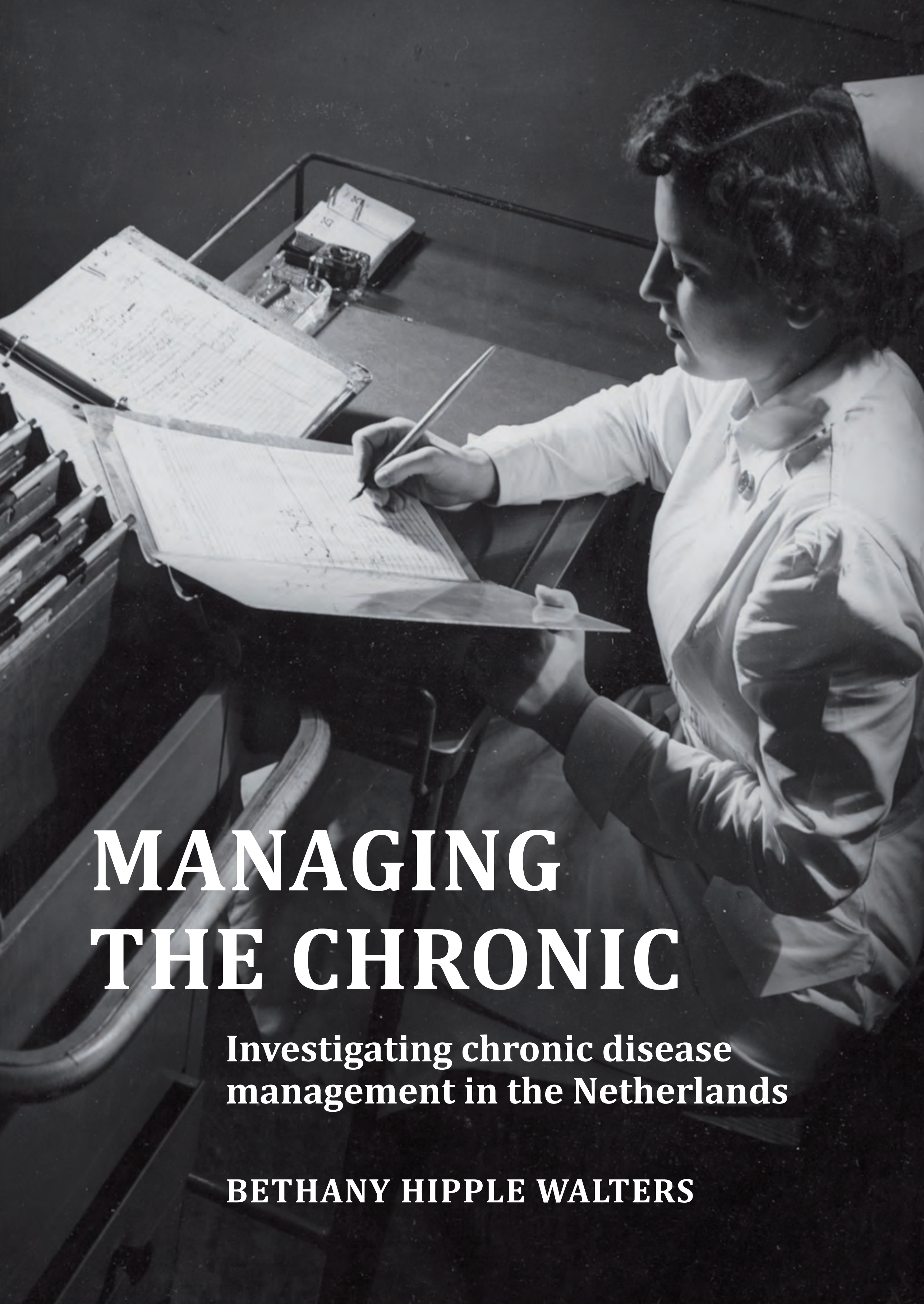

MANAGING THE CHRONIC

Investigating chronic disease management in the Netherlands

BETHANY HIPPLE WALTERS

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Het management van chronisch zieken:
een onderzoek naar chronisch ziektemanagement in Nederland

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to obtain the degree of Doctor from the
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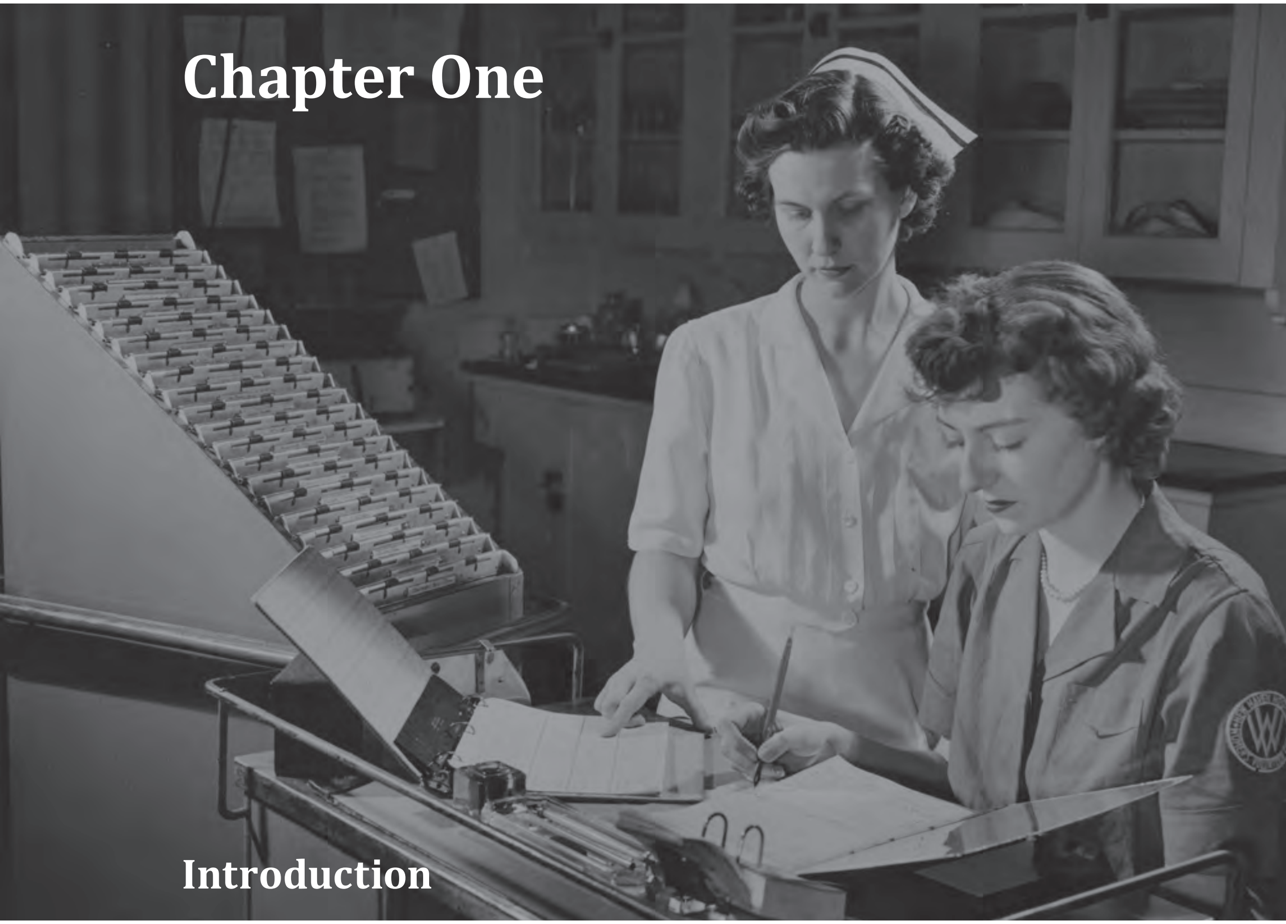
Chapter One



