth as the use of ICT for health, as stated by the WHO initiative Global Observatory for eHealth. Our research builds on and contributes to the eHealth field, as defined by Eysenbach (22): "eHealth 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" (13).

For the purpose of our study, we initially defined PCC-ICT as a category of Internet technology that connects patients to health care professionals and enables them to interact and exchange information, including multimedia data such as audio (voice), video, and images. The PCC-ICT category covered different modes of Web communication including dedicated telemonitoring and/or telemedicine systems, Internet-based systems, telephone, and mobile phones. It excluded electronic patient record systems, public health information, and clinical and decision support systems for health care professionals only.

The outcome terms health-related quality of life and cost efficiency in the research question were only mentioned because they received considerable attention from health care managers and scholars, but in the scoping review we were not restricted to these two outcomes. On the contrary, we conducted this scoping study to explore, extract, and describe all relevant outcomes used in the studies.

Stage 2: Identifying Relevant Studies

To identify original studies suitable for answering the research questions, we searched EMBASE, PubMed, and the Cochrane Library. To determine the relevant search words (keywords differ between databases), a medical information specialist devised an initial search strategy based on the research questions and definitions of key concepts, and on ten seed articles (4,5,15,16,24-29). The strategy was refined in the light of other published scoping review searches and other relevant sources (15,30,31). A medical information specialist checked the final search syntaxes.

The search syntax was composed of "person-centered care," "ICT," and their synonyms, including the different types of spelling (US and UK), such as "person-centred care," "self-care," "self-management," "e-health," "Web 2.0," "decision support techniques," "videoconferencing," "cellular phone," "remote consultation," "user-computer interface," "Internet," and "telemedicine" combined with "chronic disease," "diabetes mellitus," "cardiovascular," and "chronic respiratory diseases," "cancer," and "stroke" and their synonyms.

Only those studies published between January 1989 and December 2013 were included. The start date of 1989 was chosen because the Internet went public in 1989. The end date was the last date on which we accessed the medical electron-

ic databases. The search was limited to studies in English because of the costs and time involved in translating material in foreign languages such as French, German, Polish, Spanish, Russian, and Chinese. The search excluded letters, editorials, and news items. To manage the digital output from the search, we used EndNote software. The EndNote database comprised 9380 references with links to the digital portable document formats (PDFs) of the studies stored in the source database of the journals.

Stage 3: Study Selection

For the selection of studies, inclusion and exclusion criteria were developed and applied iteratively over four rounds of duplicate screening involving all authors as reviewers (see Table 2.1).

First Review Step

In the first round, we screened titles and abstracts and excluded studies published before 1989, studies in which no ICT was involved, non relevant studies in which "mobile" was used in the sense of mobility (eg, mobile teams), non relevant studies focusing on mobile phones and the risk of brain damage as a result of mobile phone usage, studies on preventive care and public care involving screening and prevention activities, and studies on acute diseases (eg, acute stroke).

Furthermore, studies focusing on children as the main target group were excluded because children do not manage their health on their own. Retained for inclusion were all articles addressing topics of direct relevance to the research questions: the big five chronic diseases, chronic care, PCC, ICT intervention, and an outcome measurement of some sort, including health-related quality of life and cost efficiency. In this round, the database was subdivided into the five chronic diseases.

Second Review Step

In the second round, the articles in each subdivision of chronic diseases in EndNote were reviewed based on title and abstract. The researchers determined whether the studies included connected-care communication of some sort that involved both the patients and their health care professionals, and ICT intervention (including telephone) to facilitate communication and interaction. In this round, we established separate folders of groups in EndNote based on our inclusion and exclusion criteria. In the separate folders, we excluded addressed applications for only health care professionals, community applications for online self-help groups, self-tests (diagnoses) for patients, and intramural health care settings. Even though we do consider that these applications are important, they do not meet our criterion that these applications should be part of an established relationship and collaboration between a patient and his or her health care professional.

Third Review Step

The third screen involved extracting the data by reviewing the abstracts and full text of the articles within each of the five databases on chronic diseases. The classification scheme for extracting the data addressed the categories: time (year

Table 2.1 Inclusion and exclusion criteria.

	Inclusion criteria	Exclusion criteria
Collection of studies for the research data base	Publications after the invention of Internet (1978) onwards from 1989 when the first studies have been reported on e-health, in which Internet technology is applied in the health domain	Publications before 1989
	Publications in English language	Publications in other languages than English
	Published studies in EMBASE, PubMed and Cochrane Library	Letters, editorials, news items and conference abstracts
First review step	Persons coping with one or more of the "big five" of chronic diseases	Persons coping with an acute disease, such as acute stroke
	Chronic Care for persons already diagnosed with a chronic disease	Preventive Care and Public Care involving screening and prevention activities.
	Person centered self management and self care involved	Children (since they are taken care of by their parents)
	ICT involved	No ICT involved in the study Mobile in sense of mobility (mobile teams) The risk on brain damage through the use of cellular phone
	Medical study relating outcomes to ICT-intervention	Managerial study outcomes of for example cost estimationcomparisons, or proposed strategies, care models etc
	Theoretical study outcomes such as frameworks	
	Study outcomes measuring	
	Health related quality of life (HRQL) and Quality of Life (QoL) Study outcomes measuring	
	Cost efficiency	
	Study outcomes measuring other impact and performance factors	
	Documenting, monitoring and interaction applications for person-centered care	
Second review step	Connected care communication: multiple target groups as users of the application	One target group of the Health care application
	Related to a person or patient	No patients mentioned or involved
	Minimal two users involved; a patient person with chronic condition and health care professional	Health care professional applications Patient community applications
	Home health care setting: care activities at home connected to care activities at other health care settings	Care only in a hospital or other intramural setting Self tests at home (for example, self-diagnosis)
Third review step	Telephone as device to connect patients with caregivers, in combination with remote health care services	
	Share personal health concerns	
	Manage own personal health information	Personal health records and other medical records applications for other usage
	Manage personal care plan	
	Virtual Reality for rehabilitation of stroke	
	Twitter	
	Skype	

of publication); origin (country); type of ICT intervention (mode of communication, data type, users); type of connected care (type of disease management, mode of PCC), and outcomes (person outcomes, health care professional outcomes, organisation outcomes, and technical outcomes). General information such as gender, age, and background were not included since this scoping review study was intended to "map" relevant literature in the field of interest rather than collect evidence for a highly focused research question.

Additional criteria were developed iteratively to retain a set of articles. For example, telephones were identified as the first connection devices that made remote health care service between patient and health care provider possible. For exclusion, the criterion was developed on personal health records and other medical record applications for uses other than PCC-ICT self-management.

Fourth Review Step
This step involved analysing the systematic reviews to determine which studies had been carried out in an evidence-based manner, meeting the inclusion and exclusion criteria of the scoping review. Some of the studies that were described as "a systematic review" did not in fact meet the criteria set for a systematic review. However, these studies were not excluded because a scoping review does not assess the quality of the studies (22).

An additional exclusion criterion was that publications that did not include a full study (ie, ones that consisted merely of protocols or structured abstracts) were left out. An inclusion criterion concerned technologies that were incidentally described within the searched databases. These included the usage of Skype, social media such as Twitter, or robot assistance for rehabilitation. We expect these applications—and others such as wearable devices—to be studied and described more frequently in the years to come and thus included them in the existing list of criteria.

The reviewers met a couple of times at every reviewing round to discuss the selection of studies and to refine the inclusion and exclusion criteria. The criteria were used in an iterative way, meaning that where necessary the reviewing procedure was repeated to ensure that the references were covered in a comprehensive way.

Stage 4: Charting the Data
For the critical fourth stage, we carefully crafted the classification schemes in such a way that ICT interventions used for PCC were classified into mutually exclusive and cumulatively exhaustive categories. This required a number of iterations in refinement and modification of the categories to ensure reliability of the study classification.

To answer the research questions, we created charts for:
1. Study context identification: time and geographical origin of the study;
2. Process intervention studied: types and modes of ICT intervention used for connected-care activities;

3. Per targeted population of patients with a chronic condition: the monitoring, documenting, and interacting devices per connected-care activity;
4. Study outcome measures.

We coded ICT interventions into four categories: (1) telephone-based, (2) mobile phone–based, (3) Internet-based, and (4) dedicated telemonitoring/telemedicine system–based. Distinctions in applications for each of these types of hardware and software were made according to their data source (telephone, smartphone, Internet, or telemonitoring/telemedicine) and their primary function: documenting, interacting, and/or monitoring.

In this stage, we compared the studies first within the chronic care management domain and then across the different chronic disease domains. We undertook this process manually using tabulation charts in Excel as visual aids. Each study was charted in a table per chronic care management activity and the ICT intervention for either activity to connect disease management and/or support person–centred activities. We determined patterns of commonalities and differences among the ICT interventions and care management activities.

Stage 5: Collating, Summarizing, and Reporting the Results

Having charted the information, we were able to numerically analyse the included studies. We then answered the research questions based on the analysis overviews. Through the systematic reporting and charting of the data, we were also able to make comparisons across ICT interventions, identify contradictory evidence regarding specific interventions, and identify research gaps in the existing research evidence.

Results

Overview

From the initial 9380 search results from EMBASE (n=6702), PubMed (n=1866), and the Cochrane Library (n=812), we identified 350 studies that qualified for inclusion (see Figure 2.1). Classified according to the participation of persons with a chronic condition, the number of studies by condition was as follows: diabetes mellitus (n=103), cardiovascular disease (n=89), chronic respiratory disease (n=73), cancer (n=67), and stroke (n=18) (acute stroke was excluded) (see attachment Multimedia Appendix I).

First, we excluded the duplicates (n=1283). In the first screening round, we excluded both the ones published before 1989 and non relevant studies (n=6337) according to the exclusion criteria we developed in this round (see Figure 2.1), leaving 1760 studies.

In the second screening round, 1098 articles appeared not to address the research scope in terms of the inclusion criteria. In the third screening round, 269 were excluded, leading to 393 articles. Finally, in the fourth screening round, we

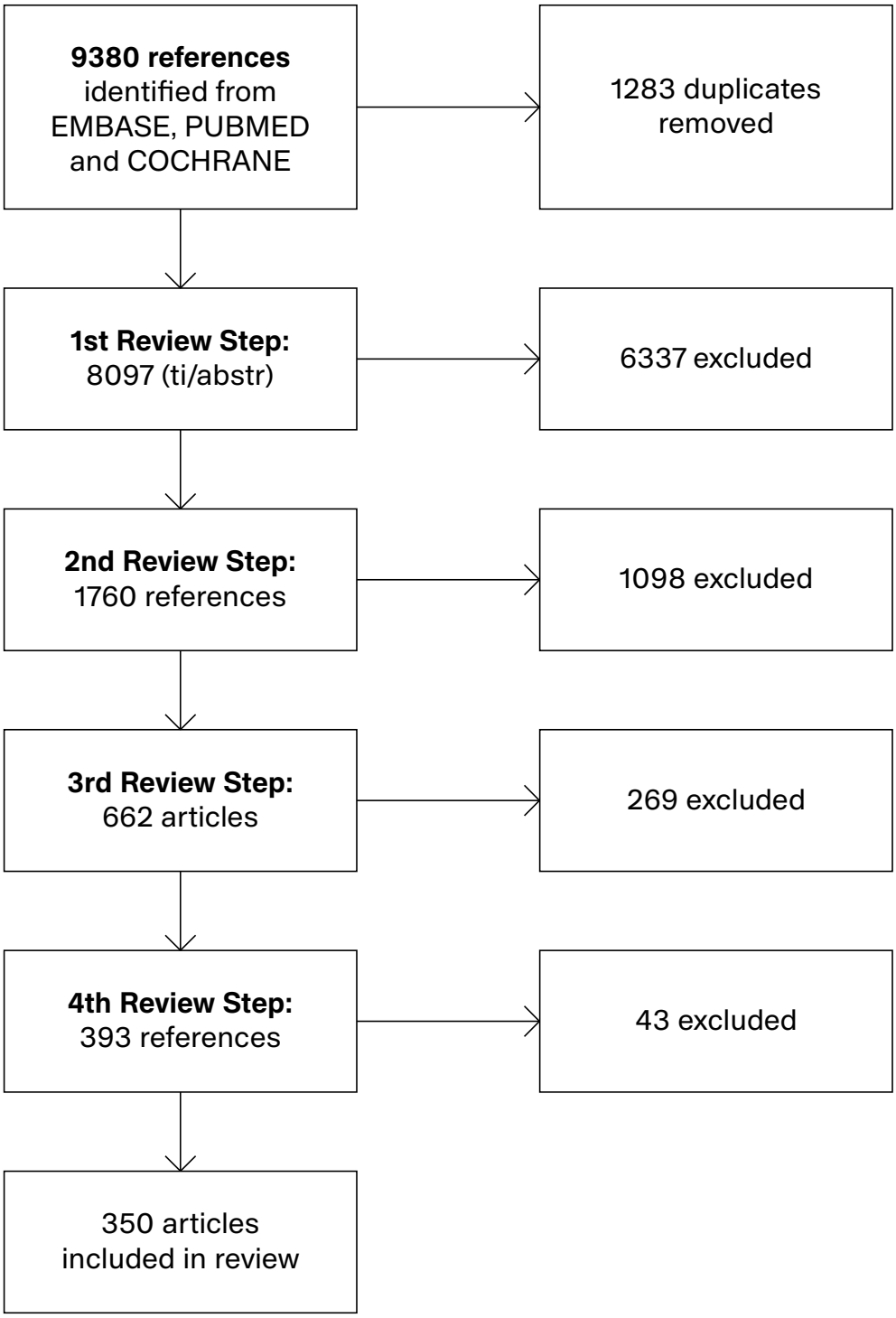


 Figure 2.1 Search and screening results.

charted the systematic reviews from the separate EndNote folder from the 105 systematic reviews; 62 were eventually included and 43 excluded. We were left with 350 studies.

Study Characteristics

In characterizing the included studies by origin, 40 countries are represented: Europe (147/350, 42.0%), North America (138/350, 39.4%), Pacific region (39/350, 11.1%), Asia (20/350, 5.7%), Middle East (8/350, 2.3%), and Latin America (3/350, 0.9%) (see Table 2.2).

Figure 2.2 shows that almost 10 years after the starting point of our search strategy (1989), the number of studies published annually increased until 2013. Within the domain of cancer, the first studies were identified on connected care in 1997. Around 2005, attention to connected care seemed to rise, with an even more substantial increase in publication volume from 2010 onward. The trend lines differed for the big five chronic conditions, with chronic respiratory conditions showing the steadiest increase and the others more fluctuation; cardiovascular conditions showed a slight decrease in recent years.

Information and Communication Technology Enabling Person-Centred Care for Diabetes Mellitus

From the total number of relevant studies concerning PCC in which patients with a diabetes condition were central (n=66), ICT applied for self-body measurement (eg, with a glucose meter device and monitoring system) was the most used (48/66, 47%) (see Table 2.3).

The second in line was personal lifestyle sharing (16/103, 15.5%), which is distinctively related to diabetes care. ICT for shared treatment decisions ranks low, with two studies found (2/103, 1.9%). In broader terms, connected care for diabetes, the most studied ICT intervention, addressed education with transfer of diabetes knowledge from the care provider to the patient (26/103, 25.2%).

The most commonly used ICT intervention employed telemonitoring/telemedicine systems (42/103, 40.8%). Internet interventions ranked second (29/103, 28.2%), whereas mobile phone interventions accounted for 24.3% (25/103) and telephone interventions for 16.5% (17/103). Interestingly, text messaging was used in 9.7% (10/103) of the studies. Glucose monitoring devices plus systems ranked third (13/103, 12.6%). These and other modes of telemedicine systems were mostly used (21/103, 20.2%) for the PCC activity of self-body measurement versus 9% used for physical care with measurement by the physician.

Within the category of mobile phone interventions, 9% used a monitoring app. A personal e-diary app is worth mentioning as a personal means of sharing health information with the care provider. Within the category of Internet interventions, most of the interventions concerned monitoring, but were integrated with interaction via the Web app (6%). Another type of Web-based app used more than once was a documenting Web app that was mostly employed for sharing lifestyle information with the health care professional. The last category of charted ICT intervention studies indicated a high research interest (17%) in

Table 2.2 Representation of the studies according to geographical location.

Continent and country	Overall, n (%)	Chronic disease, n (%)				
		Diabetes	Cardiovascular	Chronic respiratory	Cancer	Stroke
	N=350	n=103	n=89	n=73	n=67	n=18
Europe						
Netherlands	24 (6.9)	5 (1.4)	5 (1)	10 (3)	4 (1)	
Belgium	1 (0.3)		1 (0)			
United Kingdom	47 (13.4)	10 (2.9)	1	14 (4)	12 (3)	
Germany	17 (4.9)	5 (1.4)	1 (3)	1 (0)		1 (0)
France	3 (0.9)	1 (0.3)	10 (3)		1 (0)	
Italy	21 (6.0)	5 (1.4)	1 (0)	4 (1)	1 (0)	4 (1)
Poland	6 (1.7)	3 (0.9)	7 (2)			
Austria	1 (0.3)	1 (0.3)	3 (1)			
Switzerland	2 (0.6)					1 (0)
Spain	8 (2.3)	1 (0.3)	1 (0)	3 (1)	1 (0)	
Denmark	5 (1.4)		3 (1)	5 (1)		
Finland	3 (0.9)	1 (0.3)			1 (0)	1 (0)
Sweden	3 (0.9)				3 (1)	
Portugal	1 (0.3)			1 (0)		
Cyprus	1 (0.3)		1 (0)			
Norway	4 (1.1)		2 (1)		2 (1)	
Total	147 (42.0)	32 (9.1)	45 (12)	38 (11)	25 (7)	7 (2)
North America						
United States	116 (33.1)	48 (13.7)	23 (7)	13 (4)	29 (8)	3 (1)
Canada	22 (6.3)	2 (0.6)	9 (3)	7 (2)	3 (1)	1 (0)
Total	138 (39.4)	50 (14.3)	32 (9)	20 (6)	32 (9)	4 (1)
Asia						
China	4 (1.1)	2 (0.6)		2 (1)		
Taiwan	5 (1.4)	2 (0.6)		2 (1)		1 (0)
Korea	4 (1.1)	3 (0.9)			1 (0)	
Thailand	1 (0.3)	1 (0.3)				
Hong Kong	3 (0.9)			1 (0)		2 (1)
Japan	1 (0.3)		1 (0)			
India	1 (0.3)		1 (0)			
Sri Lanka	1 (0.3)	1 (0.3)				
Total	20 (5.7)	9 (2.6)	2 (1)	5 (1)	1 (0)	3 (1)
Middle East						
Saudi Arabia	2 (0.6)	1 (0.3)	1 (0)			
Israel	4 (1.1)	1 (0.3)	3 (1)			
Iran	2 (0.6)	2 (0.6)				
Total	8 (2.3)	4 (1.1)	4 (1)			
Latin America						
Chile	1 (0.3)	1 (0.3)				
Brazil	1 (0.3)	1 (0.3)				
Panama	1 (0.3)	1 (0.3)				
Total	3 (0.9)	3 (0.9)				
Pacific						
Australia	37 (10.6)	5 (1.4)	9 (3)	10 (3)	9 (3)	4 (1)
New Zealand	2 (0.6)		1 (0)	1 (0)		
Total	39 (11.1)	5 (1.4)	10 (3)	11 (3)	9 (3)	4 (1)

[a] More than 1 country possible due to consortia (n=5). Percentages estimated by total number of studies (N=350).

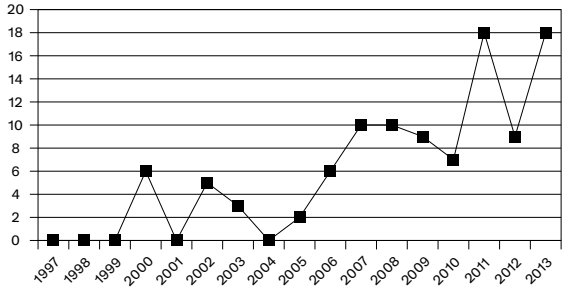
Chapter 2

Table 2.3 Information and communication technology intervention used for person-centred care for diabetes (n=103).

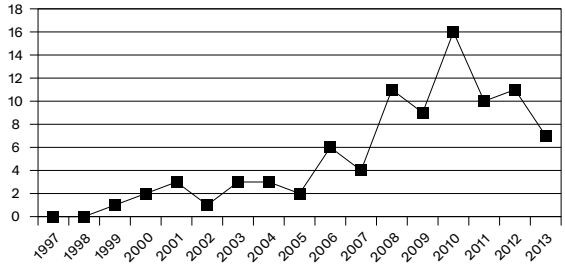
ICT Intervention	Overall, n (%)	Person-centered care activity, n (%)					
		Physical care	Behavior therapy	Education	Self-measure-ment	Lifestyle sharing	Shared decisions
	n=103	n=8	n=10	n=26	n=48	n=16	n=2
Telephone intervention	17 (16.5)	1 (1)	2 (2)	4 (4)	6 (6)	4 (4)	
Nurse telephone calls	8 (7.8)	1 (1)	2 (2)		2 (2)	3 (3)	
Automated telephone calls	8 (7.8)			4 (4)	4 (4)		
Nurse call center	1 (1.0)					1 (1)	
Mobile phone intervention	25 (24.3)		2 (2)	6 (6)	11 (11)	5 (5)	
Smartphone calls	1 (1.0)				1 (1)		
Text messaging	10 (9.7)		1 (1)	4 (4)	2 (2)	3 (3)	
Video messages	1 (1.0)			1 (1)			
e-Dairy messaging app	2 (1.9)				1 (1)	1 (1)	
Monitoring app	9 (8.7)			1 (1)	7 (7)	1 (1)	
Interaction app	2 (1.9)		1 (1)				
Internet intervention	29 (28.2)	2 (2)	3 (3)	7 (7)	10 (10)	4 (4)	1 (1)
Secure messaging app	1 (1.0)						
Health knowledge base	3 (2.9)			2 (2)			1 (1)
Documenting app	4 (3.9)		1 (1)			3 (3)	
Personal health record app	3 (2.9)		1 (1)	1 (1)	1 (1)		1 (1)
Monitoring app	3 (2.9)				3 (3)		
Monitoring device + app	2 (1.9)	1 (1)		1 (1)			
Interaction app	3 (2.9)				1 (1)	1 (1)	
Monitoring + interaction app	6 (5.8)	1 (1)		2 (2)	3 (3)		
Monitoring video conferencing	2 (1.9)				2 (2)		
Virtual clinic	2 (1.9)		1 (1)	1 (1)			
Telemedicine intervention	42 (40.8)	5 (5)	3 (3)	9 (9)	21 (20)	3 (3)	1 (1)
Video phone visits	1 (1.0)			1 (1)			
Monitoring device + system	13 (12.6)	1 (1)			10 (10)	2 (2)	
Telemonitoring system	7 (6.8)	2 (2)			5 (5)		
Telemedicine system	21 (20.4)	2 (2)	3 (3)	8 (8)	6 (6)	1 (1)	1 (1)

[a] More than 1 (person-centered) connected-care management activity possible.
Percentage estimated by total number of studies (n=103).