Introduction

This story begins with travel, documentation, chronic illness, and disease management on a personal scale. When I fly, it is quite likely that I am carrying multiple forms of identity cards: my Dutch residency card, my Dutch driver's license, my US identity card, my blue US passport, a vaccination passport with updated stamps for yellow fever, polio, the measles, and tetanus, and a red medical passport.

While the vaccination passport is more likely to stay home than not, the medical passport comes with me at all times. It is not very official-looking, just two sheets of A4 paper, with the name of my pharmacy on the outside and my official prescription to carry 60 5mg tablets of oxycodone on the inside. Much like I carry the problem that needs the tablets, I carry the medical passport with me, tucked in a coat pocket or in my bag. These pills and this passport are among the steps that I take, with the help of my clinicians, to manage my chronic condition.

I have chronic Eustachian tube dysfunction, which is blocked or inflamed Eustachian tubes due to allergies, a narrowed Eustachian tube, or bruxism. It gets worse in times of stress, such as when you are trying to finish your PhD. Recently, when I asked my Ear, Nose, and Throat (ENT) specialist if it was chronic, he replied with a question of his own: "We define chronic as more than 3 months. Has it bothered you for more than three months?" With that, my Eustachian tube dysfunction became chronic.

Not surprisingly, my Eustachian tube dysfunction has gotten worse in the past 18 months. When my ears started bothering me more this year, my Eustachian tube dysfunction began to be medically managed by a team of experts, with help from my family and friends (my community, as Wagner (2001) would put it), and most of my treatment data shared in a networked electronic medical record. I self-manage (or not) by wearing a night brace on my teeth, by doing my exercises, by taking my painkillers as needed, and by trying to reduce stress. There have been multiple visits to the general practitioner (GP), the physical therapist, the ENT, the Urgent Care Center, and the maxillofacial specialist. This has been, as others before me have noted, hard work for me and for my clinicians (Sav et al., 2013). It requires the work of adaptation, flexibility, and planning (Strauss, 1985). Together, my clinicians and I watch, too, for changes in my condition, for new treatment options, and for new clinicians to help.

Since I started the research for my PhD, my goal has been to understand how disease management programs happened in practice from the point of view of the clinicians, project leaders, and patients involved. I had no idea that during the course of the research, I would get a very personal look at managing a condition gone chronic.

As I learned with my own chronic condition, much of healthcare involves watching and working by patients, their families, and their clinicians. This is not a new concept; as Osler noted when training students at Johns Hopkins in the early twentieth century:

> *Observe, record, tabulate, communicate. Use your five senses....Learn to see, learn to hear, learn to feel, learn to smell, and know that by practice alone you can become expert.*

> *Medicine is learned by the bedside and not in the classroom. Let not your conceptions of disease come from words heard in the lecture room or readfrom the book. See, and then reason and compare and control. But see first.* (in Bryan, 1997)

Watching and work is inherent in the treatment and management of chronic diseases and conditions. This watching and work takes place through the efforts of actors[1] distributed over time and place. In fact, the one feature that is common in all chronic diseases is chronicity – the long term nature of the symptoms, illness, and (quite often) treatment and management (Martin, 2009).

Chronic disease is an incredibly broad category, including conditions that you are born with (such as cystic fibrosis), infections that are managed (hepatitis, HIV), diseases with genetic causes (MS, ALS), illnesses that can be influenced by your lifestyle (type 2 diabetes, COPD), and even the risk of acquiring a disease (risk of cardiovascular disease). The diagnosis of these diseases and conditions has been increasing in the past fifty years due to a wide variety of factors, including but not limited to the reduction of the mortality of infectious diseases, longer life expectancy, scientific advances, broader diagnosis criteria, earlier diagnosis and intervention, and a more sedentary lifestyle. The singular notion of 'chronic disease' is an umbrella categorization created by changing definitions as to what is a disease and by lumping multiple diseases into a more manageable group (Kelly & Field, 1996). Through the creation of this broad category, chronic disease became a somewhat messy problem that could be managed, though not cured (Arney & Bergen, 1984). However, the management of chronic disease can be expensive, unorganized, and time-consuming for policymakers, clinicians, and patients and their social networks; those with a chronic disease often see more than one clinician for their illness, and many have multiple chronic diseases (Bodenheimer et al., 2002). Ministries of health, health insurance providers, and healthcare collectives have been turning to disease management programs as a potential 'solution' for the unsolvable epidemic of chronic disease.

The focus of care changes through the development and implementation of disease management programs. No longer preoccupied with a cure, the core feature of disease management programs becomes longitudinal, coordinated care for those with (a) chronic condition(s). Disease management programs often focus on shifting more responsibilities for care to non-physician clinicians (nurses, nutritionists, physical therapists) and to the patients and/or their social networks themselves (Bodenheimer et al., 2002; Solberg et al., 2006; Wagner et al., 2001). Care, then, is shared between multiple parties and technologies, with more responsibilities for care taken over by patients and informal caretakers. The sharing of care between multiple clinicians (and, at times, the patient) is often facilitated by computer-support systems, such as forums, websites, and (networked) electronic medical records

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[1] Actors are both human and non-human; in essence, people or things that 'act' or play a role in the disease management programs are actors.

(Bodenheimer et al., 20002; Wagner et al., 2001). Disease management programs are put into place to enhance care coordination, reduce expenditures, and/or improve the general quality of care for those with a chronic disease.

Self-management aspects of disease management programs are one common way that responsibilities are shifted to patients. Patients are educated in self-management by several different types of clinicians. This education is tailored to the patient's condition and focuses on managing their chronic condition at home, improving their lifestyle through increasing exercise, losing weight, quitting smoking, managing medication regimes, and/or collecting biometrics related to their illness (Barlow et al., 2002; Bodenheimer et al., 2002; Holman & Lorig, 2004). Self-management shifts knowledge and expertise toward the patient, making educators of clinicians and students of patients. Disease management programs teach and guide patients, clinicians, and project leaders to watch and work on (the consequences of living with) chronic conditions (Bauer & Olsén, 2009; Kaziunas, Ackerman, & Veinot, 2013). This watching and working comes through the use of the ICT (information and communications technology) systems, through the coordination of care, and through the push towards self-management.

But what, really, does it mean to watch and to work in regard to chronic disease and chronic disease management programs? And what are the implications of this watching and working for clinicians, patients and the organization of healthcare? This book explores these questions.

It's best to start with watching. From a theoretical point of view, this book views watching as a form of power from a Foucauldian perspective, with influences from Steve Mann's work on veillance (Armstrong, 1997; Foucault, 1995; Foucault, 2003; Lupton, 1997; Mann & Ferenbok, 2013; Mann et al., 2003; Mann, 2013). Much of the writing of Foucault, especially the work used in this book, focuses on how power is constructed in society, how power is shared between actors, and how this power impacts (and is impacted by) relationships. Woven through Foucault's books and essays is the role of watching in power relationships; watching influences how power moves between actors. As this book explores, watching is built into the architecture of disease management programs. Project leaders watched, in many different ways, the numbers and information associated with patient populations to understand the needs of the populations for better care delivery through the disease management programs. Clinicians watched patients' behavior and health while training patients to watch their own health, chronic illness, and behavior. By looking at watching, this book examines why watching occurred in disease management programs, what roles watching played in the programs and in care delivery, how watching shaped roles and disciplined actors, and how watching interplayed with other aspects of the disease management programs.

For a better understanding of the technologies of power and watching, Foucault studied, among other organizations, the penal system. In *Discipline and Punish*, he explored how bodies and minds are shaped (or disciplined) by external actors, including the people in and the architecture of schools, prisons, hospitals, and churches (1995). This shaping comes initially externally, exercised through different modalities of control. These modalities of control are discrete coercion and steering through, for example, the creation of daily routines, the creation and discovery of the body as a subject of power such as through medical and prison structures, and (seemingly or potentially omnipresent) surveillance through panoptic physical structures (Foucault, 1995). Surveillance has been increasing in medical care, tied to the rise of non-acute illnesses and changes in the care structure (Armstrong, 1995). Yet surveillance is not the only form of watching and governing apparent in disease management programs.

A broader, more theoretically deep notion of watching can be understood as veillance, with multiple forms of watching. These forms of veillance include lateral watching or coveillance (Mann et al., 2003), self-surveillance, dataveillance (Clarke, 1997), infoveillance (Eysenbach, 2011), and watching from below, or sousveillance (Mann et al., 2003). Each of these forms of veillance is a technology of power and can be seen in disease management programs. Patients, project leaders, and clinicians are disciplined by the very possibility of veillance; as this book will show, patients, project leaders, and clinicians changed their behavior as a result of the watching built into the programs. Through the programs, patients were trained to watch themselves, to conduct self-surveillance; this self-surveillance was integral to both patient self-management activities and, more broadly, to the care of the self, as one must know oneself to fully care for oneself (Foucault, 1988). The change towards new forms and implementations of watching through the disease management programs has impacted the ways and means that actors in the disease management programs are disciplined.

Veillance and discipline provide data that can shape laws, policies, funding, research, and care delivery; this process is known as biopolitics. Biopolitics is a way of dealing with these new problems, as it is “the set of mechanisms through which the basic biological features of the human species became the object of a political strategy” (Foucault et al., pg 1, 2009). As further explored by Rose, biopolitics refers to “specific strategies involving contestation over the ways in which human vitality, morbidity, and mortality should be problematized, over the desirable level and form of the interventions required, over the knowledge, regimes of authority, and practices of intervention that are desirable, legitimate, and efficacious” (Rose, 2007, pg 54). Biopolitics is the ways and means of systematically reviewing populations, creating and gathering knowledge of solutions for problems created by statistics, granting authority to political figures, and organizing efforts to intervene at a systemic level.

Through research on the disease management programs, the biopolitical paradigm of disease management becomes clear. Defined by Epstein, a biopolitical paradigm is a “framework of ideas, standards, formal procedures, and unarticulated understandings that specifies how concerns about health, medicine, and the body are made the simultaneous focus of biomedicine and state policy” (Epstein, 2008, pg 67). In the disease management programs and research on the programs, as I show, people are sorted into niche standardizations through scientific and biomedical processes for easier management by the state, by biomedical institutions, and by other governing authorities. The biopolitical paradigm is an intricate, impactful, and organized form of watching and action.

Watching impacts the types of work that are done, as will be analyzed in the exploration of chronic disease management programs, but also the other way around: watching needs many actors to do many types of work. Without watching, it's impossible to know what type of work needs to be and is done by whom, and without the work of data collection, aggregation, and cleaning, it is impossible to watch. Strauss conceptualized work in healthcare projects as "made up of many tasks done over time, and divided up according to various criteria among the actors (persons, classes of persons, departments or other organizational units)" (Strauss, 1985b, pg 2). Strauss further categorized the work done by medical professionals in treating chronic illness as machine work, safety work, comfort work, sentimental work, and articulation work in *The Social Organization of Medical Work* (Strauss, 1985). Machine work, safety work, comfort work, and sentimental work are most commonly conducted at or around the care delivery level. Articulation work, defined as work "done to assure that the staff's collective efforts add up to more than discrete and conflicting bits of accomplished work" (ibid, pg 151), is often work done behind the scenes but is necessary for the success of a given program or endeavor. In healthcare, this work is often done by nurses and by those leading projects (Bowker & Star, 2000; Strauss 1988). This work is done to ensure that standard operating procedures and care protocols run smoothly in the face of changes, to make sure that interruptions are dealt with quickly, and that allow routines to be established or continued (Strauss, 1985; Star & Strauss, 1999). Cooperative work is also a large component of the work done in disease management programs. Cooperative work "interleaves distributed tasks" and people (Star & Strauss, 1999, pg 10). Much of the work done in chronic disease programs and studies is done around the creation and coordination of information and data. Also called information work, this work focuses on creating and gathering numerical data, staff information, collecting, cleaning, and sharing budgets, reviewing and documenting processes, and gathering literature with which to make informed decisions.

Project leaders worked and watched throughout the course of the disease management programs and studies. Early in the programs, project leaders steered and maneuvered the programs from paper to action, working as travel guides as the programs moved from concepts to reality. Disease management programs can be understood as "traveling technologies," which are healthcare doctrines or programs that move between more international, academics arenas and local practices in clinics, conducted by project directors, clinicians, and patients (Nielsen, 2010). In the disease management programs, the project leaders and managers were responsible for this movement and travel; the travel from global to local and from paper to actions required that the project leaders conduct various forms of work, while watching the actions and interactions of others with the disease management programs. Work and watching interwove throughout the disease management programs.

By looking at the work and watching in disease management programs, this book explores the deeper implications of what it means to patients, clinicians, project leaders, and researchers to implement a disease management program in practice. The empirical data for this book comes from data collected from 2009-2014 in disease management programs in the Netherlands; the case will be explored further in the following section.