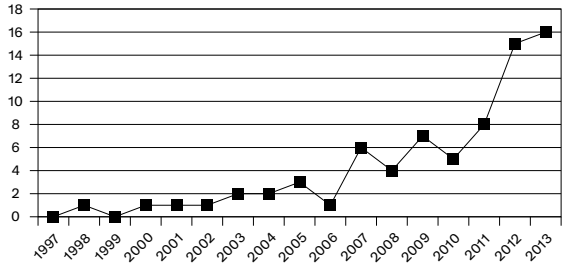
Diabetes connected-care studies (person-centred) n=103



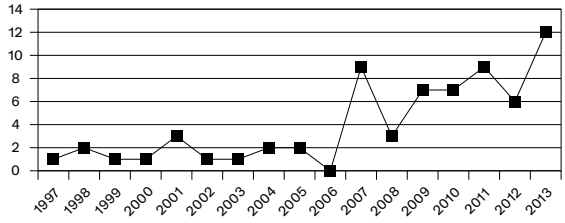
Cardiovasculair connected-care studies (person-centred) n=89



Chronic respiratory connected-care studies (person-centred) n=73



Cancer connected-care studies (person-centred) n=67



Stroke connected-care studies (person-centred) n=18

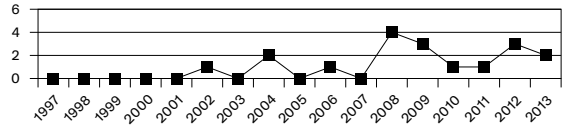


Figure 2.2
Number of studies conducted over the years for the "big five" chronic conditions.

low-tech technology interventions via telephone, the first connecting device enabling remote care management by means of follow-up telephone calls made by nurses.

Information and Communication Technology Enabling Person-Centred Care for Chronic Cardiovascular Diseases

The studies in which cardiovascular patients participated showed a clear preference (71%, 63/89) for telemonitoring/telemedicine system interventions applied for PCC, self-measurement of the body (38%, 34/89), versus interventions applied for connected physical care (17%), and education (9%) as a way to connect the patient and the health care professionals providing advice and service (see Table 2.4). In almost one-quarter of the studies (23%, 21/89), telephone interventions—in particular nurse telephone calls (21%, 19/89)—were used.

Of the 89 studies in the scope of cardiovascular conditions, the most studied person-centred care activity was self-measurement of the body (38%, 34/89). We discovered three studies addressing self-rehabilitation exercises by a virtual clinic app on the Internet and a telemonitoring system. A telemedicine system was used for shared treatment decision making in only 1% (1/89) of the studies.

Another 8% (7/89) of the studies dealt with the use of remote monitoring and a cardiac implant device for self-measurement of the body. These are remote monitoring apps for implanted cardiac pacing systems, which enable persons and health care professionals to (self) monitor the heart implant and are used specifically for cardiovascular patients. Mobile phone interventions were used in 8% (7/89) of the studies; in 7% (6/89) of the studies, monitoring apps were used to self-measure the body, whereas 1% (1/89) were used for educational purposes. We also found combinations of interventions (eg, telephone support by nurses for the educational part and a monitoring device with a Web app for self-monitoring and sharing the data with health professionals).

Information and Communication Technology Enabling Person-Centred Care for Chronic Respiratory Conditions

Within the group of studies addressing patients with chronic respiratory disease (n=73) (see Table 2.5), more than half of the studies (52%, 38/73) used Internet interventions; this was the highest score among the five categories of chronic diseases and much higher than in the category of studies addressing cardiovascular patients (13%), for example. In 28% (21/73) of the studies, telemonitoring/telemedicine system interventions were used.

One-fifth (20%, 15/73) used telephone interventions with nurse telephone calls accounting for 16% (12/73) and mobile phones for 14% (11/73). Furthermore, we extracted and added Skype as a new Web intervention (1%, 1/73).

Concerning person-centred care, we found two studies (3%, 2/73) in which a self-care plan was created and decided on, one with a monitoring videoconference app on the Internet and one with a telemedicine system. Also noteworthy, only 5% (4/73) of the studied telemedicine system interventions were used for

Table 2.4 Information and communication technology intervention used for person-centred care for chronic cardiovascular conditions (n=89).

ICT Intervention	Overall, n (%)	Connected-care activity, n (%)				Person-centered care activity, n (%)				
		Consult	Medication	Physical care	Education	Self-measurement	Rehabilitation exercises	Lifestyle sharing	Shared decisions	Self-care plan
	n=89	n=10	n=3	n=19	n=20	n=47	n=3	n=1	n=1	n=1
Telephone intervention	21 (24)	5 (6)	1 (1)	4 (4)	8 (9)	2 (2)		1 (1)		
Nurse telephone calls	19 (21)	4 (4)	1 (1)	3 (3)	8 (9)	2 (2)		1 (1)		
Nurse call center	2 (2)	1 (1)		1 (1)						
Mobile phone intervention										
Monitoring app	7 (8)				1 (1)	6 (7)				
Internet intervention	13 (15)	3 (3)	1 (1)		3 (3)	5 (6)	1 (1)			
Secure messaging app	1 (1)				1 (1)					
Health knowledge base	2 (2)				2 (2)					
Documenting app	1 (1)	1 (1)								
Personal health record app	1 (1)	1 (1)								
Monitoring app	3 (3)		1 (1)			2 (2)				
Monitoring device +app	1 (1)					1 (1)				
Monitoring + interaction app	3 (3)	1 (1)				2 (2)				
Virtual clinic	1 (1)						1 (1)			
Telemedicine intervention	63 (71)	2 (2)	1 (1)	15 (17)	8 (9)	34 (38)	2 (2)		1 (1)	1 (1)
Monitoring system + cardiac implant	7 (8)					7 (8)				
TV channel system	1 (1)				1 (1)	16 (18)	2 (2)			
Telemonitoring system	33 (37)	1 (1)		13 (15)	1 (1)	1				
Telemedicine system	22 (25)	1 (1)	1 (1)	2 (2)	6 (7)	1 (12)			1 (1)	1 (1)

[a] More than 1 (person-centred) connected-care management activity possible. Percentage estimated by total number of studies (n=89).

Table 2.5 Information and communication technology interventions used for person-centred care for chronic respiratory conditions (n=73).

ICT Intervention	Overall, n (%)	Connected-care activity, n (%)					Person-centered care activity, n (%)		
		Consult	Medication	Physical care	Behavior therapy	Education	Self-measurement	Rehabilitation exercises	Self-care plan
	n=73	n=5	n=3	n=7	n=4	n=12	n=46	n=6	n=2
Telephone intervention	15 (21)			6 (8)	2 (3)	5 (7)		2 (3)	
Nurse telephone calls	12 (16)			4 (5)	2 (3)	5 (7)		1 (1)	
Automated telephone calls	2 (3)			1 (1)				1 (1)	
Nurse call center	1 (1)			1 (1)					
Mobile phone intervention	11 (15)		1 (1)		1 (1)	2 (3)	6 (8)	1 (1)	
Text messaging	3 (4)		1 (1)			1 (1)	1 (1)		
Monitoring app	6 (8)				1 (1)	1 (1)	4 (5)		
Music app	1 (1)							1 (1)	
Interaction app	1 (1)						1 (1)		
Internet intervention	38 (52)	1 (1)	2 (3)	1 (1)	1 (1)	5 (7)	26 (36)	1 (1)	1 (1)
Health knowledge base	3 (4)				1 (1)	2 (3)			
Documenting app	1 (1)		1 (1)						
Personal health record app	1 (1)			1 (1)					
Monitoring app	4 (5)						4 (5)		
Monitoring device + app	14 (19)		1 (1)				12 (16)	1 (1)	
Monitoring + interaction app	13 (18)	1 (1)				3 (4)	9 (12)		
Monitoring video conferencing	1 (1)								1 (1)
Skype video app	1 (1)						1 (1)		
Telemedicine intervention	21 (29)	4 (5)					14 (19)	2 (3)	1 (1)
Monitoring device + system	1 (1)	1 (1)							
Telemonitoring system	8 (11)	1 (1)					6 (8)	1 (1)	
Telemedicine system	12 (16)	2 (3)					8 (11)	1 (1)	1 (1)

[a] More than 1 (person-centred) connected-care management activity possible. Percentage estimated by total number of studies (n=73).

consultations and few (7%, 5/73) of the telephone interventions focused on physical care or education. This indicates that the transformation to PCC is still in its early phase in disease management for chronic respiratory diseases. Similar to the category of patients with cardiovascular diseases, the category of patients with chronic respiratory diseases also had an additional PCC activity—compared to the other groups of chronic patients—namely exercises for self-rehabilitation, which is of importance for this group; 8% (6/73) of the studies were targeted toward this type of activity.

Information and Communication Technology Enabling Person-Centred Care for Cancer

The category of cancer care was the broadest one, with ICT interventions used and studied for a wide variety of self-care and connected-care activities (see Table 2.6). Cancer care management appeared to be one of the most progressive ones in our findings, as involved cancer patients actively used the latest ICT innovations and the highest number of studies (n=23) related to shared management activities in PCC (excluding self-measurement of body activities that are not typically used among those with cancer). Only here did we find studies in which patients and their care providers used the social medium Twitter for PCC for social support.

The most studied interventions for persons with a cancer condition (n=67) addressed Internet interventions for educational purposes (12%, 8/67) of connected care, especially Web portals (6%, 4/67) versus 7% (5/67) of sharing cancer knowledge in a person-centred way. This differs from the other conditions, where intervention for self-measurement of the body ranked the highest. An explanation could be that body measurements related to cancer are performed by health professionals (for the most part), illustrated by our findings that 7% (5/67) of the studied telemedicine interventions focused on physical care.

A new type of PCC activity emerged from our data: 5% of the Internet interventions were applied for self-reporting symptoms. This self-care activity was distinctive and not found among studies concerning the other types of chronic diseases. A monitoring app on mobile phones, a documenting app, a personal health record app, and two monitoring plus interaction apps supported the self-reporting of symptoms. Overall, the total number of PCC activities (n=23) included three studies on shared decision making and three studies on self-care plan creation. Compared to connected-care activities, nurse telephone calls were used in several cases, both for consultation (6%, 4/67) and education (6%, 4/67) versus PCC personal lifestyle sharing (4%, 3/67) and cancer knowledge sharing (6%, 4/67).

Information and Communication Technology Enabling Person-Centred Care for Stroke

The fewest studies of all the chronic condition conditions were encountered in the stroke category (n=18) (see Table 2.7). Six studies addressed PCC, of which five studies supported a new distinctive type of care activity: self-rehabilitation therapy. Interestingly, high-tech innovations involving a robot assistant and virtual reality gaming were studied for self-rehabilitation. Even though stroke is regarded, according to the WHO, as one of the five leading chronic diseases,

many of the studies on connected care by applying ICT are conducted in the field of acute stroke and mobile teams. We only included the studies when acute stroke turned into a chronic situation. Most studied ICT interventions were telemedicine/telemonitoring systems (12/18, 67%) addressing physical care, consultation, and education. A note on the reliability of this data: not all 12 studies were precise in what type of ICT intervention was used and some referred to it in very general terms, such as "telemedicine system." We suggest keeping this in mind when interpreting these results.

Outcomes

Overview

In addition to the (health-related) quality of life and costs efficiency outcomes, we found 33 outcome indicators (see Table 2.8). Extracted from the studied text, we classified these outcome indicators under four category definitions. We defined person outcomes (12 indicators), connected to health professional outcomes (7 indicators), organisation outcomes (9 indicators), technical outcomes (5 indicators), and no outcomes. This last category included 7% (25/350) of the studies, in which no outcome measurement was found.

Person Outcomes

A total of 15.4% (54/350) of the studies measured a positive impact on empowerment (self-care) closely followed by improvement in physical condition (14.0%, 49/350). The increase in quality of life and health-related quality of life accounted for 13.1% (46/350) and 8.0% (28/350), respectively, and self-efficacy for 5.1% (18/350).

Three person outcome indicators were found to be distinctive for one of the five chronic conditions: metabolic control was measured in 10 diabetes studies and lower mortality in 11 cardiovascular studies, whereas improvement in mental health was reported in 11 cancer studies and two stroke studies. Overall, 76.9% (269/350) of the studies reported on person outcomes, with 64.0% (224/350) reporting a positive impact versus 12.9% (45/350) reporting a negative or no impact. These findings confirm the importance of measuring the person-centredness of the ICT intervention, for which these five outcome indicators are currently commonly used.

Connected to Health Professional Outcomes

The impact for being connected to the health care professional by ICT was found to be the highest on a familiar clinical outcomes indicator. Of the total studies, 11.7% (41/350) reported an increase in clinical outcome versus a decrease in 2.0% (7/350) of the studies. Interestingly, "medication adherence" and "treatment adherence" emerged as outcome indicators in a few studies. In relation to PCC, a few other studies suggested that "documentation quality" and "communication quality" should be used to measure the concept of acquiring better insight into the patient. Overall, one-quarter of the studies (93/350, 26.6%) reported on professional outcomes connected to health, with 23.1% (81/350) reporting a positive impact versus 3.4% (12/350) reporting a negative or no impact.

Chapter 2

Table 2.6 Information and communication technology interventions used for person-centred care for cancer (n=67).

ICT Intervention	Overall, n (%)	Connected-care activity, n (%)					Person-centered care activity, n (%)							
		Consult	Medi-cation	Physical care	Behavior therapy	Pallia-tive care	Education	Self-mea-surement	Knowledge sharing	Self-reporting symptoms	Lifestyle sharing	Shared decisions	Self-care plan	Social support
n=67	n=12	n=4	n=12	n=4	n=1	n=17	n=1	n=5	n=5	n=4	n=3	n=3	n=2	
Telephone intervention	16 (24)	4 (6)	1 (1)	1 (1)	2 (3)		4 (6)				3 (4)		1 (1)	
Nurse telephone calls	15 (22)	4 (6)		1 (1)	2 (3)		4 (6)				3 (4)			
Automated telephone calls	1 (1)		1 (1)										1 (1)	
Mobile phone intervention	8 (12)		1 (1)	4 (6)						1 (1)		1 (1)		1 (1)
Monitoring app	6 (9)		1 (1)	3 (4)						1 (1)		1 (1)		
Interaction app	1 (1)			1 (1)										
Twitter	1 (1)													1 (1)
Internet intervention	30 (45)		2 (3)	2 (3)	2 (3)	1 (1)	9 (13)	1 (1)	4 (6)	4 (6)	1 (1)	1 (1)	2 (3)	1 (1)
Health knowledge base	9 (13)			1 (1)	1 (1)		4 (6)		2 (3)					
Documenting app	1 (1)									1 (1)				1 (1)
Personal health record app	6 (9)		1 (1)				2 (3)			1 (1)	1 (1)		1 (1)	
Monitoring device + app	1 (1)					1 (1)								
Interaction app	2 (3)				1 (1)		1 (1)							
Monitoring + interaction app	7 (10)		1 (1)	1 (1)				1 (1)		2 (3)		1 (1)	1 (1)	
Skype video app	1 (1)						1 (1)							
Virtual clinic	1 (1)						1 (1)							
Internet support groups	2 (3)								2 (3)					
Telemedicine intervention	20 (30)	8 (12)		5 (7)			4 (6)		1 (1)			1 (1)		
Video phone visits	3 (4)	3 (4)												
Monitoring device + system	1 (1)											1 (1)		
Telemedicine system	16 (24)	5 (7)		5 (7)			4 (6)		1 (1)					1 (1)

[a] More than 1 (person-centered) connected-care management activity possible.
Percentage estimated by total number of studies (n=67).

Chapter 2

Table 2.7 Information and communication technology interventions used for person-centred care for stroke (n=18).

ICT Intervention	Overall, n (%)	Connected-care activity, n (%)					Person-centered care activity, n (%)	
		Consult	Physical care	Behavior therapy	Cognitive therapy	Education	Self- measure-ment body	Rehabilitation exercises
	n=18	n=2	n=6	n=3	n=1	n=3	n=1	n=5
Telephone intervention								
Nurse telephone calls	1 (6)			1 (6)				
Mobile phone intervention	1 (6)							
Video messages				1 (6)				
Internet intervention	7 (39)							3 (17)
Monitoring device + app	1 (6)						1 (6)	
Monitoring video conferencing	4 (22)		1 (6)	1 (6)		1 (6)		1 (6)
Gaming (virtual reality)	2 (11)							2 (11)
Telemedicine intervention	12 (67)	2 (11)	5 (28)		1 (6)	2 (11)		2 (11)
Robot assistant	1							1 (6)
Telemonitoring system	4 (22)		4 (22)					
Telemedicine system	7 (39)	2 (11)	1 (6)		1 (6)	2 (11)		1 (6)

[a] More than 1 (person-centred) connected-care management activity possible.
Percentage estimated by total number of studies (n=18).

Chapter 2

Table 2.8 Outcomes of the information and communication technology interventions for person-centred care.

Outcomes	Overall		Diabetes		Cardiovascular		Respiratory		Cancer		Stroke	
	N=350		n=103		n=89		n=73		n=67		n=18	
	Pos n (%)	Neg n (%)	Pos n (%)	Neg n (%)	Pos n (%)	Neg n (%)	Pos n (%)	Neg n (%)	Pos n (%)	Neg n (%)	Pos n (%)	Neg n (%)
No outcomes	25 (7)		11 (3)		6 (2)		3 (1)		5 (1)			
Person outcomes	224 (64)	45 (13)	79 (23)	9 (3)	45 (13)	12 (3)	45 (13)	19 (5)	42 (12)	4 (1)	13 (4)	1 (0)
Quality of life	46 (13)	6 (2)			28 (8)	1 (0)	8 (2)	3 (1)	8 (2)	2 (1)	2 (1)	
Health-related quality of life	28 (8)	18 (5)	8 (2)	5 (1)	3 (1)		14 (4)	12 (3)	3 (1)	1 (0)		
Mental health–related quality of life	1 (0)		1 (0)									
Mortality (less)	1 (0)	11 (3)			1 (0)	11 (3)						
Self-efficacy	19 (5)	4 (1)	8 (2)	1 (0)	5 (1)		1 (0)	2 (1)	3 (1)	1 (0)	2 (1)	
Empowerment (self-care)	54 (15)	2 (1)	22 (6)		7 (2)		11 (3)	2 (1)	11 (3)		3 (1)	
Physical condition	49 (14)		30 (9)				10 (3)		5 (1)		4 (1)	
Metabolic control	9 (3)	1 (0)	9 (3)	1 (0)								
Pain reduction	1 (0)								1 (0)			
Behavior change	3 (1)		1 (0)		1 (0)		1 (0)					
Mental health condition	13 (4)	2 (1)		2 (1)					11 (3)		2 (1)	
Loneliness		1 (0)										1 (0)
Connected to health professional outcomes	81 (23)	12 (3)	11 (3)	3 (1)	32 (9)	1 (0)	23 (7)	7 (2)	6 (2)	0 (0)	9 (3)	1 (0)
Medication adherence	12 (3)		3 (1)		5 (1)		4 (1)					
Treatment adherence	8 (2)				4 (1)		3 (1)				1 (0)	
Clinical outcomes	41 (12)	8 (2)	5 (1)	3 (1)	17 (5)		11 (3)	4 (1)	1 (0)		7 (2)	1 (0)
Effectives of intervention		4 (1)				1 (0)		3 (1)				
Documentation quality	5 (1)				1 (0)		1 (0)		2 (1)		1 (0)	
Communication quality	9 (3)		3 (1)		2 (1)		2 (1)		2 (1)			
Health knowledge	6 (2)				3 (1)		2 (1)		1 (0)			
Organization outcomes (care model)	73 (21)	59 (17)	18 (5)	6 (2)	26 (7)	31 (9)	12 (3)	19 (5)	11 (3)	3 (1)	6 (2)	0 (0)
Cost efficiency	38 (11)	6 (2)	9 (3)	1 (0)	15 (4)	1 (0)	7 (2)	4 (1)	7 (2)			
(Time) efficiency	11 (3)		5 (1)		4 (1)				1 (0)		1 (0)	
Quality effectiveness	4 (1)	1 (0)	1 (0)		2 (1)		1 (0)	1 (0)				
Productivity	1 (0)								1 (0)			
Less hospitalization	6 (2)	43 (12)		2 (1)	2 (1)	26 (7)	4 (1)	13 (4)		2 (1)		
Reduced comanagement	1 (0)				1 (0)							
Implementation enablers / barriers (including ethical)	6 (2)	6 (2)	2 (1)	3 (1)	2 (1)	2 (1)		1 (0)			2 (1)	
Improve office visits / replace face-to-face consult	1 (0)	3 (1)	1 (0)			2 (1)				1 (0)		
Improve access difficulties	5 (1)								2 (1)		3 (1)	
Technical outcomes	91 (26)	2 (1)	19 (5)	0 (0)	22 (6)	0 (0)	22 (6)	1 (0)	23 (7)	1 (0)	5 (1)	0 (0)
Feasibility	35 (10)		7 (2)		6 (2)		9 (3)		10 (3)		3 (1)	
Usability	21 (6)		5 (1)		6 (2)		4 (1)		6 (2)			

Organisation Outcomes
Remarkably, the most studied impact on organisation outcome was not cost efficiency itself, but the related impact of less hospitalization (43/350, 12.3%), closely followed by cost efficiency (38/350, 10.9%). Time efficiency was a third outcome indicator appearing in a few studies (11/350, 3.1%). Overall, 37.7% (132/350) of the studies on connected-care and person-centred ICT interventions reported on organisation outcomes.

To a certain extent a positive impact was reported (20.9%, 73/350), which was challenged by a relatively large number of studies that reported a negative outcome; 59 studies (16.9%) reported a negative impact regarding organisation outcomes. Most reported were both a decrease in cost efficiency (1.7%, 6/350) and an increase in hospitalization (1.7%, 6/350).

Technical Outcomes
As far as technical outcomes related to the implementation of the ICT innovation were concerned, the most measured outcome was technical feasibility (10.0%, 35/350) followed by satisfaction (8.0%, 28/350) with the ICT intervention. Important for PCC, usability was measured in 6.0% of the studies (21/350).

In sum, a positive outcome indicator was reported 469 times (134%) versus a negative outcome indicator 118 times (34%). As a percentage of the total 350 studies, we found a relatively more positive impact in studies on diabetes (36.3%, 127/350) and cancer conditions (23.4%, 82/350) versus a relatively more negative impact in the studies on cardiovascular (12.6%, 44/350) and chronic respiratory conditions (13.1%, 46/350).

Discussion

Principal Findings
Shared decision making, personal information sharing, and setting up a care plan enabled by ICT seem to be relatively new. This indicates that the state of knowledge in the PCC field of interest is still emerging, meaning there are many research opportunities to contribute. The type of ICT mostly used by persons with a chronic condition for interacting with health care providers is ICT for self-measurement of the body (n=143) (see Table 2.9); the highest rankings were found in studies on diabetes (n=48) and cardiovascular (n=47) and chronic respiratory diseases (n=46). These are in striking contrast with the lowest ranking; only one study was found on self-measurement of the body within the group on cancer and only one on stroke. Given these types of chronic diseases (cancer and stroke), physical measurements and check-ups likely require the health care provider to use specialised professional equipment. Instead, shared care management activities are enabled by the person-centred ICT for cancer (n=23) and stroke (n=5). Overall, we found 60 studies (17%) on this type of shared decision-making ICT. Cancer ranked first in number of studies followed by diabetes (n=18).