AIMS OF THIS BOOK

This book aims to add to the academic and practical understanding of how disease management programs are developed and implemented in practices, especially the work and watching involved in developing and implementing the programs. To this end, I aim to add to the literature on disease management for clinicians and project leaders and to the academic discussion on veillance, biopolitics, and work.

RESEARCH PROGRAM

To address the rising numbers of those diagnosed with a chronic condition, the Netherlands Organization for Health Research and Development (Nederlandse Organisatie voor Gezondheidsonderzoek en Zorginnovatie [ZonMw]) funded and supported a research and implementation program to explore the development and implementation of disease management programs. The intention of the study was to understand the efficacy and efficiency of disease management programs with the goal of wider dissemination of disease management. The ways in which the *Call for Proposals* defined disease management aligns with conceptualizations of disease management in the literature, which promote self-management (Bodenheimer et al., 2002), patient-centered care (Winkelman & Choo, 2003), and sharing care between multiple professionals (Wagner et al., 2001; Bodenheimer et al., 2002).

In the Netherlands, healthcare cooperatives were encouraged to develop disease management program plans and apply for funding and support to implement the programs; in exchange for funding and support, project leaders at the selected sites agreed to participate in the evaluation of the programs. Twenty-two healthcare settings were selected to implement various disease management programs (Lemmens et al., 2011). The chronic conditions that the programs focused on included diabetes, cardio-vascular risk, COPD, eating disorders, depression, stroke/TIA, schizophrenia, and multi-morbidity (for patients with multiple chronic conditions). The settings included GP groups (multiple GP practices under one co-operative agreement), health centers, outpatient care departments of in-patient treatment centers, and hospitals. Researchers at the Erasmus University Department of Health Policy and Management were asked to evaluate the program through quantitative, economic, and qualitative research; this book centers on the qualitative findings.

Each of the disease management programs had an internal project leader, who was responsible for leading and overseeing the changes in healthcare related to the implementation of the program, working with Erasmus University on the mixed methods data collection, and attending the required training and information sessions. In some (if not most) cases, the funding was not enough to cover the costs of changing care. The project leader was then responsible for acquiring additional financing for the disease management program from health insurers, municipalities, and other potential funders (Tsiachristas et al., 2011).

The project leaders had diverse roles and backgrounds. Some of the project leaders were clinicians who assumed project leadership duties as a result of the ZonMw funding; some were external consultants hired (or continued) as a result of the awarded funding; some were staff of the GP group. The distinction can be quite fuzzy, in that GPs who assumed project leadership duties may have done so ad-hoc, as part of their role in the GP group, or because they were interested in the disease management program.

While project leaders were important actors in the disease management programs (as will be shown in this book), they were not the only actors. The patient experience of disease management was quite useful in understanding how disease management programs acted in clinical practice and beyond. Clinicians, such as GPs, nurses, nurse specialists, chronic disease specialist assistants, nutritionists, and physical therapists, all played important roles in the disease management programs. As coordinated care between multiple medical providers was an express goal of most of the disease management programs, exploring and analyzing the roles of these clinicians in relation to chronic disease is crucial to understanding how disease management programs happened in practice. Other key actors included the research team, the funding organization, disease management supporting agencies, tools, technologies, guidelines, protocols, measurements – the actors were countless, changing over the course of the projects and study – and played key roles in the development and implementation of disease management programs.

Research questions

The research questions that have driven this book were straightforward; specifically, I looked at how disease management programs and studies happened in practice, especially from the point of view of project leaders. I was particularly interested in what happens in the process of developing and implementing a disease management program and study. I was also interested in how project leaders, clinicians, and patients defined and ascribed meaning to chronic conditions, disease management, self-management, and the technologies associated with disease management over time.

To this end, I was guided by the following research questions:

- How did disease management programs get started; specifically, in what ways do project leaders move the programs from plans to realities?
- What were the facilitators of cost-effective disease management program development and implementation?
- How were patients disciplined by their chronic illness and the treatment for their chronic illness? How do patients present this disciplining when they tell the stories of their chronic illnesses?
- How were the self-management aspects of disease management programs watched by researchers, project leaders, health insurers, patients, and clinicians? How did watching influence the programs and studies?
- Who worked, and how was work conducted in the disease management programs? How was watching a form of work? How did this watching and work impact policies?

To gain a deeper understanding of how disease management programs happened over time, I analyzed the data from a primarily Foucauldian point of view (focusing on power relationships, watching, and governing), with influences from literature on work.

METHODS

To better understand how disease management programs actually happened, I used a variety of qualitative methods. These methods included interviews with project leaders, clinicians, and patients; observations of meetings and clinical practice; document analysis of project plans; and online data collection.

Cases

I conducted data collection in all 22 sites. Five cases were selected for in-depth qualitative research. The selection criteria for these five cases included location, patients treated, types of disease management program, and willingness to participate in research; the sites were selected before I began data collection. The disease management programs at the five sites focused on COPD, diabetes, CVRM, eating disorders, and multi-morbidity. To protect anonymity, the sites will be referred to by the diseases that were the focus of their disease management programs.

Data collection: Interviews

The primary source of data for this book is from the 89 interviews I conducted with project leaders, communication specialists, and medical professionals. The interviews were semi-structured, with my main research questions, literature review, and, in later interviews, the prior interviews influencing my line of questioning. The interviews focused on how disease management programs happened in practice, how project leaders and medical professionals defined and viewed disease management, how and why computerized systems were used in practice, and surprises that the project leaders and medical professionals faced. The interviews were conducted in English and/or Dutch. These interviews averaged about an hour in length.

I conducted interviews with seven patients from the diabetes program on their experiences with diabetes and treatment. Three of the seven interviews were cut short do to interviewer/patient language mismatch. The interviews with patients were conducted in Dutch, English, and/or German and lasted between 15 and 60 minutes.

Data collection: Observations

I conducted observations at the eating disorder and the diabetes sites. At the eating disorder site, I observed two meetings on the reorganization of care (one meeting with stakeholders, the other meeting with the majority of the center's staff); I also observed the second project manager presenting information about the eating disorder center's treatment options. At the diabetes site, I observed one session of a diabetes education course for patients, one half-day of nurse specialist and nutritionist visits, and one group meeting of clinicians involved in the disease management program. Field notes were taken.

Data collection: Document analysis

Document analysis helped formulate the research questions and set the stage for the first interviews. Further document analysis shaped my understanding of the role that the state played in disease management programs and research. The documents analyzed included:

- the grant application for the evaluation study
- the call for proposals
- a statement from the Ministry of Health about the need for disease management programs
- instructions about surveys
- letters and memos to practices
- project proposals from the 22 sites

Data collection: Online

I collected data from websites associated with disease management program locations. The diabetes program website provided data about the cooperative and the diabetes program; the website was directed primarily towards patients, hosting patient education materials and information about the treatment options available through the disease management program. The eating disorder treatment center hosted a website for young women with eating problems or disorders. From this website, I primarily collected data from the 'experience stories' portion of the website, as well as information about the website's rules and standards.

Transcription, coding, and translation

The interviews were recorded and then transcribed verbatim by student assistants. The interviews and data from document/web analysis were coded into themes, based on the content of the interviews. My chosen method of analysis provided the opportunity to map the themes back to literature on disease management, veillance, and self-management, as noted by Creswell (2012). I translated quotes from Dutch to English; the translation was corrected and confirmed by native Dutch speakers.

ETHICS

The study was approved by the ethics committee of the Erasmus University Medical Center of Rotterdam in September 2009. I was given permission by the respondents before interviews were conducted and recorded. When observations were conducted in clinical settings, patients and clinicians gave permission for me to sit in, observe, and take notes. When I conducted observations at meetings, I was given permission to observe by the meeting organizer; I also announced by reason for attending the meeting(s) to the attendees. In cases in which I recorded meetings, I asked permission of the group to record. My online data collection was limited to (parts of) the relevant websites that are open to the public; for the website data collected from the eating disorder treatment center's support website, I also sought and was awarded permission from the project director to collect and publish data.

All data has been presented anonymously. When possible, the interviewees approved the quotes before use in presentations, journal articles, and reports.

LAYOUT

This book is based on qualitative research conducted as part of a larger mixed methods study of disease management programs. In the following chapters, I present my empirical data on disease management programs. The chapters are based on published peer-reviewed journal articles or on papers submitted to peer-reviewed journals. Chapters Two and Three focus on the costs and changed roles associated with the disease management programs; these chapters center on the outcomes of implementation, while Chapters Four, Five, and Six look at how the programs (and the research on the programs) happened through a Foucauldian theoretical framework.

Chapter Two [Disease management projects and the Chronic Care Model in action: baseline qualitative research] and Chapter Three [Identifying and explaining the variability in development and implementation costs of disease management programs in the Netherlands] concentrate on the work done in disease management programs by project leaders, managers, and clinicians.

Chapter Two analyzes the disease management programs in relation to the Chronic Care Model, focusing on how project leaders served as travel guides for the program plans, assisting and overseeing the programs as they traveled from global plans to local actions (Nielsen, 2010). This analysis found that project leaders, while hypothetically in control of the programs, in fact shared the work and control of the traveling of the programs with patients, clinicians, and outside consultants.

Chapter Three [Identifying and explaining the variability in development and implementation costs of disease management programs in the Netherlands] explores the outcomes of the work of project leaders, managers, and clinicians in the disease management programs, highlighting the factors that can explain the variability in costs between disease management programs. This research showed that the history of the project leaders' work in the programs and the work done on ICT may influence the development and implementation costs of disease management.

Chapter Four [Chronic disease self-management and watching: Veillance in the expanded Clinic] illustrates and differentiates between the types of watching, better defined as veillance (Mann, 2013), conducted in the self-management aspects of disease management programs. Using the work of Mann on veillance and the work of Foucault on the medical gaze and surveillance, specifically *The Birth of the Clinic*, we illustrated that the expansion of the clinic and veillance impacts the delivery of care.

Chapter Five [Proud2Bme: exploratory research on care and control in young women's online eating disorder narratives] focuses on patients associated with an eating disorder treatment center's disease management program. This chapter built upon the ideas of control and discipline developed in Foucault's *Discipline and Punish*, as well as on literature on online storytelling, to gain a deeper understanding of the ways in which chronic diseases and their treatment control and discipline those with the condition; the ways that this control and discipline impacted the stories that the young women with eating disorders told about their condition and treatment; and the roles that online aspects of disease management programs played in the stories, control, discipline, and treatment.

Chapter Six [The biopolitics of work and the work of biopolitics: Researching disease management programs] draws on the work of Strauss on work in chronic disease, of Foucault (2009) and Rose (2007) on biopolitics, and of Epstein (2007) on the biopolitical paradigm. This chapter revealed how work on disease management programs and data collection for research on disease management studies are biopolitical instruments.

Chapter Seven [Conclusion] explores how each of the chapters work together to provide a deeper understanding of how the studied disease management programs worked in practice. This chapter revealed how the two theoretical frames (the frame of watching and the frame of work) intertwined into one frame to explore and illustrate the broader implications of the disease management programs and study. This chapter also includes practical implications of the research for project leaders, clinicians, patients, and funding organizations.

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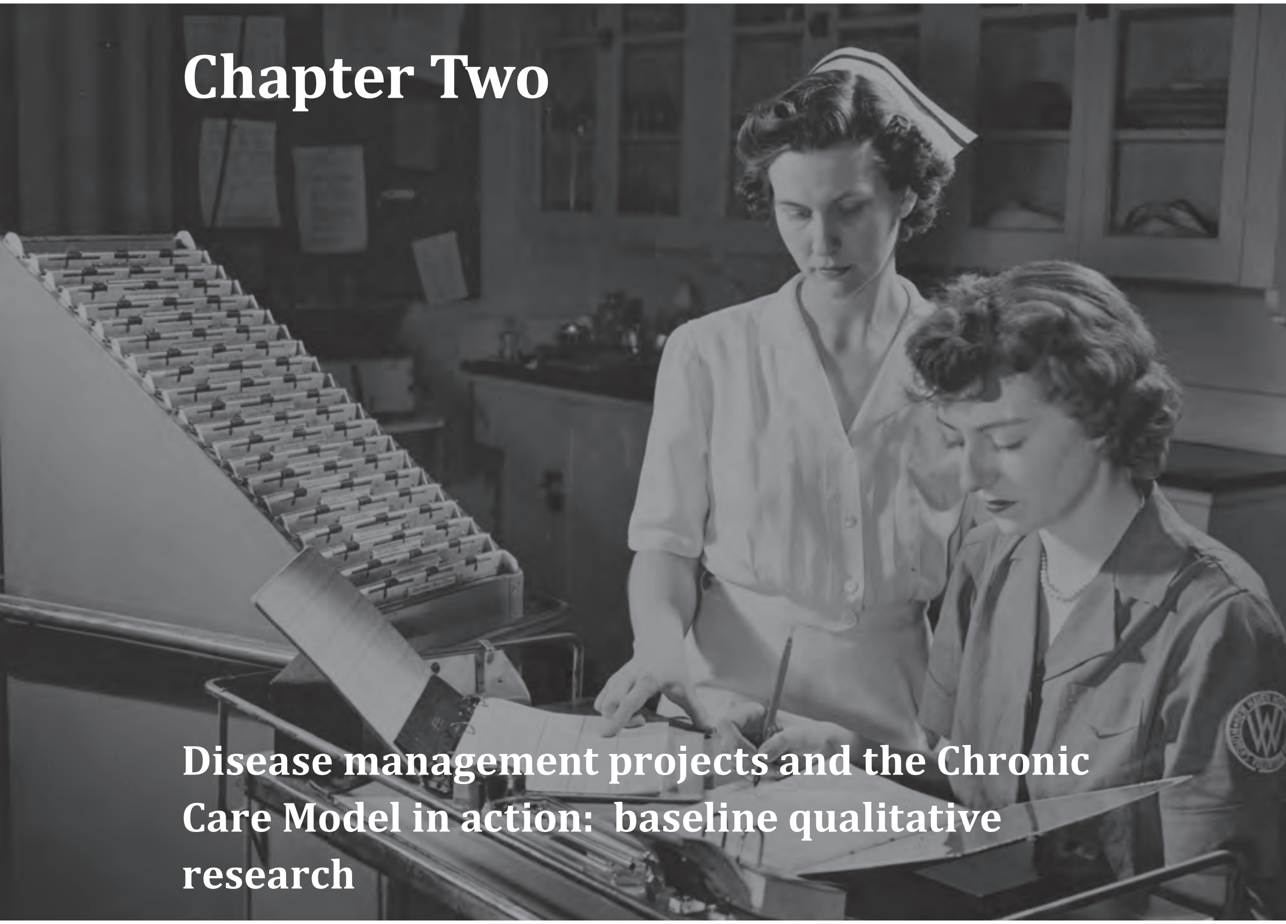