Table 2.9 Person-centred care and information and communication technology interventions used for the big five chronic connected-care activities (CCA), person-centred self-measurement (PCM), and person-centred shared management (PCS).

PCC-ICT interventions used	Total	Telephone	Mobile phone app	Internet app	Telemedicine system
Overall	398 (114)	70 (20)	52 (15)	117 (33)	159 (45)
CCA	195 (56)	51 (15)	20 (6)	50 (14)	74 (21)
PCM	143 (41)	8 (2)	23 (7)	43 (12)	69 (20)
PCS	60 (17)	11 (3)	9 (3)	24 (7)	16 (5)
Diabetes					
CCA	47 (13)	7 (2)	9 (3)	14 (4)	17 (5)
PCM	48 (14)	6 (2)	11 (3)	10 (3)	21 (6)
PCS	18 (5)	4 (1)	5 (1)	5 (1)	4 (1)
Cardiovascular					
CCA	52 (15)	18 (5)	1 (0)	7 (2)	26 (7)
PCM	47 (13)	2 (1)	6 (2)	5 (1)	34 (10)
PCS	6 (2)	1 (0)	0 (0)	1 (0)	4 (1)
Chronic respiratory					
CCA	31 (9)	13 (4)	4 (1)	10 (3)	4 (1)
PCM	46 (13)	0 (0)	6 (2)	26 (7)	14 (4)
PCS	8 (2)	2 (1)	1 (0)	2 (1)	3 (1)
Cancer					
CCA	50 (14)	12 (3)	5 (1)	16 (5)	17 (5)
PCM	1 (0)	0 (0)	0 (0)	1 (0)	0 (0)
PCS	23 (7)	4 (1)	3 (1)	13 (4)	3 (1)
Stroke					
CCA	15 (4)	1 (0)	1 (0)	3 (1)	10 (3)
PCM	1 (0)	0 (0)	0 (0)	1 (0)	0 (0)
PCS	5 (1)	0 (0)	0 (0)	3 (1)	2 (1)

[a] More than 1 (person-centred) connected-care management activity possible.

We note that hardly any of these interventions could be regarded as "fully" addressing the three routines of PCC for activities related to initiating the partnership (patient narratives), working the partnership (shared decision making), and safeguarding the partnership (documenting the narrative) (7).

Furthermore, our findings suggested that the most commonly used personalised ICT interventions involved telemonitoring or telemedicine systems (n=159) followed by Web-based applications on the Internet (n=117). In approximately one-fifth of the studies, the telephone (n=70) was used to connect patient and physician, mostly for consultation and education. For example, in the case of cardiovascular conditions, we found 18 studies on telephone intervention for connected care and in 19 studies on persons with diabetes, the telephone was used, often in combination with Internet-based interventions. In addition, the use of mobile phone apps ranked the highest in diabetes care activities (n=25).

The usage of social media, such as Twitter, was only incidentally mentioned in the reviewed studies, even though eHealth app and medical Internet-based interventions are paying increasing attention to social media (32). A possible explanation could be that Twitter is less used in the relationship between a patient and his or her health care professional, which is the starting point for this scoping review, and more for accessing health information in general.

When comparing ICT-enabled PCC innovations used in different chronic diseases, several results stand out. First, in the case of cardiac patients, high-tech innovations connect remote monitoring software to implant devices (53%), such as pacemakers. Second, persons with a chronic stroke condition are beginning to use (serious) gaming and robot devices, specifically for rehabilitation purposes, which is a necessary treatment immediately after a stroke incident.

Because technology is becoming smaller and cheaper, the possibilities of "wearable" smart technologies are increasing, and we expect to see more of these technologies in the future. Third, virtual clinics provide self-rehabilitation exercises. This technology combines a virtual clinic app on the Internet with telemonitoring systems.

The impact of PCC-ICT interventions on quality of life and health-related quality of life are positive (see Table 9). Several studies claim an increase in quality of life (46/350, 13.1%) or health-related quality of life (28/350, 8.0%). It seems that enabling a person to manage his or her own disease through ICT leads to an improvement in the perceived quality of an individual's daily life (quality of life) and an increase in the measurement of an individual's well being affected over time by the disease, disability, or disorder (health-related quality of life).

The impact on cost and efficiency seems to be positive but less conclusive. Some studies reported positive impacts (38/350, 10.9%). Some of the studies, however, indicated negative impacts, either an increase in hospital (re)admission (6/350, 1.7%) or rise in costs (6/350, 1.7%). Our study suggests that not only could a person with a chronic disease benefit from an ICT-enabled PCC approach, but also that ICT-PCC yields organisational paybacks, although not in all cases. It could

also lead, as was reported in some studies, to an increase in health care usage. Other relevant study outcomes suggest that organisational barriers stand in the way of implementation of ICT-PCC, which is also supported by previous studies (26).

Limitations

Although we covered a considerable number of studies, the search was limited to medical databases. Due to this system restriction, there is a chance that we have missed possible related articles in other domains, such as information systems research, social studies, and organisational change management research.

We realise that conducting a scoping study comes with limitations. We acknowledge the fact that the quantitative overview typical for scoping review results, unlike systematic reviews, does not appraise the quality of evidence in the primary research reports with a detailed analysis of a smaller and similar number of studies (22). Because scoping reviews do not assess the quality of the studies, we included those studies in the review even though they did not reach the quality standard of some peer-reviewed journals. This also sets limitations on the results, which could only be described in general terms such as a "telemonitoring device."

Furthermore, we acknowledge the publication bias of a tendency to publish positive results that could yield a distorted overview of the scope of conducted research on ICT-enabled PCC. Lastly, our interpretations are limited to outcomes reported in the English language.

Comparison With Prior Works

This scoping review mapped ICT-PCC interventions that are applied in chronic disease management to support patients to take an active part in their care and the decision-making process, and make it possible for patients to interact directly with health care providers and services about their personal health concerns. Our study distinguished 13 extracted care activities of connected care and PCC, which build on previous literature review studies on PCC and/or ICT, such as the one conducted by Aarts et al (17). They extracted two care activities, namely the provision of support and education to patients and the promotion of mental health for patient-focused Internet interventions within the discipline of reproductive medicine.

Corresponding to our findings of less hospitalisations are the findings of the scoping review on the effects of PCC for patients with chronic heart failure in hospital settings. Ekman et al (9) found that a fully implemented PCC approach shortens hospital stays and maintains functional performance in patients hospitalised for worsening congestive heart failure without increasing the risk of readmission or jeopardising patients' health-related quality of life.

However, Ekman's study did not involve ICT and the focus was fully on the impact of a PCC approach. A comparable conclusion was drawn in a meta-analysis conducted on the outcomes of an Internet intervention and eHealth counselling on risk factors linked to certain chronic diseases (16).

Theoretical Implication and Further Research Suggestions

This scoping research study has contributed to the growing scholarly interest in PCC and ICT interventions for self-management (of chronic conditions) by providing an overview of the extent and nature of the existing literature and evidence base involving the subset of ICT interventions in PCC for chronic conditions. Sixty relevant health studies have been identified regarding the big five chronic diseases to support patients and health care providers in the online and personalised management of these diseases.

For future research, we have three suggestions: first, given that hardly any of the studies showed a fully PCC-ICT approach, a logical next step is a qualitative study addressing the selection of the studies we found. Such a study can add qualitative insight and lead to placing an emphasis on building a framework. Second, given the 35 outcome indicators we identified, further research on the definition and measurement can help to further develop an evidence base for PCC and ICT for self-management of chronic disease. Third, we pose two challenging questions for further research:

1. How can ICT-enabled PCC be implemented in network organisations to support self-management of chronic patients in a person-centred care manner?
2. What does this mean for innovative care models?

Practitioner and Managerial Implication

Concerning the impact of ICT-enabled PCC, this scoping review study found that empowerment (self-care) of the patient was the main outcome (15%) of the ICT interventions, followed by physical condition (14%), quality of life (13%), and health-related quality of life (8%). For the health care professional, the impact was highest when looking at clinical outcomes (14%). We also found a decrease in clinical outcomes in 2% of the studies.

Regarding the most studied impact in the organisation, we concluded that the outcome is less hospitalisation (12%) and cost efficiency (11%). As far as the ICT intervention is concerned, the impact of feasibility (10%) is high. We also did find negative outcomes within the overall chronic disease categories: health-related quality of life decrease (5%), cost efficiency decrease (2%), and increase in hospitalisation (2%).

Conclusions

Hardly any of the interventions could be regarded as "fully" PCC meeting the three routines of initiating the partnership (patient narratives), working the partnership (shared decision making), and safeguarding the partnership (documenting the narrative). This review will be especially helpful to those deciding on areas where the further development of research or implementation of ICT for PCC may be warranted.

The scoping review investigated the extent, range, and nature of research activities regarding ICT interventions that have been studied to support patients and health care professionals in PCC management of the big five chronic diseases. From the initial 9380 search results, we identified 350 studies that qualified for

inclusion. The largest share of ICT interventions studied sought to support patients in self-measurement of the body.

The highest impact of ICT interventions (15%) of the studies on patients was measured on the increase of empowerment (self-care) closely followed by improvement in physical condition (14%), increase in quality of life (13%), health-related quality of life (8%), and self-efficacy (5%). Only 6% of the studies measured usability. This is disturbing since usability is an important fact for the acceptability of ICT by its users, and the lack of attention paid to usability in the reviewed studies indicates that there would be much to be gained from this.

The scoping review suggests that not only can persons with a chronic disease benefit from an ICT-enabled PCC approach, but also that ICT-PCC yields organisational paybacks, although not in all cases. It could also lead, as was reported in some studies, to an increase in health care usage. Other relevant study outcomes suggest that organisational barriers stand in the way of implementation of ICT-PCC, which is also supported by previous studies.

The impact of being connected to the health care professional by ICT is found to be the highest (12%) on a familiar clinical outcomes indicator versus a decrease in 2% of the studies. Remarkably, the most studied impact on organisation outcome is not cost efficiency itself, but the related impact of less hospitalisation (12%) closely followed by cost efficiency (11%).

Persons with a chronic disease are beginning to use (serious) gaming, social media, wearable technology, and robot devices for the management of diseases. Because technology overall is becoming smaller and cheaper, the possibilities of these smart technologies are increasing and we expect to see more of these technologies in the future.

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Conflicts of Interest
None declared.

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Chapter 3

Information and Communication Technologies to Support Chronic Disease Self-Management: Preconditions for Enhancing the Partnership in Person-Centred Care

This chapter is based on the following article:
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1) The published article was accepted by a journal with a preference for US English. Therefore, the title to which we refer to is in US English, whereas the body of the text was adapted to UK English, which is the base of this thesis.

Abstract

Objective: In order to alleviate the pressure on health care systems exerted by the growing prevalence of chronic diseases, information and communication technologies (ICT) are being introduced to enable self-management of chronic diseases by supporting partnerships between patients and health care professionals. This move towards chronic disease self-management is accompanied by a shift in focus on integrating the patient with his or her perceptions on the chronic disease as a full-fledged partner into the health care system. This new perspective has been described as "person-centred care" (PCC). To date, information and communication technologies only partially build on the principles of PCC. This paper examines the preconditions of ICT to enable a person-centred approach to chronic disease management.

Methods: Using cancer treatment as a case study for ICT-enabled PCC, we conducted a comparative analysis of thirteen scientific studies on interventions presented as ICT-enabled PCC for cancer treatment, to answer the research question: What are the preconditions of ICT-enabled PCC in chronic disease management? Based on the intended and actual outcomes, we distilled in several analytic steps the preconditions of ICT-enabled PCC for chronic disease self-management.

Results: We distinguished four user-related preconditions of ICT-enabled PCC: (shared) decision making, personalised ICT, health-related quality of life, and efficiency.

Conclusions: We argue that these four preconditions together can improve people's self-management of chronic diseases by strengthening the partnership between the patient and the health care professional. Moreover, the study revealed a discrepancy between intended and reported actual outcomes in terms of realizing person-centred care.

Information and Communication Technologies to Support Chronic Disease Self-Management: Preconditions for Enhancing the Partnership in Person-Centred Care

Introduction

Chronic noncommunicable diseases are the leading cause of illness, disability, and mortality, exerting significant pressure on the sustainability of worldwide health care systems (1). Management of a chronic disease is often a lifetime task for which the patient is responsible on a day-to-day basis. This requires on the one hand "self-management" by the patient, involving active participation of people in their own health care process, and on the other hand requires helping them and their families to accrue the knowledge, confidence and skills to manage their condition (2).

Successful self-management of a chronic disease allows people to handle their life with some degree of independence despite their medical condition, and to feel healthy despite their limitations (3). A key characteristic of self-management is a collaborative approach to the care of chronic illness, in which patients and professionals form a partnership focused on the patient (4). Thus, rather than perceiving health care professionals as experts and patients as subjects that bring little to the table besides their illness, a self-management partnership means that people with chronic conditions become their own principal caregivers, and health care professionals are seen as "consultants" supporting them in this role (2).

Information and Communication Technologies (ICT) are considered an important enabler of such partnerships, as ICT offer ways to connect chronic patients and their health care providers around the clock and at a distance, contributing, for example, to more self-monitoring and shorter hospital stays (5,6).

Nonetheless, the partnership is often neglected in the design of ICT applications aimed at supporting chronic disease self-management (7,8). ICT applications for health care purposes are regularly developed for — rather than with — the intended users (9). Moreover, ICT applications typically do not take into account the partnership between patients and health care professionals (10), and are focused on only one of these parties rather than considering both (11). This lack of consideration for both the patient and the health care professional, as well as their partnership, increases the risk that ICT applications are mismatched with user needs, and that the technology ends up lacking meaning in practice for both patients and health care professionals (12).

Thus, while more and more health care-supporting interventions and applications are being designed, it remains unclear whether and how such interventions in fact contribute to better self-management of chronic conditions. This is problematic, because when the promise of ICT-enabled support tools is not realised, not only significant investments in ICT solutions are wasted, but most of all: collaborative partnerships between patients and health care professionals within health and health care are not optimised.

In this paper, we aim to generate understanding of the preconditions toward realizing ICT-enabled approaches to support chronic disease self-management. We opted for the term preconditions as these best describe the necessary — but not exclusive — characteristics to realizing actual use. Identifying preconditions to ICT-enabled chronic disease self-management is an important step in improving the technology design process toward better support of the partnership between the patient and health care professional.

Building on our analysis, we explain how ICT can be better tailored toward self-management of chronic diseases, for both patients and health care professionals. We draw on the concept of person-centred care (PCC) to guide this analysis, whereby a patient's personal context and situation informs and guides the design and implementation of their health care. Our case study, based on an analysis of thirteen studies in which ICT was presented as an important means to support person-centred chronic disease management of cancer, is therefore guided by the research question: What are the preconditions of ICT-enabled PCC in chronic disease management?

We identified four preconditions for ICT-enabled person-centred care, but found that while these preconditions are sometimes met, the intended outcomes of ICT-enabled person-centred care are not always realised. We explain this discrepancy by drawing on an affordances perspective, which forefronts the actual use, and not only the designed intent of technology. We first introduce the theory on person-centred care that informed our study.

Person-Centred Care

Person-centred care (PCC) is a systematic approach to disease management that involves the patient as an equal partner in the care process (13). Initial studies on person-centred care suggest that a fully implemented PCC approach keeps people more resilient, shortens hospital stays and improves quality of care (14,15). PCC involves three core components: initiating the partnership, by eliciting a detailed patient narrative; working the partnership between patient and health care professional, by implementing the narratives in the care process through shared decision making; and safeguarding the partnership, by documenting the partnership in the patient record (13). The patient narrative is the person's personal account of his illness and symptoms, and their impact on his life. It captures the person's suffering in an everyday context, in contrast to medical narratives that reflect the process of diagnosing and treating the disease (13). The PCC components build on each other, and can be reiterated.

PCC can be considered a specific type of shared-decision making, which involves an interaction process established in the partnership between patient and health care professionals (7,15). Through the combination of this process orientation with a narrative orientation, PCC emphasizes the need to build partnerships based on the personal, individual meaning that a (chronic) disease has in a person's life. As this is a highly personalised process, ICT applications have the potential through their flexibility to be particularly suitable for supporting these partnerships (6). Yet, the development of such ICT support for PCC is still in its infancy (7,8). Our study seeks to further develop this understanding by way of a case study that we now introduce.

Methods

Setting and Sample

Our dataset consisted of thirteen cases (see attachment Multimedia Appendix I) derived from a prior large scoping review of literature on ICT interventions in a wide variety of self-management and connected-care activities (8), which presented ICT-enabled health care as an important means to support person-centred chronic disease management. The studies we selected for our analysis followed what could be considered as ICT-enabled person-centred care for chronic conditions, meaning the ICT interventions were aimed at meeting the three established components of person-centred care: Initiating the partnership (patient narratives); working the partnership (shared decision making) and safeguarding the partnership (documenting the narrative) (13).

We focus on a single chronic condition — cancer care — as a means for comparison across studies. By focusing on one chronic condition we were better able to compare across studies. Cancer is one of the main types of non-communicable chronic diseases and the condition is a leading cause of disease worldwide. The sample of cancer yielded the largest category within the scoping review of the "big five" chronic conditions (diabetes mellitus, cardiovascular disease, chronic respiratory disease, cancer, and stroke) studied in chapter 2.

Moreover, ICT interventions to support cancer care cover a wide variety of self-management and connected-care activities and are, in that sense, a good example of ICT-enabled PCC toward chronic disease management (16,17).

Study Design

We analysed thirteen cases of cancer care by following the initial steps for structuring qualitative data in new concept and theory development, as described by Gioia (2013). The Gioia methodology is a systematic approach using interpretative coding, which was useful for our aim of distilling the preconditions of ICT-enabled PCC based on evidence derived from the selected cases. First, initial (open) coding was conducted in each of the thirteen studies, using NVivo software, whereby we particularly sought to identify how ICT usage was described as a support of chronic disease management in a person-centred approach to care. Second, the first author's coding was reviewed by the other authors, after which the group of authors grouped them according to similarities and differences in ICT-enabled person-centred care. We created categories by seeking similarities among the codes, grouping these under so-called first-order concepts (summarised in Figure 3.1), and discussing and adapting these to ensure these first-order concepts were appropriately captured. We looked for patterns among the core concepts, distilling how the described ICT interventions supported disease self-management of cancer in a person-centred approach to care. Third, we identified theoretically-supported second-order themes ("preconditions") that emerged from the first-order concepts. In the preconditions we articulated the outcomes of the first-order concepts in the interventions studied that afforded a person-centred approach to care, enabled by ICT. The resulting data structure is shown in Figure 3.1.

We based our preconditions on the ICT interventions mentioned in the studies. However, not all intended outcomes described were realised. To distinguish intended versus actual outcomes in terms of PCC, we reverted to the originally selected text segments in the cases we studied (summarised in Table 3.1). These categories were used to recognize if the ICT interventions enabled person-centred care in chronic disease management not only in theory, but also in health care practice.

Results

We derived seven so-called "first-order concepts" related to ICT-enabled PCC: contributing to empowerment; exchanging information; supporting physical wellbeing; supporting psychosocial wellbeing; enhancing usability; enabling telemonitoring; and strengthening efficiency (see Figure 3.1). These first order concepts can be seen to represent on the one hand person-centred-care-related activities (A) and on the other the supporting technology (B).

Regarding the person-centred care activities (A), we first identified activities contributing to empowerment (1) that engage patients to "make active choices

Table 3.1. Described intended use versus reported actual outcome.