Chapter Two

Disease management projects and the Chronic Care Model in action: baseline qualitative research

Hipple Walters, B., Adams, S. A., Nieboer, A. P., & Bal, R. (2012). Disease management projects and the Chronic Care Model in action: baseline qualitative research. *BMC Health Services Research*, *12*(1), 114.

ABSTRACT

Background

Disease management programs, especially those based on the Chronic Care Model (CCM), are increasingly common in the Netherlands. While disease management programs have been well-researched quantitatively and economically, less qualitative research has been done. The overall aim of the study is to explore how disease management programs are implemented within primary care settings in the Netherlands; this paper focuses on the early development and implementation stages of five disease management programs in the primary care setting, based on interviews with project leadership teams.

Methods

Eleven semi-structured interviews were conducted at the five selected sites with sixteen professionals interviewed; all project directors and managers were interviewed. The interviews focused on each project's chosen chronic illness (diabetes, eating disorders, COPD, multi-morbidity, CVRM) and project plan, barriers to development and implementation, the project leaders' action and reactions, as well as their roles and responsibilities, and disease management strategies. Analysis was inductive and interpretive, based on the content of the interviews. After analysis, the results of this research on disease management programs and the Chronic Care Model are viewed from a traveling technology framework.

Results

This analysis uncovered four themes that can be mapped to disease management and the Chronic Care Model: (1) changing the health care system, (2) patient-centered care, (3) technological systems and barriers, and (4) integrating projects into the larger system. Project leaders discussed the paths, both direct and indirect, for transforming the health care system to one that addresses chronic illness. Patient-centered care was highlighted as needed, and a paradigm shift for many. Challenges with technological systems were pervasive. Project leaders managed the expenses of a traveling technology, including the social, financial, and administration involved.

Conclusion

At the sites, project leaders served as travel guides, assisting and overseeing the programs as they traveled from the global plans to local actions. Project leaders, while hypothetically in control of the programs, in fact shared control of the traveling of the programs with patients, clinicians, and outside consultants. From this work, we can learn what roadblocks and expenses occur while a technology travels, from a project leader's point of view.

BACKGROUND

The diagnosis of chronic disease has increased in the developed world in recent years, thought to be due to the aging population and the more successful treatment of acute illness. Many healthcare decision makers have been seeking methods of more efficiently and effectively treating chronic disease; frequently, these methods include the development and implementation of disease management programs [1]. While there are many specific definitions of disease management, for this article and for the projects discussed here, disease management has been defined as a "broad programmatic approach to chronic diseases, a comprehensive care chain that consists of diagnosis, treatment and support, as well as prevention, early detection, and self-management. The broad approach is set in multidisciplinary care standards and is organized around the patient and his illness, where possible tailored specifically to his environment" [2].

Disease management programs have been implemented in and tailored by healthcare providers around the world. As such, they can be understood as a 'traveling technology'; traveling technologies are programs or healthcare principles that travel between a global (often academic) stage and the local practices and actions of healthcare leaders and providers. The traveling technologies also include the "translations that occur when an object travels from one place to another" [3]. In the process of traveling from the global (a general program or model) to the local (through application at a specific practice site), the programs become adapted and negotiated in their local contexts by project leaders, healthcare managers, clinicians, and patients. When viewed as a traveling technology, the local practices of healthcare providers and patients are as important as the global principles that frame those practices. Disease management programs are an excellent example of traveling technologies. While disease management programs originate from similar ideologies of patient-centered coordinated care, the local actions vary widely, as does the implementation and, in some ways, the redefinition, through the actions of local actors, of the tenets of disease management.

In this paper, we have collected data from the project leaders and managers of five disease management programs in the Netherlands. The overall aim of the study is to explore how disease management programs are implemented within primary care settings in the Netherlands. For this paper, interviews done with project leadership teams conducted during the development and early implementation phases of the disease management programs have been analyzed from a traveling technologies viewpoint. This research provides a unique perspective on traveling technologies by showing how project leaders are crucial in the traveling of disease management programs at many levels, as the project leaders interpret, translate, adapt, and adopt the tenets of disease management programs to their local settings. This article uses the project leaders' point of view to addresses the following question:

- How can disease management programs be understood as a traveling technology through the actions and reactions of project leaders?

Disease management programs and the chronic care model

One of the more popular and pervasive models for framing disease management programs is the Chronic Care Model (CCM), which has influenced and been influenced by disease management programs. The Chronic Care Model "summarizes the basic elements for improving care in health systems at the community, organization, practice, and patient levels" [4]. The model, developed in the United States by a team led by Edward Wagner in the 1990s, is a synthesis of many components of disease management programs [5, 6]. While there are other guides for disease management programs, none are as prolific as the Chronic Care Model; as such, the elements of the CCM will be used in this paper as a definition of the elements of disease management.

Much research has been or is currently being conducted on disease management programs, including those directly guided by the CCM [7, 8], yet little research has focused on the implementation of disease management programs in their early phases. As well, there is need for more research now that disease management programs are increasingly being taken up in countries outside the US, as can be seen in Germany [9], New Zealand [10], the UK [11], and the Netherlands.

Disease management programs are increasingly popular in the Netherlands, due, in part, to changes within the healthcare financing and delivery system. Having undergone major reforms in 2006, the new regulated market health insurance system is continuing to adapt to the needs of insurers, healthcare providers, and patients [12]. Through the new system, every resident of the Netherlands is required to purchase health insurance. The cost of a basic health insurance plan, which covers preventative and essential curative services, is fixed; subsidies are available for those unable to pay. In 2008, the Ministry of Health, Welfare, and Sport emphasized the need to develop disease management programs for those with chronic diseases [13].This resulted in the creation, in 2009, of a research and implementation program to improve upon the development and execution of disease management programs by the Netherlands Organization for Health Research and Development (ZonMw). ZonMw sent out a call for proposals for projects from practice groups in the Netherlands. The call for proposals for the projects emphasized the need for disease management programs that focus on self-management, co-morbidity, and/or information and communications technologies (ICT) in healthcare.

Twenty-two healthcare provider groups were granted funding for developing disease management programs. In exchange for funding, project leaders and clinicians agreed to develop and implement a disease management program that meets the needs of their patient population and to facilitate qualitative, quantitative, and economic research conducted at the site [14]; five were selected for further in-depth qualitative research, based on maximum variation between diseases and practices. Through the qualitative research, the research team explored how disease management programs are implemented in the Netherlands by the project leaders and clinicians. This research also included how disease management programs move from plans to actions, how the programs are altered and tailored to the situation, and, toward the end of the project timeline, how clinicians and project leaders embed notions of disease management into everyday practice. The clinicians at the project sites, under the guidance of their project leaders, selected the chronic condition that they would like to address to improve the healthcare of their patients. The project leaders developed project plans, often with intensive feedback from healthcare providers, and submitted the plans for funding to ZonMw. ZonMw funded the projects thought to be most likely to succeed and impact a large population of patients with chronic disease.

METHODS

The qualitative study was part of a larger effort to understand the impact of disease management programs on clinical systems, clinician behavior, patient perception of care, health outcomes, and on the financing of treatment. The larger goal of the qualitative component of the study was to understand the impact of developing and implementing disease management programs on project leaders, clinicians, and patients; this paper looked at the impact on project leaders, while future work looked at the clinicians and patients. The study was approved by the Review Board of Erasmus MC.

Settings/study sites

The five qualitative sites were selected as a purposeful sample on the basis of maximum variation, with respect to the planned development and use of information and communications technologies, interaction between primary and secondary care, type of intervention, role of the patient, and changes for professionals. They also represent a range of chronic conditions, including eating disorders, diabetes, and cardiovascular risk management.

Research participants

Each study site had a project leader or a project leadership team, including project leaders who manage small projects within the large disease management project (known in this article as mini-project leaders), to guide the work of the program and project; many of these main project leaders or managers have had training prior to the study (as part of a Master’s or as separate certification courses in healthcare organizations) in healthcare systems or disease management, though this was not a requirement of the programs or study. While many of the project leaders had education in healthcare management and program leadership, it is unclear to what degree project leaders were cognizant of the specific literature on the Chronic Care Model. The project leaders oversaw the projects, worked with clinicians at each GP office or department, collaborated with the research team on the economic, qualitative, and quantitative research, and developed and/or tailored the disease management program. Furthermore, the project leaders supported projects by being contact points for ZonMw and for the two other supporting agencies, Vilans and Picasso for COPD. The project leaders were also expected to attend Inspiration Days, one-day conferences that address themes of interest to the projects, such as eHealth programs, program leadership, and patient education. The project leaders were granted much latitude in how the projects are conducted, though support and education was available on request.

Design

At each of the five selected sites, semi-structured interviews were conducted with the project leaders and members of the project leadership team. Eleven interviews were conducted at the five selected sites with sixteen healthcare professionals; all of the interviews were conducted by the first author. The interviews were conducted at the program site in Dutch or English and ranged from 45 minutes to 90 minutes. The interviews were recorded; equipment malfunction resulted in two interviews with missing recordings. In all cases, in the event of equipment malfunction, the interviewer took detailed notes, including exact quotes from the interviewees, during the interviews. Interviews were transcribed verbatim and the interview data was analyzed inductively. The interview quotes used in this manuscript were sent to the respondents in order to confirm use in the manuscript, as well as check any confusion in language. The respondents edited the quotes with minor changes and gave express permission to use the quotes in this manuscript.

Table 1: Projects selected and interviewed for qualitative research

Project Site	Chronic Illness	Team	Program
Clinic for eating disorders and addictions	Eating disorders	On-site leadership team 1 project leader (MD) 1 project manager (Social worker) 4 mini-project leaders	Four-fold project to reduce barriers to access to support and treatment for eating disorders
GP practice group	Cardiovascular risk (CVR) management	On-site leadership team 2 project leaders (MDs) 1 project manager (RN)	Manage CVR through patient portals, patient care plans, and interdisciplinary care teams
GP practice group	Diabetes	Consultant leader 1 project leader (Healthcare consultant)	Train clinicians and other healthcare givers to manage diabetes in first line care
GP practice group	Chronic obstructive pulmonary disease (COPD)	Consultant leader 1 project leader (Healthcare consultant)	Find and recommend an effective ICT system and an expert COPD training team visiting each practice
GP practice group	Multi-morbidity	Consultant leaders 2 project leaders (MD, RN)	Develop integrated approaches for the management of co-morbidity and chronic illness

Table 1 gives an overview of the sites; Table 2 summarizes the interviews conducted at each site. All project leaders were interviewed about their projects, their practice settings, and the changes being made as a result of the development and implementation of the disease management project. Table 3 contains a sample from the interview guide, which guided the interviews with project leaders and managers. Table 4 outlines the major themes uncovered in the data collected from the interviews, including the themes covered in this manuscript, as well as other themes that will be explored further in future articles.

Table 2: Interviews conducted

Project Site	Interviews
Clinic for eating disorders and addictions	One-on-one interview with project leader One-on-one interview with project manager Three one-on-one interviews with mini-project leaders Joint interview with mini-project leader and department head Total interviews: 6
GP practice group	Joint interview with project leaders One-on-one interview with project manager Total interviews: 2
GP practice group	One-on-one interview with project leader Total interviews: 1
GP practice group	Joint interview with project leader and outside expert Total interviews: 1
GP practice group	Joint interview with project leaders Total interviews: 1

Baseline interview questions were developed from the literature in disease management [15, 16], the Chronic Care Model [17-19], and conditions related to each site [20-24]. Further questions were developed after a review of the data collection methods of the quantitative and economic aspects of the study; the first author also met regularly with the economic and quantitative researchers and discussed the qualitative data collection to ensure harmony and inclusiveness of the qualitative data collection within the overall study goals. The qualitative data collection questions also covered areas that were not fully addressed by economic and quantitative aspects of the study to ensure complete data capture for the entire study, such as barriers to implementation at this point, challenges to the development of the project, an exploration of the team dynamics, communication strategies used with the project team, and any (un)pleasant surprises that they encountered.

Project leaders were asked about their own experiences in developing, tailoring, and implementing the disease management programs, as well as any interest or criticisms that they had heard from other professionals and clinicians involved in the disease management programs. While the answers to these questions were analyzed from a traveling technology framework, the questions themselves mapped back to the primary aim of the study, understanding how disease management programs are implemented in primary care in the Netherlands; Table 3 has a sample of the interview guide. From this information, the research team was able to gather information about how the disease management programs were being implemented in the sites, as well as how the disease management programs were best understood as traveling technologies as they were implemented and altered by the project leaders.