Study	Described intended use	Reported actual outcomes
Care related		
Barlett et al (2012)	Provide information for follow-up care Follow-up at distance Replace face-to-face contact Self-management	No actual outcomes reported (only intended use)
Gustafson et al (2008)	Regain competence Increase health competence Empower decision-making Speed recovery Enable social presence	Enabled social support Increased interactive support Increased quality of life Increased health competence Enabled feelings of relatedness
Izquierdo et al (2011)	Increase patient knowledge Promote shared decision-making Support therapy choice Empower decision-making	Increased shared decision-making Achieved realistic expectations of disease Reduced passivity decision-making Increased knowledge on illness
Lieberman et al (2003)	Encourage empowerment patients Reduce loss of hope Reduce loss of control Reduce unwanted loneliness	Reduced depression Reduced reaction to pain Increased social support Enabled anonymity Increased contact outside scheduled hours
Lieberman et al (2005)	Support peers Support self-direction Social support	Increased psycho-social quality of life
Ligibel et al (2012)	Increase physical activity	Changed behavior Increased physical activity Reached lifestyle intervention
Osei et al (2013)	Increase health-related quality of life Support family members	No actual outcomes reported (only intended use)
Ruland et al (2010)	Prepare for consultation Document patient care	Managed symptoms
Ruland et al (2013)	Manage symptoms Support clinicians in more patient-centered, illness-oriented consultation Tailor individual patient needs Manage disease Manage symptoms	Reduced symptom distress Improved patient-centered care Supported symptom management
Seckin et al (2012)	Empower patient Self-manage care	Prepared for consult Supported coping with cancer Empowered info-decision support
Sugawara et al (2012)	Exchange information	Enabled anonymity Empowered through tweeting information Supported peers (using Twitter) Supported psychologically Connected users
van den Brink et al (2007)	Improve quality of life Communicate Support peers Retrieve information	Increased impact quality of life Decreased physical complaints Reduced uncertainty and fear Increased self-efficacy Improved symptom control
Yount et al (2013)	Relieve symptom distress	Failed to demonstrate efficacy
Technology related		
Barlett et al (2012)	Cost-efficient Release burden on health care system Monitor telehealth Develop user-friendly website	Wanted to maintain face-to-face contact patient-health care professional (but not reached) Trained prescription Involved users in development of eHealth interventions (partly reached) Patients wanted “personalized” website with links to the clinical team (not reached) Accessed Internet had more to do with personal choice and attitude than ability due to costs Differentiated factor of age
Gustafson et al (2008)	Integrate system of services	Integrated system of services more helpful than usual care
Izquierdo et al (2011)	Facilitate patient/physician decision-making	Increased understanding of disease Deepened awareness of other patients’ experiences Encouraged shared decision-making Improved quality of decisions
Lieberman et al (2003)	Deliver electronic support groups through Internet	Occurred technological problems Worried clinicians that facilitation would be difficult because of lack usual cues
Lieberman et al (2005)	Validate Internet bulletin boards	Validated first step bulletin boards
Ligibel et al (2012)	Intervene with telephone-based exercise	Changed behavior test possible
Ruland et al (2010)	Tailor individuals through computerized assessment	Improved patient-centered care and patient outcomes, including reduced symptom distress and reduced need for symptom management support
Ruland et al (2013)	Support cancer patients in illness management	Effectively supported by computer tool
Seckin et al (2012)	Empower patients Manage computer technology-based information on diseases	Cyber supported patients for knowledge about their illness and treatment
Sugawara et al (2012)	Role Twitter in the life cancer patients	Exchanged information via Twitter
van den Brink et al (2007)	Tele monitor to bridge gap after discharge	Felt secure
Yount et al (2013)	Monitor symptoms	Efficiency not shown

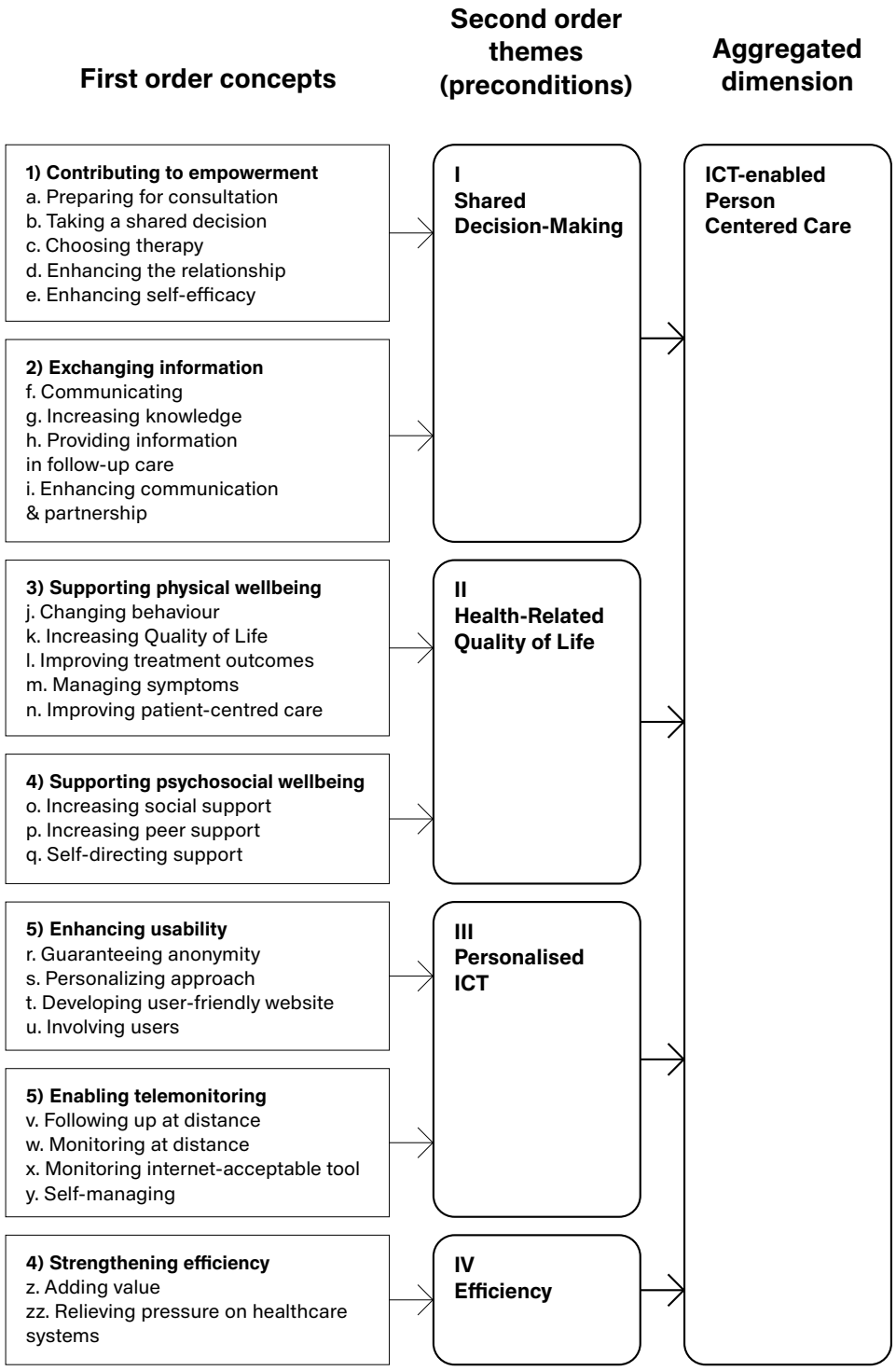

 Figure 3.1 Data structure of ICT enabling PCC.

in their recovery" such as electronic support groups for breast carcinoma (19). These activities were manifested in the form of: preparing for the consultation (1a), taking shared decisions (1b), choosing therapy (1c), enhancing the relationship between the patient and the health care professional (1d) or enhancing self-efficacy (1e). For instance, patient empowerment was mentioned in four studies as being the result of "info-decisional empowerment" (information provision to support decision making), sharing information, and interactive health communication (20,23).

The second first order concept we identified was exchanging information (2), which involves staying in touch outside of regular scheduled sessions, not only with health care professionals but also with supporting peers (19). Exchanging information was manifested through communicating (2f), increasing knowledge (2g), providing information in follow-up care (2h) and enhancing communication and partnership (2i). Articles describing these activities suggested that ICT increased the opportunities for accessing and exchanging information (eg, (23,17)), as described in the study on the development of a useful, user-friendly website for cancer patient follow-up by Bartlett and colleagues (2012): "Use of the internet for information exchange between patients and health care staff may provide us a useful adjunct or alternative to traditional follow-up."

Supporting physical wellbeing (3) is the third first order concept we distinguished, and involves striving to be as healthy as possible despite the disease. This was manifested in the form of changing behaviour (3j), increasing quality of life (3k), improving treatment outcomes (3l), managing symptoms (3m) and improving patient-centred care (3n). For instance, physical well-being, either through behaviour change or management of symptoms or treatment, was one of the desired outcomes either through a telephone-based physical activity intervention (24), an online support group for prostate cancer survivors (25), an eHealth application for personalised illness management support (26), a telemedicine system supporting head and neck cancer patients, and symptom telemonitoring in advanced lung cancer (27). All cases aimed to have an impact on health-related quality of life. For example, telemedicine systems supporting head and neck cancer patients during the postoperative period at home were beneficial for the quality of life of this group of cancer patients and added to the physical wellbeing of the patients (16).
Next, supporting psychosocial wellbeing (4) involves increasing psychosocial support from being connected to others, for example through a novel patient community. For instance, patients who used an Internet-based, interactive, integrated support system for cancer patients experienced greater social support during the intervention period (28). Social media also played an important role in psychosocial wellbeing, in particular the use of Twitter as described by Sugawara et al (23), due to its ability to promote direct interaction between cancer patients.

We also found references to the supporting technology (B), and how it supported cancer self-management in a person-centred manner. First, we identified technology related to enhancing usability (5), which involves the ease of use or

the learnability of the ICT applications.

One of the few studies that suggested user-involvement in the development process as a means to strengthen usability was Bartlett and colleagues' (2012) analysis, whereby the authors suggest that: "Involving users at developmental stages of eHealth systems is generally considered good practice and can ensure the application under development is both user-friendly and perceived as useful." Within the cases, usability was represented by guaranteeing anonymity desired by the patients (5r), personalising approach (5s), developing user-friendly website (5t) and involving users (5u). For example, one of the studies focused on the usability, feasibility and acceptability of a user-friendly and useful website with the potential for use in a "training and website" follow-up model in cancer care (17).

Enabling telemonitoring (6) in a person-centred approach to care included combining various information technologies for remotely monitoring patients (16,28,29), providing the possibility to following -up at distance (6v), monitoring at distance (6w), monitoring if Internet is an acceptable tool (6x) and self-managing (6y).

Finally, strengthening efficiency (7) involves a substitute for traditional face-to-face follow-up, which might not be the most (cost-) efficient use of physician and patient time. ICT can offer ways to connect chronic patients and their health care providers around the clock and at a distance. For both the patient and the health care providers the substitute of ICT should be efficient and adding value (7z). Efficiency was sometimes mentioned under the umbrella term "relieving the pressure on health care systems" (7zz). Here, ICT was used for follow-up at a distance replacing follow-up visits. This is efficient for both patient and health care professional but is also a means to reduce the pressure on the health care system, including the health care professionals (17).

Preconditions of ICT Enabling Person-Centred Care

In our third analytical step we developed so-called second order themes based on an iterative analysis between our empirical findings and the literature on person-centred care. We identified four second order themes or "preconditions" of ICT as enabling person-centred care: shared decision making; health-related quality of life; personalised ICT; and efficiency (as summarised in Figure 3.1).

First, our analysis revealed that shared decision making was a prominent aim in ICT-enabled person-centred care. Shared decision making entails developing the health professionals' skills in involving patients in decisions related to their treatment, with the aim of increasing the patient's role in implementing this treatment, and ultimately improving decision quality (30).

ICT supported shared decision making by enabling patients to access online information and thereby gained additional knowledge and a better understanding of their illness, ultimately supporting shared treatment decisions. For instance, Izquierdo et al (2011) show how a breast cancer Patient Decision Aid (PDA) allowed patients to adopt a more active role in the choice of treatment options in accordance with their medical and personal preferences.

Second, health-related quality of life consists of both physical and psychosocial wellbeing, which were important first-order concepts in the studies we analysed. For example, health-related quality of life was mentioned as an outcome of the use of ICT, realised for example through telemedicine, in supporting patients during follow-up, and resulting in the perceived improvement of symptom control (16). This was also realised through the use of social media and websites to enable peer support, resulting in an increase in psychosocial wellbeing [23].

The aim of an online self-help support for breast cancer patients was: "We hypothesized that breast cancer bulletin boards would prove to be effective in improving participant's quality of life as measured by a decrease in depression, and increase in psychosocial well-being and an increase in personal growth." (18)

We identified personalised ICT as a technology-oriented precondition of ICT-enabled PCC. This was manifested, for instance, through distance monitoring and follow-up in support of chronic disease self-management, where the capacity for personalised ICT interventions was recognized as a means to accommodate different needs among patients (17) indicate: "Differences were found between breast and prostate cancer patients and between patients with a first time diagnosis and metastases or recurrences. The large variations among patients in their use of WebChoice components demonstrate that patients' needs for support vary." (32). We also found that peer-to-peer contact was particularly salient as a form of personalised ICT, in that online health communities afforded social support according to personal needs and preferences (20).

Finally, the precondition efficiency arises from the assessment of how ICT could be efficient for both the patient and the health care professional (7z) or to relieve pressure on the health care system (7zz). However, some studies demonstrated concerns that aiming for efficiency through ICT might replace human contact, rather than supporting regular health care efforts. That is, a one-sided emphasis on efficiency through ICT can weaken the partnership between patient and health care professional. For instance, the intended outcome of the ICT intervention of one of the studies was to develop a useful, user-friendly website for cancer patient follow-up and the site was tested on usability, feasibility and acceptability (17). Its aim was to use the Internet for follow-up at a distance between patients and health care staff as a useful adjunct or alternative to traditional face-to-face contact for persons with a low risk of recurrence and with a low level of need. However, the study was initiated to address the burden imposed on health care systems by the growing amounts of follow-up visits, which put pressure on the workforce of health care professionals. Remote monitoring was proposed as a way to diminish this pressure and decrease the costs, and considered as a low-cost solution to encourage patient self-management. It turned out that patients indicated they wanted to have a way of contacting their health care team without "causing hassle". However, this was "out with the scope of this study" (17). Even though the patients were heard through focus groups and interviews, the intervention did not offer the services they wished for with their clinical team. Despite the fact that the authors of the study stated that user involvement in website design can ensure that patients' needs are met,

the expressed wish of the patients for a "personalised" website was not realised. Thus, the intended use of personalised ICT was not the actual outcome.

Person-Centred Care: Technology in Use

As a final analytical step we sought to understand whether the preconditions we identified actually afforded ICT-enabled person centred care in the studies we analysed. We compared the described intended use to the reported actual outcomes ("affordances") of the studies on ICT interventions in practice.

We identified three categories describing whether these routines were actually realised. The first category contained studies that did not report the actual outcome, for example when this was not part of the study design. The second category contained studies whereby the reported actual outcome was equal to the described intended use. The third category comprised studies whereby the reported actual outcome differed from the intended use. The described intended use and the reported actual outcomes are summarised in Table 3.1.

A second category contained studies where the reported actual outcome was equal to the intended use described. An example of this category is the study by Van den Brink and colleagues (2007), which focuses on the impact on quality of life of a telemedicine system in support of cancer patients. In this case, the partnership was supported. The intervention group was provided with a laptop and access to a telemedicine support system during the first six weeks after discharge. The system offered possibilities for communication, access to information, peer support and monitoring at home. The study reported that the telemedicine system proved to be beneficial for the quality of life of cancer patients (16).

A third category, which we encountered most often, comprised studies where the reported actual outcome differed from the intended use. These studies revealed a discrepancy between what was described as the intended use of ICT to support chronic disease management and how ICT was actually used in practice, in terms of realizing person-centred care. For instance, in a case describing the development of a useful, user-friendly website for cancer patient follow-up, the study disclosed that the explicit wish of the patients was to have a way of contacting their health care team without "causing hassle." (17) However, in the actual realised outcome, the focus was primarily on relieving the burden imposed on health care professionals and the health care system in general through the growing amounts of follow-up visits. Thus, while remote monitoring of persons with a low risk of recurrence and a low level of need was proposed as a low-cost way to diminish this pressure, decrease costs, and support patient self-management, the intervention ultimately did not offer the services and interactions with their clinical team the patients wished for, even though the patients were consulted in the design process. The intended outcome — more patient involvement and patient self care — was not realised because patients' wishes were not met in the design and development process of the ICT-intervention.

Across these categories, only a few studies showed a clear focus on the partnership involving both patients and health care professionals. Nonetheless, partnership is a prerequisite following the original definition of person-centred care by Ekman and colleagues, stating that person-centred care is a systematic approach to disease management that involves the patient as an equal partner in the care process (33). An example where this prerequisite was met was the development process of a patient decision aid (PDA), in which both breast cancer patient and health care professional were involved. "The PDA for breast cancer... has succeeded in improving the quality of decisions for specific situations and has encouraged a shared decision making approach in which both patients and health care professionals take on a participative role." (31) Clearly, inclusion of the partnership remains a challenge that has, yet, to be overcome if the promise of ICT-enabled PCC is to be met.

Discussion

The resources needed to support chronic diseases are putting increasing pressure on health care systems. To alleviate this pressure, information and communication technologies (ICT) are being introduced to support self-management of chronic diseases. This move towards chronic disease self-management involves integrating the patient as a full-fledged partner, also described as "person-centred care" (PCC). We argued that ICT only partially builds on the principles of PCC (8), and that explicit understanding of the mechanisms supporting the partnership between patients and health care professionals in ICT-enabled person-centred care is lacking. We therefore sought to identify ICT preconditions in support of chronic disease management as a means to better facilitate a person-centred approach to care and the partnership between the patient and the health care professional in particular.

By analysing studies reporting a person-centred approach to ICT-enabled cancer care we identified four preconditions: shared decision making, personalised ICT, health-related quality of life, and efficiency. Each of the preconditions involves participation of both patient and health care professional, and emphasizes their collaboration in a partnership rather than treating each partner as an isolated entity.

Several studies show that the partnership between patient and health care professional is changing (2,4,15,32). In participatory medicine, for example, patients are encouraged to act as full partners and are valued as such (32). ICT has the potential to support participatory medicine by equipping, enabling, empowering and engaging patients, thereby creating a more equal partnership between patients and the health professionals and systems that support them (34).

Through our focus on the health care partnership we extend prior studies addressing the use of ICT to support self-management of chronic diseases that attend to either the experiences of the patients or the health care professionals,

but not the participation of both (7,8). Indeed, we argue that upfront inclusion of different stakeholders of care (35,36) is critical toward more successfully developing and eventually integrating ICT interventions in the health sector. Based on these arguments, we propose the preconditions for a person-centred approach to ICT-enabled care to enhance the effectiveness of the care partnership.

In addition to the four preconditions, we found that the intended use of ICT interventions to enable person-centred care often diverged from the actual use. By analysing both the intended as well as reported actual outcomes, we sought to understand not only what technology was designed for, but also what it engendered in health care practices. To explain this discrepancy, a "technology affordances" lens is appropriate. Technology affordances relate to the possibilities and opportunities that arise from users engaging with the technology, and take into account the resulting potential behaviour changes (33). In other words, sometimes users tend to use ICT applications differently than intended (37,38) which makes it crucial to examine how users actually engage with a technology over time within a particular setting, and how ICT applications are embedded in their daily practices.

A second insight that the affordances perspective has to offer is that people need to engage with ICT applications to make them have impact. The extensive integration of ICT ushers in significant changes to the actual "fabric" of professional engagement (39). Our analysis confirmed that simply replacing parts of the workflow with ICT-enabled ways of working barely affects practices (36,40), and ICT cannot be simply added on as an afterthought.

The majority of the cases that we studied (see Table 3.1) showed a discrepancy between the intended use and the reported actual outcomes. Either, the reported outcomes differed from the intended use or the outcomes were not reported at all. Our findings suggest that such a mismatch between intended use and reported actual outcomes might be prevented in future by meeting the preconditions for ICT-enabled PCC.

Limitations and Further Research

For this study we relied on secondary data of a large scoping review that were not collected for the aim of this study, so we may have missed relevant preconditions that were not described in the studies used. However, we only selected studies that were explicitly aimed at describing the outcomes of ICT-enabled PCC interventions. This means that the likelihood of important omissions is small. Nonetheless, case studies aimed at analysing ICT-enabled PCC in practice would be useful to validate our findings. This would also enable more in-depth analysis of the ways in which the technology is being embedded within the partnership and the wider organization in which the patient and the health care professional participate.

Another limitation of the study is that it comprises a sample of ICT-enabled cancer treatment cases, excluding other chronic diseases. By limiting ourselves to cancer, we may have missed activities that are specific to other chronic diseases. Further research comparing different chronic disease is a useful way to overcome this limitation and extend the validity of our findings.

This study reflects data from thirteen studies. Since not all of them include a complete overview of the demographics, we lack detailed insights of the interactions between the technology used and the demographics of the persons using it. We therefore do not know to what extent certain outcomes are specific to certain groups, such as effects of education level, cultural background, or age on the engagement with ICT applications.

Overall, more knowledge is needed on the actual use of ICT interventions in practice and how this supports the partnership between patients and health care professionals in particular. Drawing on the basis we provide in this study, a next step is to combine health innovation research with research on the design of technology-enabled health applications (or "eHealth" (32,34,35)) in a person-centred approach, taking into account the context in which technology is being applied, and most importantly, how people using these technologies experience them in relation to their disease self-management.

Conclusion

The primary aim of this study was to determine the preconditions of ICT-enabled person-centred care to support a self-management partnership between chronic disease patients and health care professionals. By examining ICT as an important means to facilitate a partnership between patients and health care professionals, we contribute to a nascent body of literature on ICT-enabled health care (or eHealth), and to the relatively new field of research that combines person-centred care and ICT (6,7).

We identified four preconditions to ICT-enabled PCC: shared decision making, personalised ICT, health-related quality of life, and efficiency; but also found that intended and actual use of interventions often diverged. The preconditions all involve participation of both patients and health care professionals as partners in the self-management process. This makes ICT-enabled PCC a partnership that can prove fruitful in furthering participatory medicine.

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Chapter 4

Technology supporting the partnership between patients and health care professionals towards chronic disease management: Practices in Australia and the Netherlands

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Abstract

This study analysed the fit between Information and Communication Technology-enabled Person-Centred Care (ICT-PCC) and support for the patient-health care professional partnership in practice. The research builds upon the notion of policy makers that ICT can provide stronger support for the partnership between patient and health care professionals over distance and around the clock. This is of particular relevance to chronic disease management, which is often a 24/7 and lifetime task. While ICT is increasingly applied to document and exchange information, monitor and interact, a mismatch occurs between the intended and actual support provided for the patient-professional partnership in practice. We conducted an in-depth qualitative analysis of people with experience of ICT-PCC interventions to study how ICT affords the partnership between patients and health care professionals in practice, towards chronic disease management. Interviews were conducted in Australia and the Netherlands, juxtaposed in terms of geographic size and the density of ICT infrastructure. In our study we distinguished four affordances to better understand how ICT is used in practice to support the patient-professional partnership: facilitating data collection and sharing, consulting where and when needed, using intuitively, and strengthening the care relationship. The study suggests that ICT affords support for the patient-professional partnership, but can at the same time evoke unintended consequences to the partnership.

Technology supporting the partnership between patients and health care professionals towards chronic disease management: Practices in Australia and the Netherlands

Introduction

Over the past 25 years we have witnessed an increase in the amount of Information and Communication Technology (ICT) interventions in the health care sector (1). As a result, a growing number of studies have sought to theorize the changes induced by the widespread introduction of ICT in the health care environment. Person-Centred Care (PCC) has been increasingly used as the starting point of these studies (2,3). Studies on the support of PCC through ICT (ICT-PCC) have showed promising results, such as shorter hospital stays, enhanced self-monitoring, improved health-related quality of life, increase in shared decision-making and efficiency, and improved clinical outcomes (2,4,5).

However, previous research on ICT-PCC also revealed a discrepancy between *intended* and reported *actual* outcomes in terms of supporting the partnership (3). We argue that by preventing this mismatch in the future, the partnership within ICT-enabled PCC may be strengthened. Therefore, in this study we will focus on how ICT affords the partnership between patients and health care professionals in practice. To this end, we posed the research question: *How does ICT-PCC afford the partnership in health care practice between patients and health care professionals towards chronic disease management?* Thereby, we focused on chronic disease management, since persons with a chronic condition often require a long period of supervision, observation or care by a group of diverse health care professionals working in ever-closer partnership (6-8).

This study is structured as follows. After introducing the method, examples of ICT-PCC are introduced from the participants, followed by the description of their experiences with its use in practice. The experiences with ICT-PCC are analysed for its consequences on the partnership. Affordances of ICT-PCC are

distinguished to specify the interaction between the intended use of ICT and actual use in practice in the context of the health care partnership. In the discussion and conclusion, the different ways how ICT affords the partnership and its implications are argued and examined in the light of existing knowledge. At the end of the discussion, readers should have a richer vision of how ICT in health care practice affords the partnership *in practice* between patients and health care professionals towards chronic disease management.

Materials and methods

Research setting and description

We focused on a diverse set of experiences with ICT-enabled PCC to support the partnership in health care practice, in the context of chronic disease management. We held semi-structured interviews as a means to gather information on ICT-enabled person-centred care. Our focus was not so much on the technology itself, but on how ICT facilitated a person-centred approach to care by supporting the professional-patient partnership. We therefore included a wide range of users to get a broad overview, combining different angles. Besides the primary users (patients and health care professionals), we involved secondary users, consisting of developers of ICT-enabled PCC, policy makers and health insurers occupied with the implementation of these technologies, and researchers studying ICT to support chronic disease management.

Seventeen participants were interviewed, including ten from Australia and seven from the Netherlands (9). In the category of primary users we interviewed four participants in Australia, and two in the Netherlands. In the group of secondary users we interviewed six participants from Australia and five from the Netherlands. To study how ICT supports the partnership over distance we juxtaposed two characteristics, namely geographical challenges due to country size and density of ICT infrastructure. The Australian health care context was chosen as a setting because Australia is a very large, relatively sparsely populated country, where patients and health care professionals are geographically separated; at times ICT may be the only way to facilitate the partnership.

In contrast, the Netherlands is a small, densely populated country; distances are hardly a reason to use ICT to support the partnership between patients and health care professionals. In addition, the Netherlands has a high level of overall Internet penetration and the country has shown itself to be a global leader in adopting and using ICTs (10). This makes the Netherlands potentially an ideal context in which to introduce ICT-enabled PCC and apply it in support of the patient-professional partnership.

Sampling

We used convenience and snowball sampling (interviewees identify further participants) to select our participants, all of whom were involved in the use of ICT to support chronic disease management. Participants were first recruited in Australia. We informed all participants of the research through an information letter about the purpose and context of the study. They were asked for their par-

ticipation via email. The principal researcher re-introduced the study verbally at the outset of each interview. Subsequently, we recruited participants in the Netherlands. All methods used and the questionnaire were checked and approved by the researchers' host institute.

Interviews

Interviews were conducted between 11 November 2015 and 8 June 2016. The first author conducted all interviews. They were held either in English or in Dutch. All interviews were conducted face-to-face or, if a meeting could not be scheduled otherwise, by Skype or phone. The interviews lasted between 27 and 76 minutes and were all tape recorded. Each interview consisted of two parts, whereby part (a) consisted of questions regarding ICT-enabled PCC interventions towards chronic disease management; part (b) addressed the use of these ICT interventions in real-world health care practice and how it supported the patient-health care professional partnership. The participants were asked in an open, semi-structured way about their experiences with these ICT interventions in practice.

Data analysis

The first author transcribed the interviews. Next, transcribed data were imported into NVivo, a software tool to enable data management, to facilitate the coding and categorizing of the data for the qualitative content analysis. Subsequently, the transcriptions were coded and the codes categorized. The first author identified and grouped the described examples of ICT-PCC. The data were analysed in an iterative manner, meaning we returned to the data several times during and after the various cycles of data collection (11) to develop the concept of ICT-enabled PCC affordances while retrieving and analysing the data.

In previous studies we identified a mismatch between intended and actual use of ICT-enabled PCC, so we did not take the examples of ICT-enabled PCC for granted in this study. The data from the interviews were analysed on ICT-PCC preconditions, followed by the grouping in iterative steps of the data to find patterns on ICT-enabled PCC affordances. The first author identified overarching categories of affordances related to ICT-enabled PCC through open coding of the seventeen transcribed interviews. This step was discussed with the other authors, and adapted where appropriate.

The illustrative quotes used in the paper are derived from the interviews and help bring the arguments to life. No attempt is made to precisely describe the ICT-PCC interventions at hand, as this extends beyond the scope of this study. Based on this analysis we conceptualise the fit between ICT-enabled PCC preconditions and support for the partnership in health care practice.

Ethics approval

All participants agreed voluntarily to participate in the study. The interviews were carried out in accordance with relevant guidelines and regulations. The interviews were conducted when all authors were affiliated to the Vrije Universiteit Amsterdam. According to the Dutch legislation, this study is a non-WMO study, that does not involve medical research, as was endorsed by the Human Research Ethics Committee of the Vrije Universiteit Amsterdam. The only legis-

lation which apply to this study is the Personal Data Protection Act. The study presented conform to this regulation.

Furthermore, the researchers did not have access to and did not use personal information or datasets, and they also neither collected nor used bodily material. All personal information was anonymized and we did not ask participants for private information. The quotes chosen were sufficiently general to preclude identification of individual participants. All methods used and the questionnaire were checked and approved by the researchers' host institute.

Results

Examples of ICT-PCC

Participants addressed each an intervention from their own experience, which resulted in a set of 17 examples. Closer inspection of these examples suggested that it would be helpful to divide the ICT interventions into three categories: Internet-based systems, telemedicine systems, and electronics patient record systems. Table 4.1 itemizes these examples. We then addressed whether the preconditions of these ICT-PCC interventions were met in health care practice. It was not our intention to delve deeply into this data, but rather to get a first impression of the fit between the preconditions of ICT-enabled PCC interventions and the support for the partnership in practice.

In chapter 3 we distinguished user-related preconditions of ICT-enabled PCC, comprising (shared) decision-making, personalised ICT, health-related quality of life, and efficiency. Together these preconditions can strengthen the partnership between the patient and the health care professional. However, the study also revealed a discrepancy between intended and reported actual outcomes in terms of realizing person-centred care. To identify whether the preconditions of the mentioned examples of ICT-enabled PCC interventions were in fact met in practice, we had a closer look at the examples provided by our participants. The results are summarised in table 4.2.

Our results show that the actual outcomes of the ICT-PCC interventions vary according to category. More particularly, the category of telemedicine systems showed the highest predominance in terms of meeting the preconditions for ICT-enabled PCC in practice, both in the Netherlands and Australia. For example, the chronic pain condition management system in Australia appeared to meet the preconditions of ICT-enabled PCC. That is, the system enabled the precondition of *(shared) decision-making* between patient and health care professional through telecoaching and teletreatment; the ICT was *personalised* to support the partnership between patients and professionals (an easily accessible online system based on Chrome browser); further, health-related *quality of life* increased and led to a more *efficient partnership* (for example, reduced travel time for both patient and health care professional).

In contrast, the category of electronic patient record system (EPR) was least in accordance with the preconditions of ICT-enabled PCC (see Table 4.2). We did, however, identify a difference between the Netherlands and Australia with respect to these systems. Namely, during the course of this study, the Dutch personal health record had not as yet been fully implemented. As such, we were

Table 4.1 Itemization of ICT-PCC interventions

INTERNET-BASED SYSTEMS	TELEMEDICINE SYSTEMS	ELECTRONIC PATIENT RECORD SYSTEMS
AUSTRALIA		
Accessing a database that is web-based with exercises following evidence-based critical practice guidelines (HCP, AU)	Managing chronic pain condition over distance (patient, AU)	Be able to personally control the health record (researcher, AU)
Making online appointments with the healthcare professional (researcher, also patient, AU)	Managing chronic pain through HealthDirect (HCP, AU)	Access to My health record (policymaker, AU)
Accessing eHealth intervention on compensation for traffic accident victims (researcher, AU)	Real-time monitoring of patient through chronic care programme (policy maker, AU)	Enabling employment through a good consumer record, which is focusing on ability instead of disability (policy maker, AU)
Being able to execute a 'point of care' diagnosis (designer, AU)		
THE NETHERLANDS		
Implementing the personal care plan Mijn Gezondheidsplatform (HCP, NL)	Telemonitoring of heart failure patients; SmartHealth + facilitating self-management of heart failure patients (Zelfzorg ondersteund; Cardiologie Centra Nederland) (policy maker, NL)	Accessing Personal Health record (Patient1, Quli, Portavita) (patient, NL)
	Checking the eye condition of diabetes patients through ophthalmologic telediagnosis (SME/ ICT-developer, NL)	Accessing personal health record (Health Communicator; Patient1) (health insurer, NL)
	Supporting blended care programmes for mental health (SME/ICT-developer, NL)	

Table 4.2 Preconditions of ICT-PCC interventions met in practice

Preconditions ICT-PCC vs ICT-PCC systems	(Shared) decision-making	Personalized ICT	HRQL	Efficiency
INTERNET-BASED SYSTEMS				
THE NETHERLANDS				
Mijn Gezondheidsplatform	-	-	-	?
AUSTRALIA				
Database that is webbased with exercises	-	-	+	+
Making online appointments	-	+	?	+
eHealth intervention on compensation for traffic accident victims	+	-	+	?
A 'point of care' diagnosis	+	+	+	+
TELEMEDICINE SYSTEMS				
THE NETHERLANDS				
Telemonitoring of heart failure	?	?	?	?
Telediagnosing of eye condition	+	+	+	+
Supporting blended care programmes for mental health	+	+	+	+
AUSTRALIA				
Enabling management of chronic pain condition over distance	+	+	+	+
Counselling chronic pain through HealthDirect	+	+	+	+
Real-time monitoring of patient through chronic care programme	?	?	?	?
ELECTRONIC PATIENT RECORD SYSTEMS				
THE NETHERLANDS				
Accessing Personal Health Record (Patient1, Quli, Portavita)	?	?	?	?
Accessing Personal Health Record (Health Communicator, Patient1)	?	?	?	?
AUSTRALIA				
Being able to personally control the health record	-	-	-	-
Accessing My health record	-	-	-	-
Enabling employment through a good consumer record, which is focusing on ability instead of disability	-	-	-	-

[+] positive impact, [-] negative impact, [?] uncertain impact, ICT under development during study

unable to fully judge whether the preconditions were met in practice. However, the Australian *My Health Record* had already gone through different steps of adaptation and the system was implemented on a national scale, but our analysis disclosed that the preconditions of ICT-PCC were not met. Based on this preliminary analysis of the examples in line with ICT-PCC preconditions, we shifted our focus onto the relational dimension of the health care partnership in practice, as we now illustrate.

Affordances of ICT-enabled PCC

In order to interpret the mismatch between intended and actual outcomes in the practice of ICT-PCC we draw on the affordance approach (14,15,19,20). Identifying these affordances helps us to understand how ICT shapes the patient-professional partnership in health care practice. The data from the interviews were analysed and grouped in iterative steps to further detail patterns in whether and how ICT affords the patient-professional partnership. Our analysis led to four different clusters of ICT-enabled PCC affordances, illustrated in figure 4.1.

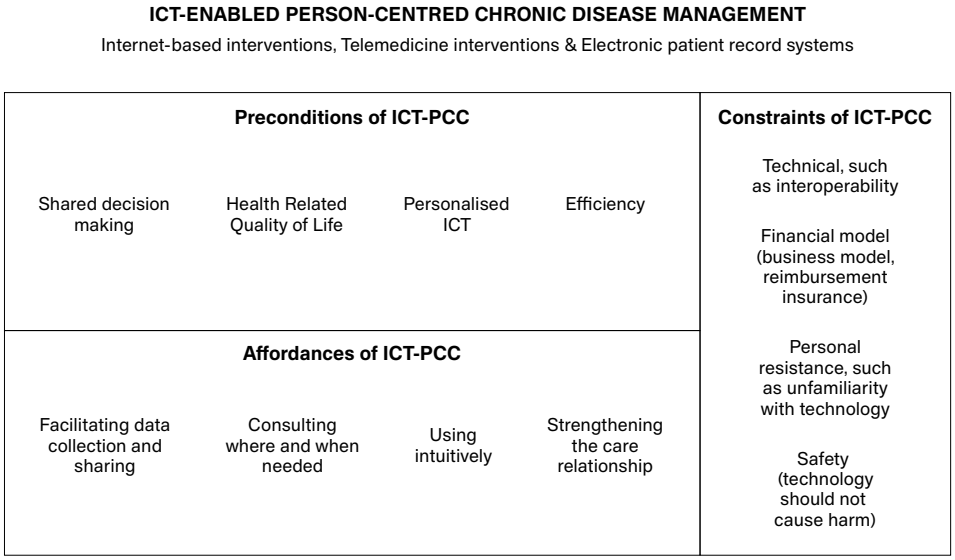

Figure 4.1 Frame of ICT-enabled PCC in practice

As shown in figure 4.1, ICT-PCC interventions afford several practices for their users within the context of chronic disease management, which we grouped into the following four clusters: facilitating data collection and sharing; consulting where and when needed; using intuitively; and strengthening the care relationship. We combined these affordances with the results of our preliminary analysis into a framework through which to better understand the role of ICT-PCC in supporting the patient-professional partnership in health care practice, as shown in figure 4.1.

In what follows, the four clusters of ICT-PCC affordances are illustrated in more detail, with examples from our case study. In distinguishing the affordances, we also identified some constraints of ICT-enabled PCC. These include technical issues (for example, interoperability), financial barriers (including reimbursement by health insurance), personal resistance (such as unfamiliarity with the technology), and safety (the technology needs to be safe and must not cause harm), also included in figure 4.1.

I) Facilitating data collection and sharing

Both in Australia and the Netherlands, several participants named electronic patient record systems as an example of ICT-enabled person-centred care. These examples showed that ICT facilitates the centralized storage of data so that, potentially, patients and health care professionals – and third parties, when they are permitted – can easily access these data. The technology thus shapes the ways in which (medical) data are collected and shared between patients and health care professionals.

In Australia participants referred to My Health Record, an *electronic patient record system* that keeps track of important health information and stores it in one place so that both the health care professionals and the patient (and his or her family) have access to the data. Comparably, participants in the Netherlands referred to several *personal health record* initiatives such as Patient1, Quli and Portavita. The Australian examples quite clearly disclosed that that this system did not suffice in terms of providing the patient and the health care professional with a complete overview of the (medical) data:

'Personally controlled electronic health records started 20 years ago. It is an opt-in system. Who wants to be in, can opt in. General practitioners and health care professionals are in the lead. Patients have access themselves. They can read what the doctor has uploaded to the system. The doctor records what he or she wants to record. If a patient wants a summary, he or she has access to the part the doctor uploaded. It is a double system so the part the patient has access to does not have to be the same as the doctor. The doctor may or may not put all the information in the personally controlled electronic health records. For example, he or she could put in all the information about cancer of a patient but the information on mental diseases that is stigmatizing he could leave out. He or she could choose not to upload that information.' (researcher, AUS)

As the example shows, in this case it is quite exclusively the health care professional who decides which information is or is not made accessible to the patient, without any say in this choice at the side of the patient.

The paradox of the electronic patient record systems in terms of person-centred care is that personal, legal and organisational issues prohibit the collecting and sharing of data between patients and health care professionals. In addition, while ICT opens up possibilities to support data collecting and sharing amongst patients and health care professionals, fear of misuse by data by others than the patients and health care professionals dissuades users from harnessing the potential of data collecting and sharing. As such, instead of electronic patient record systems that provide both patients and health care profes-

sionals with transparency and an overall overview of patients' data, users end up with a system that does not foster a partnership.

II) Consultation where and when needed
ICT affords a process optimisation of the care process, which is time and place independent, and which facilitates the patient-professional partnership when and where it is needed. For example, counselling chronic pain patients in remote areas in Australia through a telemedicine system makes a check-up possible without the person with a chronic condition and his/her health care professional(s) having to travel for hours to see each other. Contact is established with the patient through the chronic pain management telemedicine system.

Moreover, the design enables professionals to work together in care within this virtual relationship. For example, one specialist team was located at one end of the country, while a physiotherapist or a psychologist worked locally. The team of health care professionals was able to see the patients, observe their body language, and watch them walking around in their own homes. One health care professional in Australia described this as follows:

'The pain management model consists of a multidisciplinary assessment beforehand. A treatment plan is set up that has different disciplines involved, and can support the patient in their own home through telecounselling. The health care professionals can actually see the patient. So, when the patient says: "It is all OK", he or she can see when it is not OK. What you can cover up in a phone call is a lot more disclosed than when you actually see someone and have a conversation with him or her.'
(health care professional, AUS)

In a vast country with geographical challenges such as Australia, a check-up that is place and time independent can have, without doubt, major advantages. For patients with chronic pain, having to travel for hours back and forth to see the (team) of health care professional(s) is a severe impediment; similarly for the health care professional not having to travel can save a lot of time. In facilitating the patient, an added affordance is the involvement of distributed teams, which allows specialised care for a broader group of patients. Another reason for the success of the chronic pain telemedicine system was described by one of the participants:

'The reason we have been so successful in telehealth of chronic pain management is that we have been on it every step of the way, with every hospital. We go there, we look at the problem, we do a follow-up, we make sure everything is working well. So, it is not that we just give them the toolkit, give them the technology and away you go!'
(health care professional, AUS)

Also in the Netherlands – a small country where geographical challenges hardly exist – ICT affords this involvement of distributed teams of health care professionals:

'The person used to go to the ophthalmologist, now he or she goes to a laboratory where images of the retina are made. The optometrist at a distance decides if the retina is OK or not. An opthalmologist can be available at a distance in case of doubt. And the general practitioner is also involved. This whole process is independent of time and place.'
(developer of ICT, NL)

However, what this example also disclosed is that the distribution of care did not fit into the existing Dutch health care system. For example, an ophthalmologist who used to see his or her patient at the hospital was involved in a teleconsultation construction with the optometrist. However, this resulted in fewer patient consultations to the ophthalmologist. Moreover, the health insurance indicated that this type of treatment was costlier since more health care practitioners were involved through the distribution of care (optometrist, ophthalmologist, GP) and did not reimburse the care. In view of these constraints, we found that financial and organisational issues hindered consultation where and when needed – which inadvertently led to the failure of the whole initiative. Or as a Dutch participant framed it:

'That is one of the reasons why a lot of initiatives fail: they have insufficiently mapped the stakeholders nor have they mapped what the pros and cons are of the ICT.'
(developer of ICT, NL)

The unintended consequence of this example of telemedicine is that a consultation when and where needed called for an entirely different way of working and adaptation of the overall care process. That is, while the design afforded distributed teams working together virtually and supporting the patient-professional partnership over time and distance, this was not achieved in practice.

III) Using ICT-PCC intuitively
ICT can afford an intuitive way to manage a chronic condition by, for example, empowering the patient and exchanging information with the health care professional(s). One research participant referred to a case in Australia whereby health care professionals were given a tablet during ward rounds as a means to enable them to exchange information for instance by showing patient results and graphs pertaining to their health. As an Australian researcher explained:

'The doctors used the iPads, but only once did they turn the screen around to show it to the patient. We interviewed the doctors afterwards and told them: "We gave you these tools and you said that shared decision-making is important. Not once did we see you show the patient the screen. 'The clinicians said: "Ward rounds aren't the time for shared decision-making." So, maybe we observed during the wrong time. They said: "Shared decision-making happens in the clinic, in the office, but not on ward rounds because there are so many patients to go through and they are not well. [...] The focus is to get them out of hospital, not to talk to them about what they want." And you may or may not agree on that, but [those] were the responses we got. In a way, having the computer, having the opportunity to show them stuff, showing

them graphs on how they are doing, showing them x-rays might be useful. But I haven't seen in practice that it really happened that way.'
(researcher, Australia)

The design enabled patients and professionals to make shared decisions and adopt a more collaborative approach to medical care that involved chronic patients actively in the care process in an intuitive manner but as we saw, in practice this did not fit into the process as it was.

Other ICT interventions such as interactive apps are increasingly being developed to support a more collaborative approach, and were also shared by our participants. However, as one of them explained:

'What I do not like about the interventions is that if you have three conditions, you have three different apps. It becomes too much for a patient to add the information into three different systems. I would like to see an overall app that brings everything together.'
(researcher, AU)

To be able to use ICT-PCC interventions in an intuitive manner, we found that it was necessary for the design to more clearly match the needs of intended users. The development of the electronic health record system in Australia lacked this component, according to one of our participants:

'They tried to build the system in a very technical, functional way. Never did they consider the doctor's perspective or the patient's as a whole. [...] They have not considered a different way of working at all. That is a reason why it won't work.'
(health care professional, AU)

Another complication we identified is that each patient-professional relationship is likely to be different: patients may be active or passive in terms of their treatment plan, and health care professionals also have different profiles. Thus, the wide range of types of users complicates the design and development of ICT-PCC. As an interviewee explained about the Australian electronic patient record system:

'There were consultations where the users could say what they wanted. Then there were so many opinions that they were moulded into one product; everyone got the worst of everything. I think it is good to engage people, but at the same time you need to draw a line [regarding] what is possible and what they could have a say in.'
(researcher, AU)

Clearly, ICT-enabled health care systems are used by different users in different contexts. While ICT affords intuitive use to support the patient-professional partnership in different ways (shared decision-making, documenting information in a health record system and so forth), the results showed the barriers for particular users when specific settings were considered.

IV) Strengthening the care relationship
The examples we studied showed that ICT-PCC affords confidence in strengthening the patient-professional partnership, which may in turn lead to an increase in the self-management and efficacy of the patient. However, introducing ICT to support the partnership also modified the relationship, which sometimes led – in the worst case scenario – to an undetermined relationship. One of the Dutch participants vividly described this issue:

'When introducing ICT, the doctor-patient relationship is actually at stake. If you want the intervention to work well, you need to trust the technology and the patient. In the sense that the doctor shifts part of his or her responsibility towards the patient, which is one of the biggest hurdles. There is a lot of pain in that. "My patient would not be suitable for that." Of course, that is not true at all. But there is a kind of suspicion that a patient could not do something for him or herself.'
(researcher, NL)

In order to make ICT 'work' to support and strengthen the care relationship, the interests of both patient and health care professional need to be taken into account, as one of our research participants underlined:

'What you seldom see, and what takes a lot of effort, is to include the interests of both the patient and the health care professional equally in the development of an eHealth platform.'
(researcher, NL)

In sum, while ICT affords confidence in strengthening the relationship between patients and health care professionals, most of the technology studied was not shaped to meet the different needs of the various users in practice. The technology rarely integrated the different interests of both patients and health care professionals in a flexible manner in order to make it work as intended in managing the chronic condition.

Discussion

The main aim of this study was to analyse how Information and Communication Technology (ICT) shape the patient-professional partnership. We addressed this by researching the fit between ICT-enabled Person-Centred Care (ICT-PCC) and the patient-health care professional partnership in health care practice. To expand our understanding of how ICT enables the patient-professional partnership, we drew on a technology affordances approach (14,15,19,20) as a useful means by which to analyse the interaction between intended and actual use of ICT. We distinguished four affordances in our study related to ICT-PCC, namely facilitating data collection and sharing, consulting where and when needed, using intuitively, and strengthening the care relationship. In so doing we contribute to scholarly knowledge on ICT-PCC in practice. Our results also disclosed that while ICT is intended to strengthen the patient-professional partnership,

in practice the support provided for the partnership through ICT tended to become unpredictable, outcomes were sometimes unintended, and at times the introduction of ICT even weakened the partnership.

In our study we build upon Dedding's (16) literature review identifying possible changes – both positive and negative – in the partnership between patients and medical professionals as a consequence of the introduction of ICT (replacing face-to-face consultation, supplementing existing relationships, creating circumstances for strengthening patient participation, disturbing the relationship, and demanding more frequent patient participation), expanding on the actual changes in practice. So far, studies on actual changes in the patient-professional partnership through ICT have remained largely unaddressed.

Therefore, we distinguished actual support from possible support for the patient-professional partnership in health care practice as a consequence of implementing ICT, thereby extending existing knowledge on ICT-PCC. This knowledge is not only relevant for health care practitioners, but also for policy makers involved in implementing ICT in a health care setting, when demanding increased patient participation and enforcement of the patient-professional partnership in the management of chronic conditions through ICT.

Furthermore, we elaborated on previous debates on the consequences of introducing new technology in organisations, and the changing roles and patterns of (social) interaction as a consequence (13,14,17,18). These debates posit that technology is shaped through its users who employ particular technologies in specific contexts (19), with more recent research focusing on the relational view of the introduction of technology into organisations by taking into account the intentions of its users (20). However, our study also concentrated on how technology shaped the *partnership* between different users in practice, and specifically the patient-professional partnership in health care practice, thereby offering an empirical contribution of an important social context.

In addition, since one of the characteristics of ICT-PCC is that the technology enables support for the patient-professional partnership over distance, we studied ICT-PCC in both Australia and the Netherlands as a set of affordances. Surprisingly, we did not find major dissimilarities in the outcomes between the two settings, despite the distinct characteristics of geographical challenges and density of the ICT infrastructure. While we would expect different outcomes because of these different contexts (21,22), one of the explanations for the 'similarity' in the results between the Netherlands and Australia might be that certain affordances of the technology in supporting the partnership were not foreseen, and that the technology had not been adapted to users in different contexts, which may also explain the 'failure' of some of the described ICT-PCC interventions to support the partnership in practice.

Moreover, the different categories of ICT-PCC interventions (Internet-based systems, telemedicine systems, and electronics patient record systems) showed that the electronic patient record systems provided the least support to the partnership. However, when comparing Australia and the Netherlands, there is a difference in the examples of the electronic patient record systems. Whereas the participants in Australia referred to electronic health records, in the Netherlands the examples concerned personal health records. More concretely, an electronic health record is controlled by health care profes-

sionals, while a personal health record can be generated by health care professionals, hospitals, pharmacies or other sources, but is controlled by the patient.

In both cases, the systems strive to provide an overview of the patients' health data, stored in one place and easily accessible for those who are allowed to consult these – often sensitive – data. While the Australian electronic patient record system left no flexibility to support both patients and health care professionals in the partnership due to its rigid structure, the personal health records in the Netherlands were still under development during the execution of the research, and the outcomes on the support of the partnership were still unknown. Clearly, this is an important topic for further research as the system develops further, taking these differences into consideration.

Finally, more empirical work is needed to develop and specify how the ICT-PCC affordances that we identified can be better integrated into the development process of ICT-PCC from design to implementation as a way to strengthen the patient-professional partnership as envisaged, towards better chronic disease management in practice. The ICT-PCC affordances distinguished in this study provide a useful starting point to this end.

We are aware of the fact that this study has certain limitations. The gathered data were derived from a small group. Therefore our conclusions on how ICT shapes the patient-health care professional partnership in health care practice towards chronic disease management must be tentative. Nevertheless, through our study we were able to generate useful findings for further conceptualization and concretization of ICT-enabled PCC practice and policy.

Conclusion and policy recommendation

In our study we distinguished four affordances to better understand how ICT is used in practice to support the patient-professional partnership: facilitating data collection and sharing, consulting where and when needed, using intuitively, and strengthening the care relationship. The study suggests that ICT affords support for the patient-professional partnership, but can at the same time evoke unintended consequences to the partnership.

Our analysis of the relational affordances of ICT-PCC yields promising potential to usher in more tailored and accessible care that digitally supports the partnership, as suggested by Talboom-Kamp et al. (23). This contributes to scholarly research on the organisational, social, political and policy context of introducing ICT in health care practice (24), by combining the constraints of ICT-PCC and its affordances. This is of importance to policy makers concerned with implementing ICT for health care purposes. Nonetheless, the described ICT-PCC affordances deserve profounder theorization and explanation to be able to bridge the gap between intended and actual use of ICT-PCC.

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Chapter 5

Information and communication technology enabling partnership in person-centred diabetes management: building a theoretical framework from an inductive case study in the Netherlands

This chapter is based on the following article:
Wildevuur SE, Simonse LW, Groenewegen P, Klink A. Information and communication technology enabling partnership in person-centred diabetes management: building a theoretical framework from an inductive case study in the Netherlands. BMJ Open 2019;9:e025930. doi:10.1136/bmjopen-2018-025930

Abstract

Objectives: The aim of this paper is to construct a theoretical framework for information and communication technology (ICT)-enabled partnership towards diabetes management.

Design: We conducted an inductive case study and held interviews on the development and use of an artificial pancreas (AP) system for diabetes management.

Setting: The study was carried out in the Netherlands with users of an AP system.

Participants: We interviewed six patients with type 1 diabetes, five health care professionals (two medical specialists and three diabetes nurses), and one policy advisor from the Ministry of Health, Welfare and Sport.

Results: We built a new theoretical framework for ICT-enabled person-centred diabetes management, covering the central themes of self-managing the disease, shared analysing of (medical) data and experiencing the partnership. We found that ICT yielded new activities of data sharing and a new role for data professionals in the provision of care as well as contributed to carefree living thanks to the semiautomated management enabled by the device. Our data suggested that to enable the partnership through ICT, organisational adjustments need to be made such as the development of new ICT services and a viable financial model to support these services.

Conclusion: The management of diabetes through ICT requires an adjustment of the partnership between persons with the chronic condition and the health care professional(s) in such a way that the potential for self-managing the condition by analysing the newly available (medical) data (from the AP system) together leads to an experience of partnership between patients and health care professionals.

Information and communication technology enabling partnership in person-centred diabetes management: building a theoretical framework from an inductive case study in the Netherlands

Introduction

Person-centred care (PCC) actively involves the patient in the care process as an equal partner in, and expert on, living with a chronic condition (1). Persons with a chronic condition have to make decisions on a day-to-day basis about self-managing their illness, which influences the health care professional–patient partnership with respect to care services (2). The partnership between patients and health care professionals involves sustaining the relationship via deciding on goals, care planning and documentation (3). Information and communication technology (ICT) for health care—also known as eHealth (4)—might support the professional–patient partnership in PCC services and provide chronic disease management in the face of social, physical and emotional challenges (5).

ICT-enabled PCC

ICT is increasingly used within chronic disease management to document and exchange information, monitor and interact. The results of the first studies on ICT enabling PCC (ICT-PCC) in chronic care are promising, with improved clinical outcomes, better health-related quality of life and increased cost-effectiveness (6). However, there is a gap in knowledge how ICT shapes the professional–patient partnership when used in daily practice.

When applying the concept of partnership in PCC to ICT systems, the technology must be tailored to the needs of both patients and health care professionals (personalised ICT), whereby the personal context and situation of the patient informs and guides the decision-making on the care pathway (7). However, this phenomenon of enabling the partnership through ICT is not fully understood and insights are lacking on how this partnership is influenced and

transformed through ICT (8). In this study, we selected a case in which an innovative ICT-enabled PCC intervention was used for diabetes management to better understand how ICT shaped the patient–professional partnership (9).

Self-management of diabetes

Training in self-management of type 1 diabetes through personalised insulin treatment leads to significant improvements in treatment satisfaction, psychological well-being and quality of life measures (10). Even though diabetes management has improved considerably over the years, patients still suffer from short-term complications such as hypoglycaemia ('hypo' for short) and hyperglycaemia ('hyper') progressing to diabetic ketoacidosis and hyperosmolar hyperglycaemic syndrome, and long-term complications such as retinopathy, neuropathy, cardiovascular disease and nephropathy that could lead to complications such as loss of eyesight and amputation (11).

The treatment and care of patients with diabetes have seen fast progress and key innovations after the discovery of insulin in 1921: engineered insulin, the introduction of blood glucose monitoring by telemonitoring systems, internet applications and mobile devices (12). In addition, smart algorithms to control the blood glucose level have been developed (13). This innovation trajectory of applying smart algorithms to earlier discoveries culminated in the development of a first-generation system of an artificial pancreas (AP) that focuses on preventing unsafe blood sugar levels and aims to control blood glucose around a target of 120 mg/dL (=6.7 mmol/L) (14).

ICT interventions for diabetes management

Several companies worldwide are developing AP systems to regulate basal insulin delivery, by taking over the regulation of the glucose levels completely through automating insulin—and still in a development stage, also glucagon—delivery (15-18). Over the last years, significant progress has been made in AP development (19), and researchers have demonstrated the safety and feasibility of different AP systems in clinical research settings and more recently in outpatient 'real-world' environments (20,21). Most of the studies are about developing AP systems that would still require user entry of carbohydrate intake (hybrid closed -loop systems). Several meta-analyses focused on AP performance across different studies, and concluded that artificial pancreas systems could be an efficacious and safe approach for treating patients with type 1 diabetes (22-25).

The greatest benefits of the AP are the reduced burden of diabetes management during the day, and improved overnight control of glucose levels thanks to reduced glycaemic variability, improved time in target range and reduced risk of nocturnal hypoglycaemia (26–28). Although AP users with type 1 diabetes will still need to self-manage their illness, a closed -loop system with data acted on by the users could reduce the burden (29).

We chose to employ an inductive case study to focus on the dynamics of the patient–professional partnership shaped through an ICT intervention used in practice for the management of type 1 diabetes, namely an AP system. The case study was applied to answer the research question: *How does ICT enable the partnership between health care professional(s) and the patient in chronic disease management?*

Methods

Study design

We conducted an inductive case study and held in-depth interviews with both health care professionals and patients on their use of the AP system (30). This case study looks in particular into the dynamics of the professional–patient partnership and between different health care professionals, the patient experience, and how introducing ICT enables a person-centred approach to diabetes care.

Case study
We used as a case an AP system, that at the time of the study was only tested in the Netherlands. The system automatically controls the blood glucose level of patients with type 1 diabetes, and provides the substitute functionality of both insulin and glucagon delivery of a healthy pancreas. The AP system maintains the blood glucose levels in the healthy range most of the time, without restrictions with respect to factors such as diet and exercise.

The development of the person-centred AP system was started in 1994 in the Netherlands by a person who himself had been diagnosed with type 1 diabetes. His motivation for inventing a semiautonomous AP was driven by his dissatisfaction with the diabetes care treatment and the support provided with products and software applications. He started a company to develop the AP in an iterative manner, involving the users in the different steps of its development. The AP system has been described in detail by Blauw and the research group *Portable bihormonal Closed Loop for Diabetes* (31).

Device characteristics
The wearable AP integrates the following features into one device: (i) continuous glucose monitoring (CGM); (ii) glucose control algorithms (decision-making processor); (iii) infusion pump and (iv) other sensors (see figure 5.1).

The control unit (i+ii) replaces human decision-making and makes more frequent dose adjustments than a person could. The AP device transmits data to a database that is accessible via a portal (v) featuring web services for monitoring. The functions of the bihormonal AP (both insulin and glucagon) were tested with persons with type 1 diabetes in home treatment; the results indicated that the AP provided better glucose control than traditional insulin pump therapy and that the treatment is safe (32). Related studies also indicated that patients anticipate that they will accept the device (33) and that for further technical development it will feature adaptive control (34).

Participants
The participants were selected in the Netherlands via a combination of purposive and snowball sampling. With purposive sampling, we initially selected two types of participants, persons with type 1 diabetes and health care professionals

who had used the AP and would potentially be able to provide rich, relevant and diverse data pertinent to the ICT enabling of the partnership (35,36). Subsequently, through snowball sampling—in which interviewees identified further participants—we recruited both persons with type 1 diabetes and health care professionals (medical specialists and trained diabetes nurses) with knowledge relevant to the case study, and a policy advisor.

We approached the participants via telephone, email and/or face-to-face. We sent an information letter by email with an introduction to and information about the case study, and an invitation to participate. The principal researcher introduced the study orally, stressing the person's right to make their own choice to participate.

We interviewed 12 Dutch participants: six persons with type 1 diabetes, five health care professionals (two medical specialists; one paediatrician-endocrinologist and one internist-endocrinologist, three diabetes nurses), and one policy advisor from the Ministry of Health, Welfare and Sport was included because of his experience with the embedding of the AP in the health care context.

Four attempts to recruit specific participants were rejected. One participant indicated he was too busy while the other reasons for non-participation were that the participants (2) were not familiar with the AP or the subject was too sensitive (policy maker).

Patient and public involvement

The study was designed to understand the perspectives of the participants to gain access to their experiences, feelings and preferences with the use of an AP, of patients diagnosed with type 1 diabetes and others (37). The research question was developed in an iterative manner, and based on patients' and health

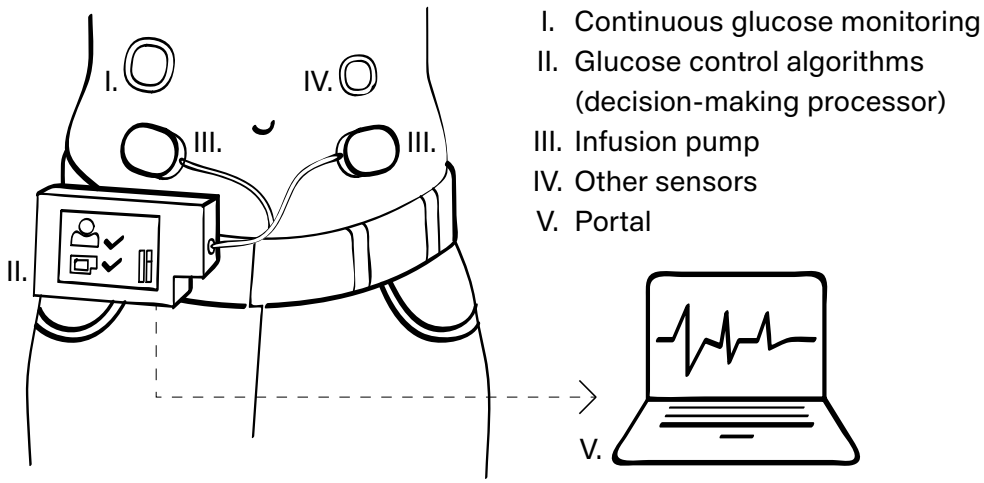

Figure 5.1 Components of the artificial pancreas system

care professionals' insights. The AP was chosen as a case study since it was a patient-driven innovation, developed by a person who was diagnosed with type 1 diabetes himself. Patients were involved in the different phases of the study, and recruited through snow ball sampling, in which participants also supported in recruiting (other) patients.

Data collection

We held in-depth, semi structured interviews with the participants. These interviews were guided by an interview protocol, with questions focusing on the overall experience with AP in clinical practice and how the AP supported and changed the professional–patient partnership in diabetes management. The interview protocol was provided in Dutch, and is available on request.

The first author conducted the interviews via telephone/Skype or FaceTime, either at home or at work. One participant was known from a previous study. No non-participants were present during the interviews. The interviews were conducted between February and April 2017. The interviews lasted between 47 and 73 minutes. Participants were recruited until no new knowledge was gained (data saturation) (38). No repeat interviews were conducted. The researcher audio-recorded the participants and took notes. We transcribed all interviews. We anonymised the data and allocated alphabet capital coding to each participant.

Analysis

In this study, we used thematic analysis to identify patterns within the data, and grouped them under codes, categories and themes, whereby we particularly sought to identify how ICT supported the partnership in diabetic/chronic disease management (39). The first two authors analysed the data in an iterative process of coding and use of NVivo software, V.12.2.0.

We started with a line-by-line coding that was derived from the research question. We processed the coding by reading and analysing the data—in which we preserved (inter-)actions using as many gerunds ('ing') as possible (40). The first and second authors reviewed the codes. After that, through focused coding, we organised and grouped the coded data that shared characteristics into categories.

In this phase, we left out codes that did not contribute to answering the research question from further analysis (such as data on specific treatment for children). We then moved to the process of theoretical coding—in which we clustered the categories into themes—to build a theoretical framework.

Ethical considerations

The study was approved by the researchers' host institute. All participants, prior to the interviews, agreed to participate. Participation was voluntary and participants could withdraw at any point. The research complied with the Helsinki Declaration of the World Medical Association (2013). In our sample design, we excluded the participation of vulnerable groups. The topic of our study was not sensitive. The researchers did not use or have access to personal information or datasets; they also neither collected nor used bodily material. All personal information was de-identified. We did not ask participants for private information or

experiences. The quotes chosen were sufficiently general to preclude identification of individual participants.

Results

Our analysis yielded three themes of ICT-enabled PCC towards diabetes management resulted from our analysis: self-managing the disease (I); shared analysing of (medical) data (II) and experiencing the partnership (III) (see the theoretical framework in figure 5.2).

These three themes were based on five categories that shared characteristics resulting from ten codes originated from the research question.

Self-managing the disease
The theme self-managing the disease indicates that the use of the AP system contributes to a substantial increase in *quality of life* thanks not only to the

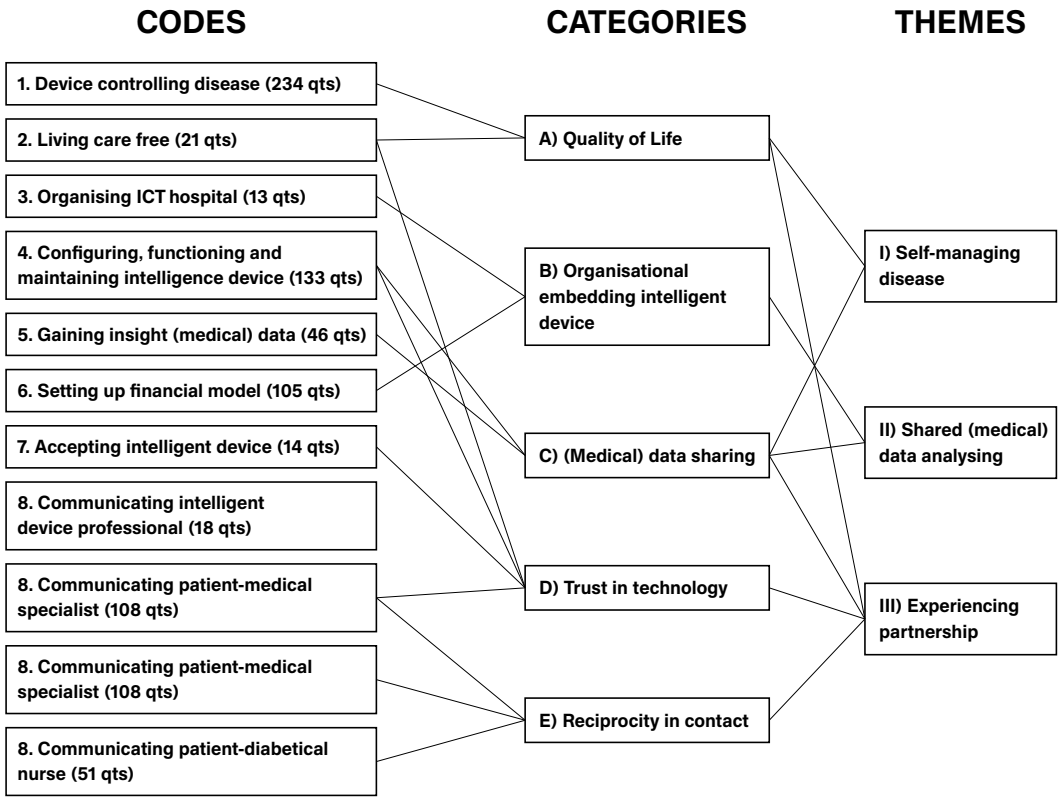

Figure 5.2 Theoretical framework of ICT enabling partnership in person-centred diabetes management. ICT, information and communication technology.

device, which takes over control of the disease (234 quotes), but also insights based (medical) data (46 quotes) that is linked to the new activity of *(medical) data sharing* (see figure 5.2).

Quality of life
Users of the AP system commonly mentioned (21 quotes) that the ICT application offers the next level of treatment for persons with diabetes, enabling carefree living that adds to their quality of life.

'If you do not have to measure five times a day, but you can just let the device do its job, that's a huge improvement for me. [...] That may seem like a very small thing for healthy people, but it is, when you have diabetes, a huge boost to your quality of life, enabling you to lead a 'normal' life.'
(person with diabetes D)

This increased quality of life is linked to the technological advancement of the AP system that takes over the activities of controlling the disease through continuously sensing measurements and algorithms. The AP semiautomates the management of diabetes by monitoring the condition and regulating the insulin and glucagon supply accordingly, giving the patient new data overviews to manage his or her condition.

(Medical) data sharing
What will change the partnership is the self-management of diabetes, which is enriched through the sharing of (medical) data among medical specialists, diabetes nurses, patients and the intelligent device professional.

'I have given permission to my diabetic nurse to look into my data. How often do you do that? Well, if I go through a period of an illness, like the flu, then maybe every week. If things go well, maybe once every two months.'
(person with diabetes D)

The introduction of the intelligent device (AP system) initiates a constant flow of (medical) data—physiological measurements and personal data—that is accessible through a portal (see figure 5.1). The new activity of (medical) data sharing is fuelled by gaining insight into (medical) data. If we stand back, we can see that the presence of an intelligent device professional changes the partnership between the health care professionals and the person with diabetes. Thus, the introduction of ICT could enable the (experience of the) partnership and the self-management of a disease, but it also introduces new demands on health care professionals, including the provision of ICT (device) support.

Shared analysing of (medical) data
The second theme, shared analysing of (medical) data, reveals the new activity in the partnership of *(medical) data sharing* when the ICT device is *embedded in the organisation* (see figure 5.2). This sharing of (medical) data relates to the

configuring, functioning and maintaining of the device (133 quotes) and the insights in (medical) data gained through the device (46 quotes). A diabetic nurse described the data sharing as follows:

'So, you can watch the person over distance. But it is not our intention to watch patients 24/7.'
(diabetic nurse C)

For an eHealth service enabling the partnership, both health care professionals and patients need to be supported by intelligent device professionals. To enable both patients and the health care professional(s) to share data from the AP and to gather data and then to store, retrieve and analyse it, the technology and its data must be embedded in the organisation (see figure 5.2).

'And of course you should also start looking at your organisation again. How do you organise this? A lot is already done digitally in the hospital, but this does not link with our system. And this type of support from the hospital has not been allocated any funding yet. So, yes, there will also be stuff that has to do with the embedding [of the device] in the organisation.'
(diabetic nurse C)

Experiencing the partnership
How the partnership is experienced is based on the reciprocity in contact, the trust in technology, (medical) data sharing and the quality of life (see figure 5.2).

Reciprocity in contact
Reciprocity in contact is linked to how the person with diabetes communicates with his or her medical specialist (108 quotes), diabetic nurse (51 quotes) and the intelligent device professional (18 quotes), and the other way around.

'We will head towards more equal care, I think. At least, if the patient wants that too.'
(medical specialist B)

The AP technology in use revealed different intensities of how the partnership was experienced by both the patient and the health care professionals. On the one hand, the interviewees foresaw a change in the moments of contact with the medical specialist.

'Once the AP system is well integrated into health care – I do not have the illusion that it heals people – the treatment is such that medical specialists can provide far less guidance [to patients].'
(person with diabetes A)

On the other hand, they expected that the partnership with the diabetic nurse would become more intensive, as was already experienced with the insulin pump:

'You actually see that when you make the switch from syringe to pump. Then suddenly the contact with the diabetic nurse becomes much more intensive and more accessible and then you can suddenly call out – side office hours.'
(person with diabetes B)

Diabetes nurses anticipate a change in the partnership with the person with diabetes as a result of implementing the AP.

'I tell my patients they do not have to come see me every 3months when there is no direct need. What matters is that the person with diabetes is doing well and if that is the case, I do not see what I could improve.'
(diabetic nurse B)

The initiative for treatment can thus be initiated through the data instead of through existing care pathways. The fear that health care professionals would become unnecessary is baseless:

'In the case of the artificial pancreas, I do not expect that suddenly a whole group of health care professionals no longer have to come to the hospital be – cause the technology takes over. They have enough other things to do.'
(policy maker)

The findings also reveal another role in the partnership, namely the communication with the intelligent device professional (18 quotes) with whom patients or the health care professionals communicate about the technical part of the AP.

'If you do not have a psychological problem and if your diabetes does not bother you, if your parameters are all right and well-regulated through the AP system, you see each other less often so the consultation is purely problem-oriented. When it is a technical issue, then the device is at fault and you contact the AP professional. The partnership will change towards shorter duration and interventions. If it is not going well, what is going on?'
(medical specialist B)

How the partnership is experienced depends also on the configuration, functioning and maintenance of the intelligent device (133 quotes). When the person with diabetes checks the ICT technology (verifying that it has enough insulin and glucagon, the battery and sensors are OK, etc), and he or she notices that the system is not working properly, then communication with the intelligent device professional (18 quotes) is necessary to make sure that the device is technically in working order.

Trust in technology
The experience of the partnership, supported through ICT, was also connected with the category of trust in technology (see figure 5.2). The trust in technology was vividly described by one of the patients:

'You are busy with the management of diabetes all day. If that is no longer the case, and you have trust in the technology to take over the management of the disease and that you do not have to think for yourself anymore; that gives a lot of freedom.'
(patient B)

Trust in technology is related to the feeling of care – free living (21 quotes), the configuring, functioning and maintaining of the intelligent device (133 quotes), the acceptance of the intelligent device (14 quotes) and communication with the intelligent device professional (18 quotes).

(Medical) data sharing
The sharing of data has influence on how the partnership is experienced, and how patients communicate with health care professionals. However, the AP does not cure the disease so yearly check-ups will still be necessary.

'Look, the patient still has to see his medical specialist every year. He remains responsible and needs to check certain parameters. That still has to be done because the patient still has diabetes. Even if the patient is doing well, he or she is not cured.'
(diabetic nurse B)

Both health care professionals and patients foresee that the self-management options ushered in by the AP system will result in a change in the partnership.

Quality of life
The outcomes expose that the experience of the partnership is linked to the quality of life, which increased when the intelligent device took over the daily controlling of the disease and reduced the feeling of stress involved in self-managing diabetes (see figure 5.2).

'The most important thing for patients is that they do not have to be busy with their condition all day long. So, a bit of freedom and being able to enjoy a cup of coffee without having to do all kinds of measurements and so forth. For the simple things that are important for daily life. That is the benefit of the artificial pancreas.'
(person with diabetes A)

Or as a medical specialist framed it:

'If you still want to get a lot out of this life as a child, adolescent, young or older adult, you obviously gain a lot when using the AP. It is just great if you do not have to think about diabetes all the time.'
(medical specialist A)

The AP replaces human decision-making, which the participants experience as carefree living because they no longer have to make dose adjustments all the time.

How persons experience the partnership varies in extent from patient to patient, but patterns can be discerned. At one end stands the person with diabetes who completely trusts the technology, allowing to take over the function of the pan-

creas and automatically manages the glucose levels. Such a person thus feels that he or she no longer requires the help of a medical specialist. At the other end stands the person with diabetes who just wants his healthcare professionals to take over. Therefore, the interaction between the technology and social components must also be considered (see figure 5.3).

The introduction of ICT simultaneously changes the partnership interaction between health care professionals and persons with a chronic condition, strengthens the interests of the patient (self-managing the disease) and yields precise analysed data on the clinical phenomenon (see figure 5.3).

Discussion

Principal findings

The aim of our study was to answer the research question: How does ICT enable the partnership between healthcare professional(s) and the patient in chronic disease management? Building on the analysis of in-depth qualitative data, this inductive study has revealed three interrelated themes of ICT-enabled PCC towards diabetes management namely self-managing the disease, shared analysing of (medical) data and experiencing the partnership. We found that ICT yielded new activities of data sharing and a new role for data professionals in the provision of care as well as contributed to carefree living thanks to the semiautomated management enabled by the device. Our data suggest that to enable the partnership through ICT, organisational adjustments need to be made such as the development of new ICT services and a viable financial model to support these services.

In a recent study, it was concluded that ICT offers a viable environment to deliver PCC through ICT for patients with chronic conditions (8). However, to maximise the potential of ICT to enable patients to manage their condition, there is a need to integrate PCC principles into ICT and its organisation. These principles have been worked out in determining the preconditions for ICT-enabled PCC (7). Our study adds to the existing knowledge base with its finding that developing PCC preconditions to enable chronic disease management is just one step, and that the three defined themes are another input for ICT-enabled PCC-principles towards chronic disease management.

The introduction of a new theoretical framework provides insight into the dynamics of how the partnership between health care professionals and persons with a chronic disease is enabled through ICT in chronic disease management of diabetes (see figure 5.2). The three themes entail reordering the partnership between the person with diabetes, the internist, the diabetic nurse and the intelligent device professional. Thus, the partnership interaction between health care professionals and persons with a chronic condition simultaneously changes the partnership, strengthens the interests of the patient (self-management) and yields precise data on the clinical phenomenon (see figure 5.3). This multinodal system is more complex than either the patient–technology or patient–professional relationship alone. Therefore, the outcomes are less pre-

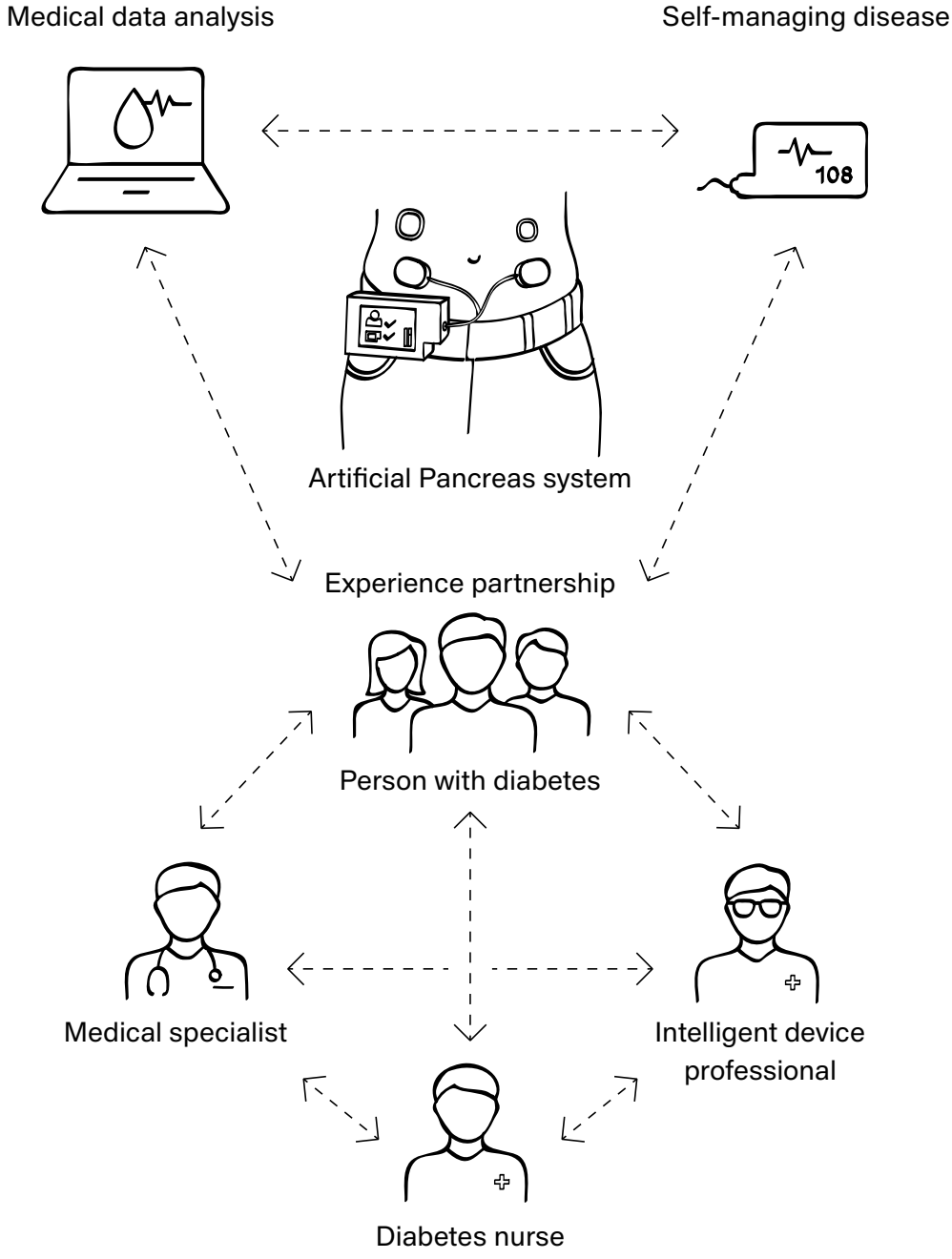

Figure 5.3 Partnership enabled through ICT (Artificial Pancreas system)

dictable and neglecting to consider the variation in the reactions of patients to the now more complicated entry points into the professional system, which can also lead to overestimation of the potential of disease self-management.

Over the last years, a growing body of scholarly work has been focusing on the use of (semi-)automated devices for diabetes management (14,15). The results of, for example, CGM systems and automated insulin delivery systems are promising in showing the benefits for type 1 diabetes by improving glycaemic control through personalised models of predictive control (17,18). Furthermore, researchers have demonstrated the safety and feasibility of different AP systems in clinical research settings and more recently in outpatient 'real-world' environments (20,21). In addition to these feasibility-focused and efficacy-focused studies on (semi-)automated devices for diabetes management, also the *experiences* of patients using these type of devices have been studied. A previous study on perspectives of experienced users of hybrid closed-loop systems among people with diabetes reported how context-level, system-level and person-level factors influenced patients' trust in an AP system (41). Tanenbaum et al (2017) concluded that when patients lacked trust in the system, they made an attempt to override the system, while trusting the system decreased stress and also decreased self-management burdens, which in our study was described by the participants as carefree living.

Additionally, a recent study highlighted the findings that acceptance of an AP system depends more on a stronger bond of the users with product characteristics (such as usefulness, complexity and compatibility) than technology readiness (such as innovativeness and insecurity) (42). However, the researchers also concluded that the results differed between self-selected and invited persons, so researchers and product developers should be cautious when relying only on self-selected persons in the design, testing and development of AP systems. While the experiences and acceptance of AP systems have been the focus of some studies, further research directions on patient experiences will yield a better understanding what factors influence the acceptance of such automated technology. Our study suggests to take the health care professional–patient partnership into account as one of the factors that affect the acceptance and the use of AP systems.

Strengths and limitations

The strength of the inductive case study approach is that we were able to gain detailed insight into how the characteristic of the partnership changed between a person with type 1 diabetes and the health care professional(s) as a result of the use of ICT. A case study enables the creation of a comprehensive theoretical framework built on the details of a particular case (30,43). The development of this theoretical framework increases the understanding of person-centred health care and ICT-enabled health services that can have implications for practice (44).

Through qualitative research, we delved into the anecdotal evidence of the interviews and used coding to show commonalities in the changes that the interviewees expected, through which we were able to build a framework that broadens the scope of evidence-based medicine; good evidence goes further than the results of meta-analysis of randomised controlled trials (45).

We also acknowledge limitations of the study. Our findings should be considered in the context of our study design. One of the inclusion criteria to participate in the study was experience with an AP system. This system was tested as part of a separate trial during which the participants were closely monitored by clinical researchers. The use of the system was reduced to a relatively short duration. Therefore, the results may not be generalised to other AP systems nor to a long-term use of the system on a larger scale.

Furthermore, to study the partnership between patients and health care professionals in chronic disease management, we chose an ICT application—the AP system—that is still under development and was not as yet available on the market during the research period. However, since our focus is neither on the technology itself nor its acceptance, but on the enabling of the partnership, the case study does add to our knowledge on ICT in partnership and service provision based on digital health care applications.

Implications for practice and research

In order for ICT to take over the burden of self-managing disease through shared (medical) data analysis, it is necessary to embed ICT services and professions in the health care organisation. The introduction of ICT introduces new demands on health care professionals and patients, influencing how the partnership is experienced.

In addition, when introducing ICT in a health care context, the technology should be studied as part of a dynamic and networked health care environment, the so-called 'fourth-generation studies' (46) and should take a participatory development approach to guide the development, implementation and evaluation of eHealth technologies and interventions (47). Our study suggests that these types of studies should also include a focus on the partnership and how this is reshaped by the introduction of ICT. The results of our study show that to support the partnership in a sustainable manner, ICT needs to be embedded in health care organisations. As a result, the care pathways also need to be redesigned so we can move towards person-centred chronic disease management, offering treatment 'when needed, where needed' based on the availability of rich data generated by an ICT system.

Previous research has pointed to the fact that human connectedness provides the necessary conditions for communication and cooperation on which formal relations of partnership can be constructed (1,3). Our study shows that introducing an ICT-enabled PCC solution structures an integrated form of professional–patient connectedness. The self-management of the disease, but also the analysis of (medical) data and the experience of the partnership, shift the focus of professional–patient connectedness from the medical specialist to the diabetic nurse. New roles take shape such as the one of the intelligent device professional, and a different network will (have to) evolve around the patient. One of the lessons could be that it becomes more important to look at the personal progression of the disease in addition to following the existing rigid care pathways.

The expected changes in the role of health care professionals as a result of introducing ICT-enabled PCC towards chronic disease self-management must be addressed with the design of a new care model integrating the changing

partnership. The next steps should be to study how to design care models that fit this changing partnership as a result of ICT-enabled PCC, and how a sustainable financial model should be determined for ICT-enabled person-centred chronic disease management.

Conclusion

The management of diabetes through ICT requires an adjustment of the partnership between persons with the chronic condition and the health care professional(s) in such a way that the potential for self-managing the condition by analysing the newly available (medical) data (from the intelligent device AP system) together leads to an experience of partnership between patients and health care professionals.

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Competing interests
None declared.

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Chapter 6
General discussion and conclusion

We started this thesis by describing an example of Information and Communication Technology (ICT) that was designed to support both the patient and the health care professional in health care practice. The example was mentioned by one of the participants in an interview held for our study and involved giving health care professionals a tablet during ward rounds to enable them to exchange information with patients and to stimulate shared decision-making. In practice, however, health care professionals barely used the technology to interact with their patients. For several reasons, the technology was not used the way researchers had anticipated.

ICT offers ways to provide more personalised and accessible care to patients that is supported digitally, remote, and improves the quality of care and clinical outcomes (Ledel Solem et al., 2019; Talboom-Kamp et al., 2018; Hanlon et al., 2017). However, even though previous research has focused on the introduction and implementation of ICT in health care settings, a remarkably limited number of ICT interventions continued beyond the research and development phase (Ross et al., 2016; Van Gemert-Pijnen et al., 2011; Broens et al., 2007; Obstfelder et al., 2007), at which point they could fully exploit ICT's potential to support chronic disease management.

6.1 Integrating PCC-principles into ICT

At the beginning of this thesis, we argued that integrating the principles of Person-Centred Care (PCC) into (the design of) ICT interventions could maximise its potential. These principles are based on the PCC-approach that encourages and empowers patients to actively take part in their care process by building a collaborative partnership between the patient (person expert) and the health care professional (care and treatment expert) (Ulin et al., 2016; Ekman et al., 2012). Since research is particularly scarce on how ICT enables a person-centred approach to care, our study connected the concepts of ICT and PCC in the context of chronic disease management. Our study was guided by the overall research question: *How does information and communication technology support patients and health care professionals in chronic disease management in a person-centred approach to care?*

The preceding chapters demonstrated various aspects of how ICT supports patients and health care professionals in chronic disease management in a person-centred approach to care. We encountered these aspects while conducting qualitative research based on *literature* (chapters 2 and 3), and on *practice* (chapters 4 and 5). In order to answer the overall research question, we asked several sub-research questions. The results of our research are brought together in four empirical papers - that form the base of this thesis - in four different chapters, each answering one of the sub-questions.

6.2 Aspects of ICT-PCC

To determine the extent, range and nature of existing ICT-PCC interventions, we scoped the field of ICT-PCC by answering the sub-question: Which ICT interventions have been used to support patients and health care professionals in PCC-management of chronic diseases? (Chapter 2) In the next step, we conducted qualitative, systematic research to answer the sub-question: What are the preconditions of ICT-enabled PCC in chronic disease management? However, we also found that the preconditions of ICT-enabled person-centred care did not always come to pass in practice (Chapter 3). Since we were interested in how technology supports a person-centred care approach in practice, and how the users interact with technology, we applied an affordances lens to answer the sub-question: How does ICT-PCC afford the partnership in health care practice between patients and health care professionals towards chronic disease management? (Chapter 4). The affordances lens integrated, enriched, and extended our insights on preconditions. Finally, we analysed the fit between Information and Communication Technology-enabled Person-Centred Care (ICT-PCC) and the support for the patient-health care professional partnership in practice through a case study, to answer the sub-question: How does ICT enable the partnership between health care professional(s) and the patient in chronic disease management in health care practice? (Chapter 5)

In this concluding chapter, we discuss the principal findings of our study, and we propose future research to broaden evidence-based knowledge on ICT-PCC. We connect our results to the scholarly literature on ICT and person-centred care, and link the research fields of Social Science and Medicine (SSM) and Information System Research (ISR), thus expanding our knowledge on how ICT-PCC interventions support the patient-health care professional partnership. ISR seeks to analyse the impact of information technologies and the influence of the design, management, use, and valuation of information technologies, while SSM focuses on social-science research on health.

6.3 Principal findings

First of all, we concluded that hardly any of the ICT-PCC interventions examined in our studies addressed all three routines of PCC activities identified by Ekman et al., (2011): Initiating the partnership (patient narratives), working the partnership (shared decision-making), and safeguarding the partnership (documenting the narrative) (Wildevuur et al., 2015). This marks a lack of consideration for the patient-health care professional partnership in (the design of) ICT-PCC interventions, which increases the chance that ICT interventions are mismatched with the needs of the user(s), and that the technology ends up lacking meaning for both patients and health care professionals in practice. On top of that, ICT interventions for health care purposes are regularly designed and developed for – rather than with – their intended users. We suggest that studies on the impact of eHealth should also include a focus on how the crucial patient-professional partnership, which is foundational to modern medicine, is 'reshaped' by the introduction of ICT.

Secondly, based on a comparative analysis of thirteen scientific studies on ICT-enabled PCC-interventions for cancer treatment we distinguished four user-related preconditions of ICT-enabled PCC, namely (shared) decision-making, personalised ICT, health-related quality of life, and efficiency. We argue that, together, these preconditions strengthen the partnership between the patient and the health care professional in ICT-PCC (Wildevuur et al., 2017). We opted for the term preconditions because it best describes the necessary 'building blocks' for ICT-PCC. Identifying preconditions for ICT-enabled PCC is an important step in improving the design and development process of technology to better support the partnership between the patient and the health care professional in chronic disease management. In addition, we also revealed a discrepancy between *intended* and *reported actual outcomes* in terms of realising person-centred care through ICT, as it turned out that the intended outcomes of ICT-enabled person-centred care did not always come to pass in practice.

Therefore, in addition to determining the preconditions for ICT-PCC, we also studied how ICT-PCC interventions *afford* the patient-professional partnership in health care *practice*. We answered this question in a study on the practice-based experiences with ICT-enabled PCC to support the patient-professional partnership towards chronic disease management, which we conducted in both Australia and the Netherlands. We distinguished four affordances of ICT

that support the patient-professional partnership, namely: facilitating data collection and sharing, consulting where and when needed, using intuitively, and strengthening the care relationship. Based on our findings, we suggest expanding the preconditions for ICT-PCC by also including the affordances of ICT-PCC interventions when developing and designing ICT-PCC interventions if we are to reach the full potential of ICT-PCC.

Based on our research, we also concluded that applying ICT to support chronic disease management in a person-centred way changes the relationship between health care professionals and patients, strengthens the interests of the patient (self-management), and yields precise data on the clinical phenomenon in question (Wildevuur et al., 2019). This multinodal system is more complex than either the patient-technology or patient-professional partnership alone. Because of this complexity, the outcomes of ICT interventions are difficult to predict in advance.

Finally, over the course of our study into ICT and PCC, the concept of partnership – which forms the basis of person-centred care – became gradually more important. When developing and designing eHealth interventions, emphasis should be put on supporting the patient-professional partnership, which can be achieved by building and maintaining a relationship between the patient and the health care professional, or to put it differently: relationship is the medium to partnership (Suchman et al., 1998, p. 30). We distinguished various aspects (preconditions and affordances of ICT-PCC interventions, for example) that help support the patient-professional partnership within eHealth interventions. We found that the patient-professional partnership is ignored in the design of most ICT interventions, and that interventions benefit when this partnership is strengthened, and vice versa.

6.4 Contribution and discussion

With our study, we built not only on studies on person-centred care (Naldemirci et al., 2018; Wolf et al., 2017; Ekman et al., 2011), but also added a new field of research that combines person-centred care with Information Communication Technology for health care purposes, which we coined Information and Communication Technology-enabled Person-Centred Care (ICT-PCC) (see Figure 6.1). In this thesis we made two theoretical contributions. First, we distinguished preconditions and affordances of ICT interventions that enable a person-centred approach to chronic disease management. When developing and designing information and communication technology the preconditions and affordances combined are of help to realize ICT interventions that truly support patients and health care professionals in a person-centred approach towards chronic disease management. Our analysis of preconditions and affordances builds on scholarly research on the explanantion of failures and successes of technology-supported programmes (Greenhalgh et al., 2018), the organisational, social, political and policy context of introducing ICT in health care practice (Greenhalgh et al., 2016), and the plead for a more holistic framework to Improve the uptake and impact of eHealth technologies (Van Gemert-Pijnen et al., 2011).

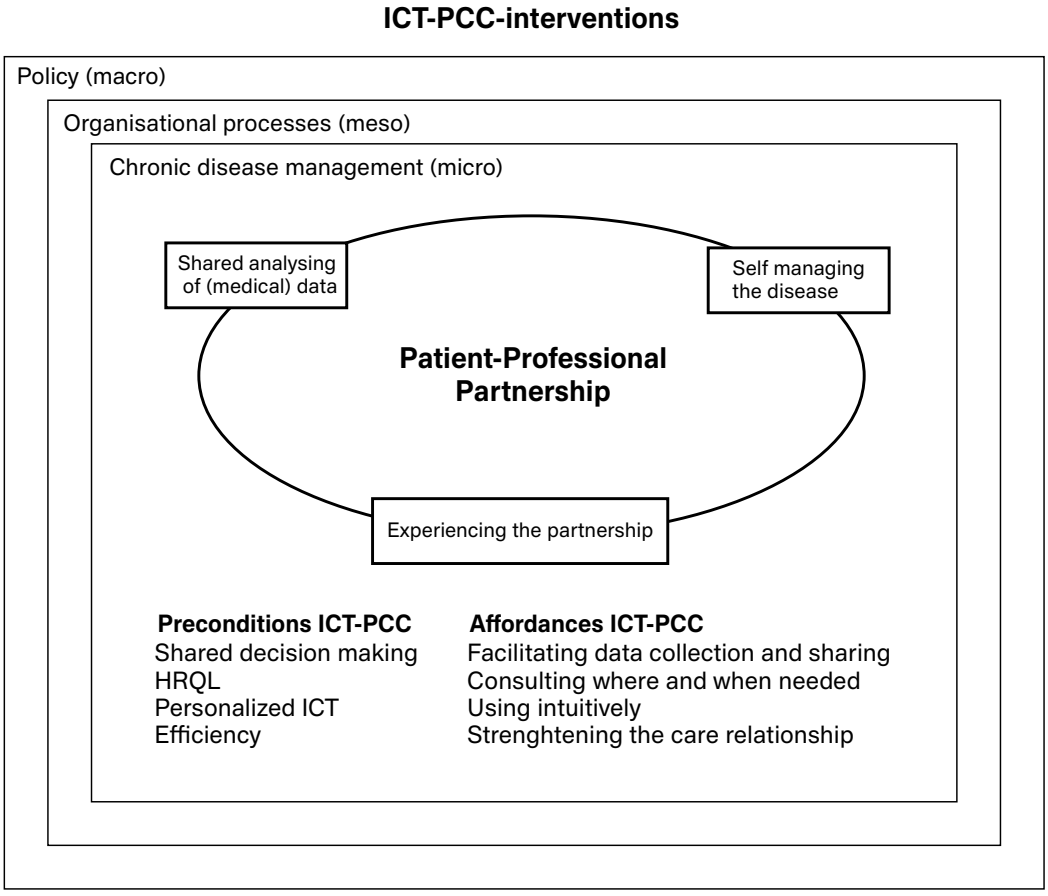

 Figure 6.1 Ecosystem of ICT-enabled PCC

We expanded the knowledge on person-centred care and on how ICT supports the patient-health care professional partnership by drawing on a technology affordances perspective (Mettler et al., 2017; Majcharak et al., 2016; Faraj & Azzad, 2012; Leonardi et al., 2011). Affordances describe the possibilities for action created in the interaction between technology and its user (Gibson, 1977) and therefore take into account the condition of geographical distance, since we know that 'distance matters' for the patient-professional relationship (Oudshoorn, 2011). The perspective of technology affordances is well suited to supporting the analysis of ICT-PCC use in health care as a useful means by which to analyse the interaction between the intended and actual use of ICT (Abrishami, Boer, & Horstman, 2014; Strong et al., 2014).

The affordances perspective helped us to understand how ICT afforded the support of the *partnership* between patients and health care professionals in *practice*. These insights are of great added value and help refine our knowledge about the mismatch between the intended use and actual outcomes of eHealth (Granja et al., 2018; Heckemann et al., 2016). By looking at technologies as sets of affordances and constraints for particular actors, we extended the knowledge on how and why the 'same' technology is used differently or has varying outcomes across contexts, thus deepening and enriching existing theories (Majchrzak et al., 2016).

Second, we contributed to the fields of Social Science and Medicine and Information System Research with qualitative studies on ICT-enabled PCC. Studies on person-centred care add to social science and medicine discourse by describing PCC as a systematic approach to disease management that encourages and empowers patients to actively participate in their care process by building a collaborative patient (person expert) - health care professional (care and treatment expert) partnership (Ulin et al., 2016; Ekman et al., 2012). Our study focused on the routine that Ekman et al., (2011) described as 'working the partnership'. We extended the knowledge on the professional-patient partnership within person-centred care and specifically on the aforementioned routine by conceptualising ICT-PCC and how it affects the patient-professional partnership in chronic disease management.

With our study, we refined the knowledge in the field of Information System Research by expanding our understanding of the relational aspects of introducing technology in an organisation and by explaining how ICT supports the partnership between patients and health care professionals towards chronic disease management in health care organisations in particular. By doing so, we respond and contribute to the discussion within Information System Research on the consequences of introducing ICT in organisations and the changing roles and patterns of (social) interaction (Sergeeva et al., 2017; Leonardi & Vaast, 2016; Majchrzak et al., 2016; Faraj & Azad, 2012). These debates posit that technology is shaped by its users, who employ particular technologies in specific contexts (Orlikowski et al., 2000), with more recent research focusing on the relational view of the introduction of technology into organisations by taking user intentions into account (Leonardi & Vaast, 2016).

Increasingly, research in the field of ISR has focused on how technology is used in practice (technology in practice) and the motivations for adopting ICT interventions (Al-Natour & Benbasat, 2009). Moreover, it is well recognised that

integrating ICT ushers in significant organisational changes (Sergeeva et al., 2015; Faraj & Azad, 2012; Fayard & Weeks, 2007). While there has been a lot of interest in research focusing on changes in organisations due to the implementation of ICT, research on the impact of technology on a more relational level - such as on the partnership between patients and professionals - still remained limited. Our results extend the findings on the importance of the social component of technology (Heckemann et al., 2016: Chambers et al., 2012; Kilduff & Brass, 2010) by determining the preconditions for ICT-PCC interventions and expanding the knowledge on how ICT-PCC affords the support of the patient-health care professional partnership in chronic disease management, and how the patient-professional partnership is actually supported (or not) in health care practice.

Within ISR, we focused specifically on the paradigm of design science research (DSR), which seeks to grow technology and science knowledge bases by creating innovative artefacts that solve problems and improve the environments in which they are instantiated; the field of health care offers many opportunities for the use of DSR (Hevner & Wickramasinghe, 2018). Our study advanced design science research by expanding insight into how ICT-PCC interventions might be developed and designed to maximise the support provided by ICT for chronic disease management to the partnership between patients and health care professionals.

Finally, our study built upon the knowledge that when ICT is introduced in a health care context, the technology should be studied as part of a dynamic and networked health care environment (Greenhalgh et al., 2016). We elaborated on previous research into how people experienced using technology with regard to managing their condition (Andreassen et al., 2015; Ulucanlar et al., 2013; Nicolini, 2010). We suggested that these types of studies should also include a focus on the patient-professional partnership and how the partnership is influenced by the introduction of ICT (see Figure 6.1).

6.5 Limitations

The main limitations of each study are discussed in more detail in the separate chapters. Various limitations are linked to the methods chosen for our studies. Although our research produced detailed qualitative results on ICT-PCC, we focused only on a select number of countries. Even though the scoping review (chapter 2) included a broad range of countries worldwide, the case study (chapter 5) focused only on the Netherlands, and the study on the practice-based experiences with ICT-enabled PCC was limited to the Netherlands and Australia. So, the transferability of our findings to other countries is limited.

The results of our study are based on data related to the support of specific chronic diseases through ICT. We have chosen the five most common chronic conditions, according to the World Health Organization, leaving out the less common ones. Therefore, the results cannot be generalised to other chronic conditions, nor to the management of conditions other than chronic ones.

We argue that the four preconditions of ICT-PCC interventions (shared decision making, health related quality of life, personalised ICT, and efficiency) together can improve the (self-)management of chronic disease by strenghtening the patient-health care professional partnership, thereby enabling a person-centred approach to care. However, since we relied for this study on ICT-PCC preconditions on secondary data of a large scoping review that were not collected for the aim of this study, we may have missed relevant aspects of ICT-PCC interventions that were not described in the studies used.

Eventhough we distinguished preconditions and affordances of ICT-PCC in separate studies, time was too limited to combine the two in one study. More profound theorisation and explanation of both aspects will help bridge the gap between the intended and actual use of ICT-PCC. The ICT-PCC preconditions and affordances we described in our study provide a valuable base.

For our study, we chose to analyse ICT-PCC interventions that supported the management of chronic conditions. However, there is a large body of possible interventions and it is impossible to include all interventions in our study. In addition, we did not always know beforehand if the interventions did what they promised they would. As a result, we definitely missed out on certain ICT-PCC-interventions, or we included ICT-PCC-interventions that, ultimately, turned out not to be ICT-PCC interventions at all.

Furthermore, the results of this thesis are based on a select number of studies. Because of the limited number of studies, we run a risk of missing possible outcomes.

In the case of the Artificial Pancreas system, we acknowledge a limitation of the study. At the time of our study, the AP system was supposed to be at a more advanced stage of development, but in reality we studied an ICT-intervention that was not mature, yet. Since we were interested in how the technology supported the patient-professional partnership, however, the study was still of value.

The time available to investigate our research problem was limited, restricting the time we had to research ICT-PCC interventions over time and the number of interviewees we could include. Preferably, we would have liked to include more interviewees for the study held in the Netherlands and Australia to develop a theoretical framework of ICT-PCC. Since the gathered data are based on a small group, our conclusions on how ICT shapes the patient-health care professional partnership in health care practice towards chronic disease management must be tentative. Despite this limitation, a strength is that the perspectives of both health care professionals and patients and the professional-patient partnership have been examined, thus providing more findings for the relatively new field of ICT-PCC.

6.6 Practical and managerial implication

Introducing eHealth interventions does not simplify collaboration within health care (Bjørkquist et al., 2018). The use of ICT for health care purposes raises barriers to the collaboration between health care professionals and pa-

tient and affects their relationship (Graves et al., 2018). We showed that introducing technology does not only lead to new requirements for organisations, but also for health care professionals and patients, since ICT influences how the patient-professional partnership is experienced. When embedding ICT-PCC in health care organisations, several features of ICT-PCC must be taken into account, namely the fact that ICT takes over the burden of self-managing the disease, increases sharing of (medical) data analysis – which must be facilitated by ICT services and professionals, and influences the patient-professional partnership.

So far, the actual changes in the *patient-professional partnership* brought about through ICT have remained largely unaddressed in research (Dedding et al., 2011). Therefore, we distinguished the *actual* support of the patient-professional partnership as a consequence of implementing ICT in health care practice from the *potential* support, thereby extending existing knowledge about ICT-PCC. This knowledge is not only relevant for health care practitioners, but also for the developers and designers of ICT interventions.

Moreover, the knowledge is relevant for policymakers, who are tasked with dealing with the increasing pressure on health care systems. ICT is seen as one of the solutions to reduce this pressure, and the investments in eHealth interventions are enormous, in terms of both time and money. Increased patient participation is demanded, as is reinforcement of the patient-professional partnership in the management of chronic conditions through ICT. Knowledge on the 'human touch' of the technology is insufficiently covered, and is needed for practitioners to meaningful support patients and health care professionals through ICT in disease management in health care practice.

Research has pointed out that human connectedness provides the conditions for communication and cooperation on which a formal partnership can be constructed (Ekman et al., 2011; Wolf et al., 2017). Our study shows that introducing an ICT-enabled PCC solution influences the patient-professional partnership. As a consequence of the introduction of ICT-PCC interventions, a different network will (have to) evolve around the patient and new roles will take shape for health care professionals. As Heckemann (2016) already pointed out, it is advisable to train health care professionals who work with ICT to develop their person-centred care skills.

6.7 Future research

In order to improve the support provided by ICT to both patients and health care professionals in the management of chronic conditions, we suggest the following topics for future research to help develop an evidence base for PCC and ICT for chronic disease management.

More knowledge is needed on the *actual* use of ICT interventions in practice and how they support the partnership between patients and health care professionals in particular. Drawing on the foundation we provide in this study, a next step is to combine health innovation research with research on

the design of technology-enabled health applications in a person-centred approach. Such studies should take into account the expected changes in the patient-health care professional partnership as a result of introducing ICT-enabled PCC when developing and designing eHealth solutions.

More empirical work is needed to develop and specify how the preconditions and affordances of ICT-PCC can be better integrated into the development process of ICT-PCC from design to implementation as a way of strengthening the patient-professional partnership towards better chronic disease management in practice. The ICT-PCC preconditions and affordances we distinguished in our study provide a useful starting point to this end.

We expect that persons with a chronic condition and their health care professionals will be using more and more new technologies to manage the disease, such as gaming, social media, wearable technology and robot devices. Since technology overall is becoming smaller and cheaper, the possibilities of these smart technologies are increasing, and we expect to see more of these technologies in the future. Research on ICT-PCC interventions should take these new types of technologies into account, as well as their influence on the patient-professional partnership.

Furthermore, we suggest conducting more in-depth studies into how ICT can be better integrated into the health care process as a way of strengthening the patient-professional partnership. To maximise ICT's potential as a means to enable patients to manage their condition, PCC principles should be integrated into ICT and the organisation thereof. Further insights are needed into how to implement ICT-enabled PCC in organisations and what that would mean for innovative care models, allowing us to move towards person-centred chronic disease management and offer treatment 'when needed, where needed' (Verhees et al., 2018).

Next steps should be studying how to design care models that fit the changes in the partnership between the patient and the health care professional resulting from ICT-enabled PCC, and how a sustainable financial model should be determined for ICT-enabled person-centred chronic disease management (Simonse et al., 2019). This should also include the expected changes in the role of health care professionals and the changing patient-health care professional partnership as a result of introducing ICT-enabled PCC.

Finally, we suggest a transdisciplinary approach of research for the complex field of designing and implementing eHealth interventions, which faces barriers at a micro (individual technology users), meso (organisational processes and systems) and macro level (national policy and wider context) (Greenhalgh et al., 2018). To address these challenges faced when implementing ICT interventions for health care purposes, we suggest to move beyond discipline-specific approaches. Design research could be of added value to 'design for the real world', and impose meaningul order through transdisciplinary teams (Papanek, 1971; Dorst, 2015). The whole is greater than the sum of its parts.

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Attachment Multimedia Appendix Overview of studies (n=350), qualified for inclusion

Diabetes

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Summary

In September 2019, the Dutch Cabinet named three Dutch National Icons, companies that illustrated the innovative power and diversity of the Netherlands. One of them was Inreda Diabetic, founded by Robin Koops, who has been diagnosed with type-1 diabetes. In 1994, he started the company to develop an Artificial Pancreas (AP) system, which regulates blood sugar levels for type-1 diabetics. The system was designed in an iterative manner, involving its prospective users in the different steps of its development.

Robin Koops was driven to invent such a semiautonomous AP due to his dissatisfaction with diabetes treatments and the support provided by products and software applications. He built the device and tested it on himself. The system ensures that blood glucose levels stay within a healthy range most of the time, without restrictions with respect to factors such as diet and exercise. We conducted a case study and held interviews on the development and use of the AP system for diabetes management. Effective ICT support for people with requires organisational changes such as the development of new ICT services and a viable financial model to support these services.

In *Designing information and communication technology to enable person-centred care in chronic disease management*, we state that a Person-Centred Care (PCC) approach is ignored in (the design of) most eHealth interventions, and with it the patient-professional partnership. We argue that integrating principles of PCC into Information and Communication Technology (ICT) interventions could maximize their potential. These principles are based on the PCC approach that encourages and empowers patients to actively take part in their care process by building a collaborative partnership between the patient and the healthcare professional.

ICT can help enable a person-centred approach that supports the patient-professional partnership, in which patients are involved and empowered to play an active part in their care and shared decision-making process. Vice versa, a person-centred approach to care might also benefit from ICT as an enabler to strengthen remote patient-professional partnerships.

Since insight is lacking on how ICT enables a person-centred approach to care that supports both patients and healthcare professionals in disease management, our study connected the concepts of ICT and PCC. To expand the knowledge on person-centred care and ICT, and specifically on how ICT supports the patient-healthcare professional partnership in chronic disease management, our study is guided by the overall research question: *How does information and communication technology support patients and healthcare professionals in chronic disease management in a person-centred approach to care?*

We increased the understanding of the relational aspects of introducing technology in a health care setting by explaining how ICT supports the partnership between patients and healthcare professionals towards chronic disease management. In doing so, we gave rise to a new field of research that combines person-centred care with Information Communication Technology for healthcare purposes, which we coined Information Communication Technology enabled Person-Centred Care (ICT-PCC).

We revealed a discrepancy between *intended* and reported *actual* outcomes in terms of realising person-centred care through ICT, as it turned out that the intended outcomes of ICT-enabled person-centred care did not always come to pass in practice. In our study, we distinguished four user-related preconditions of ICT-enabled PCC that, together, strengthen the partnership between the patient and the healthcare professional in ICT-PCC. In addition, we included affordances of ICT-PCC interventions during the design and development phase to help ICT-PCC reach its full potential.

We also concluded that using ICT to support chronic disease management in a person-centred way changes the relationship between healthcare professionals and patients, strengthens the interests of the patient (self-management), and yields precise data on the clinical phenomenon in question. This multinodal system is more complex than either the patient-technology or patient-professional partnership alone. Because of this complexity, the outcomes of ICT interventions are difficult to predict in advance.

Finally, when developing and designing eHealth interventions, emphasis should also be put on supporting the patient-professional partnership; interventions benefit when this partnership is strengthened, and vice versa.

About the author

The role of technology in society has always been the essence of the work of Sabine E. Wildevuur. Her focus is on transdisciplinary research; dynamic practices that are developed through collaboration between the arts, sciences and humanities, which reach beyond academia into society.

Wildevuur has an academic degree in Medicine and Communication Science (University of Amsterdam UvA, 1993). She is director DesignLab, at the people-first university of technology, University of Twente (UT). Before, she worked for twelve years at Waag|technology & society in Amsterdam, where she initiated and founded Waag's Care Lab. She set up and was in charge of numerous local, national and international innovative projects that bridged the domains of science, technology and design, specifically in the field of healthcare. In these projects the stakeholders were involved in the different iterative steps of the traject. She described the experiences on societal challenges in the field of ageing, in the book *Connect: Design for an Empathic Society* (BIS Publishing, 2013), which she co-authored. The authors covered in this book the overlapping fields of health, technology and design.

After completing her studies at UvA in 1993, Wildevuur worked several years for the weekly medical journal Medisch Contact (Royal Dutch Medical Association KNMG). During this time, she learned of and got interested in the dynamics of the healthcare field, specifically in the field of upcoming technology. Since the emergence of the Internet in 1990s, she has been involved in areas where the Internet and the medical field intersect, such as Artsennet, a website made for and by doctors. She has written hundreds of articles for the weekly medical journal Medisch Contact, specialising on (technological) innovation in healthcare.

In 1999/2000, Wildevuur was rewarded a Reuters Medical Journalist Fellowship for six months at Green College (Oxford University). After completing research on the *Internetion@lisation* of Medicine at Oxford University, focusing on the consequences of the Internet on medicine, she started to work in the field of Internet and Health Care as Editor in Chief NL of the Pan European health and care website Planet Medica, based in Brussels (Belgium).

In 2000 she founded the company Like Wildfire, specialised in Science & New Media. She worked with and for – amongst others – Academic Medical Centre Amsterdam, Doctors without Borders (MSF), Dutch Journal of Medicine (NTvG), MedicInfo (online platform by health insurance company VGZ/CZ), and the Royal Netherlands Academy of Arts and Sciences (KNAW).

In 2003, she was appointed Head of Internet Unit at the headquarters of the United Nations Environment Program (UNEP) in Nairobi (Kenya). In 2004, she started her research on collaborations between scientists and artists, in the field of medical imaging. As a result, her book *Invisible Vision: Could Science learn from the Arts?* was published in 2009 (Bohnn, Stafleu & Van Loghum). During the research for the book, Wildevuur was affiliated with the Centre for Visual Studies, University of Oxford, and a fellow of the University of Maastricht.

Wildevuur believes in the strength to disseminate knowledge on transdisciplinary research and the added value of design thinking to tackle societal challenges. Since she strongly believes in the dissemination of such knowledge, she has curated several exhibitions on the role of design in health: Designing Health (2013), Designing a Healthy Future (Dutch Design Week, 2017), and Chronic Health: If not us then who (Dutch Design Week, 2018). Wildevuur is also one of the founders of the Embassy of Health (Dutch Design Foundation).

Her drive is societal challenges, and how to tackle those. She started in April 2014 at the Graduate School of FSW with her research on the role that technology could play to support both patients and health care professionals in disease management. One of the reasons to do so was that so many eHealth initiatives died an early death. How come? One piece of the puzzle was found through the research described in this thesis.

Acknowledgements | Dankwoord

Twee jaar voordat ik mij inschreef als buitenpromovendus in 2014 aan de Graduate School van de Vrije Universiteit Amsterdam, bezocht ik de tentoonstelling *Brains: The Mind as Matter* van de Wellcome Collection aan Euston Road, middenin Londen. Een stop bij de museumwinkel – *"A great place to stretch your mind"* – toonde het portret van één van mijn grote inspiratoren Santiago Ramón y Cajal (1852-1934) op de voorkant van de uitgave *Advice for a young investigator*. Het werd mijn handboek tijdens mijn promotietraject, vol met onderstrepingen, bladwijzers en ezelsoren. Wanneer ik mij weer had teruggetrokken om me voltijds te storten op het uitwerken van onderzoeksresultaten, ging het altijd mee in mijn bagage.

Santiago Ramón y Cajal leidde mij langs de 'Beginner's Traps', introduceerde de 'Intellectual Qualities', the 'Social Factors Beneficial for Scientific Work', 'the Stages of Scientific Research' and gaf mij advies 'On Writing Scientific Papers'. Hij was niet alleen een groots wetenschapper - hij ontving samen met Camillo Golgi in 1906 de Nobelprijs in de Fysiologie en Geneeskunde voor zijn bijdrage aan neurowetenschappelijk onderzoek – maar ook een begenadigd kunstenaar.

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Beste Ab, op 22 mei 2012 gaf jij in Utrecht een presentatie over innovatie in de zorg op de bijeenkomst *Vitale Toekomst van de Nederlandse gezondheidszorg*. Jij was benoemd tot hoogleraar zorg, welzijn en politieke sturing aan de VU. Mijn onderwerp over het op persoons gestuurde wijze inzetten van technologie bij chronische ziekten sloot daar naadloos op aan. Wegens volle agenda's kon een belafspraak pas worden gepland op 15 augustus, de rest is geschiedenis. Behalve dan de volle agenda's... Ondanks de volle agenda's is het gelukt dat wij hier staan, mijn dank hiervoor.

Beste Peter, op een cruciaal moment in het proces werd jij mede-promotor. Toen ik je een van de eerste keren ontmoette in de Metselaarsgildekamer in Waag op de Nieuwmarkt, waar je je hoofd bukte voor de lage deuropening, sprak je: "Sommigen kunnen tegen mijn aanpak, anderen niet." Voor mij was het meteen duidelijk: Dat komt wel goed. Jij gaf na dat eerste bezoek aan dat je ernaar uitzag om in gezamenlijkheid met jou en de andere (co-)promotoren tot een goede en snelle afronding te komen. Peter, dank voor je steun, geduld, strengheid en recht-door-zee-mentaliteit tijdens deze periode.

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A person-centred care approach is ignored in the design of most eHealth interventions that support chronic disease management, and with it the patient-professional partnership. Information and communication technology can help enable a person-centred approach that supports the patient-professional partnership, in which patients are involved and empowered to play an active part in their care and shared decision-making process. Vice versa, a person-centred approach to care might also benefit from technology as an enabler to strengthen remote patient-professional partnerships. When developing and designing eHealth interventions, emphasis should be put on supporting the patient-professional partnership. This study adds a new field of research that combines person-centred care with information and communication technology, which is coined ICT-enabled person-centred care.