Table 3: Sample from the interview guide

1. Why were the projects developed?
2. What is the need?
3. What are the barriers to implementation?
4. How does communication happen?
    a. As a team?
5. What has feedback been to the implementation from staff?
6. How has your team helped in the creation and implementation of the project?
7. How was your team developed?
8. What does it mean to have a disease management system or project?
9. What good surprises have you had?

Analytical approach

Analysis was inductive and interpretive, based on the content of the interviews; in line with the inductive analytic tradition, project leaders were frequently asked to define terms that are otherwise taken for granted as a shared understanding, such as ‘disease management’ [see Table 4]. The content of the interviews focused on the implementation of the disease management programs by the project leadership team; communication and team dynamics between members of the project leadership team, the clinicians, and the patients; and changes in healthcare practices, based on the diseases addressed in the programs. This method of inductive analysis allows for the development of general themes mapped back to the literature [25]. As disease management programs contain many of the aspects of a traveling technology (traveling expenditures, movement from global to local arenas), the data

Table 4: Themes that emerged from the qualitative research

Chronic Care Model
Integration
Time
Roles
Disease management
Diabetes
Eating disorders
CVRM
Multi-morbidity
ICT/Electronic Health Record
Internet
Stepped care
Ketenzorg (Chained care)
Reducing the use of specialists
Barriers
Communication

collected through interviews with the project leaders was most clearly understood through a traveling technologies framework. All research questions have been analyzed using the same method. The data was coded by the first author and verified through close reading of the quotes in their original language and their translation, when appropriate, by the second author, SA.

RESULTS

From the empirical data, four disease management themes, as defined by the Chronic Care Model, emerged:

1. changing the healthcare system,
2. patient-centered care,
3. technological systems and barriers, and
4. integrating projects into the larger healthcare system.

Illustrative quotes from these themes have been selected from this article and are seen below in italics and off-set from the text. Through defining disease management through these Chronic Care Model themes, the research team was able to understand and explore how disease management programs travel. This research shows how project leaders manage and interact with the members of the disease management programs, and ultimately, the patients and clients impacted by the disease management programs, as well as how project leaders view the travel expenditures associated with the programs.

Changing the healthcare system

Project leaders and project leadership teams, including project managers and mini-project leaders, frequently tied their disease management project work to larger efforts in healthcare and in their healthcare system's delivery of care in specific. Project leaders sited the goals of the programs as the impetus to plan (and in the future, put in place) changes, as well as the goal of improving patient care.

> *The end goal is to reach more people in a better way with a continuous quality of care during the, on average, 5 to 7 year illness period. That's the idea. That's ambitious. Yeah, it's very exciting because we have to change the whole way of thinking here and change the whole organizational model as well. . . So we have inner barriers to continuity in care as well. Lack of flexibility there as well, so we need to reorganize internally this year.* (Interview with E, project leader for the eating disorder project)

The latitude afforded to the project leaders in developing their programs meant that the translation from the project plan on paper to action in practice could be done in a number of ways: as a drastic reorganization, in phases, or first as a project with later spoken or unspoken plans for integration into the system. It also involved translation work in relationship to stakeholders:

> *I have to tell [the GPs] that it's just a project and that we will need an evaluation of the project before it comes to be common practice.* (Interview with X, project leader with the CVR project)

Patient-centered care

Patient-centered care, as defined by the Chronic Care Model through the Self-Management Support element of the model, highlights "the patient's central role in managing their health" [26]. While the majority of the project leaders did not mention the Chronic Care Model as inspiration for the changes that they plan to make, a few did and directly tied their actions to the model.

> *For example, that together with the patient, you look at the self-management of that patient and that you look according to the Chronic Care Model, like yeah, I have to work along with the patient on all the factors and not only give information, because that isn't going to help that patient. That's what is important, that I can see now in a broad perspective and then you can make the most of giving care.* (Interview 1 with H, project manager with the CVR project)

> *And then another thing was the Chronic Care Model is a patient-centered model. And we are not used to working [in a] patient-centered [way]. It's becoming more and more [popular]. What's new in our system is that we choose to work in a patient-centered way.* (Interview with X, project leader with the CVR project)

However, as noted in the quote, working in a patient-centered way was a change within the system, a change that costs time and effort. This expenditure of time and effort was for a common goal: involving patients in their healthcare to improve their health.

> *Well and involving the patient now is one of the most important things because what we've discovered and what worldwide they discovered is that lifestyle change is one of the most important issues that can make a difference on the long term, but is also one of the most difficult things to realize. And the only way to do that is getting patients involved, and getting them to participate in their own disease.* (Interview with B, project leader for the diabetes project)

Project leaders emphasized how becoming more patient-centered impacts the providers and how providers needed to change how care was delivered.

> *The two things that are the most important are the self management of the patients themselves because the patient is the main issue of gaining a long term benefit out of the system. So that's one thing. But what's also necessary is that the care givers, the doctors, the physicians, the nurses, they have to make a switch in not only being a healthcare giver but being a coach, being able to give the support to the patient that they can make their own self-management system and that they can make their own choices and that will really make a difference, instead of the choice of the healthcare giver.* (Interview with B, project leader for the diabetes project)

Other project leaders placed emphasis on the changed role of the patient and their involvement in their care process.

> *But it's the process of the client, not the process of the one who's giving the support. So the process of the client is leading. That's a difficult part of it, but the essential part of it. Do you know what I mean? I mean. . . I can tell you what you've got to do to recovery, what's good for you. But that won't be necessarily your way… I've got to connect with your approaches. And look together with you and support you to empower you to find your own path in recovery.* (Interview with P, mini-project leader for the eating disorder project)

Patient-centered care can be a challenge for healthcare providers, as it may require them to change the ways in which care is presented and delivered to patients. Healthcare providers must think and act in new ways, as well as continue to alter their healthcare systems to sustain this new way of providing care.

> *The challenge is to know who needs support and who can self- manage.* (Interview with H, project manager for the CVR project)

> *To learn to think about the client is the most difficult thing [to do]. To really think about the client. Not that I know what is best for the client. The client knows best. That's a hell of a job.* (Interview with K, project manager for the eating disorder project)

Technological systems and barriers

For the project leaders, implementing a disease management program was a process of harmonizing the movement of information and actions between practice sites, patients, and the project leaders. In all cases, this change to the healthcare system involved new communication technology. The improvement or addition of a technological system was a common way to change the mode of healthcare delivery and was emphasized in the call for proposals for the projects. The planned changes in the projects included the development of patient portals to assist patients in self-management, patient health records, computerized communication systems to connect general practitioners and other healthcare professionals, and websites for patients/clients to connect with clinicians and others. These changes were seen as important for organizing and improving care for both patients and clinicians.

> *So now all general practices have their own registration and programs. And we think it's very important that the general practices and the hospital work together and can see the registration and can communicate together. And we think that we need another program for that.* (Interview 1 with AC, project leader for the COPD project)
>
> *But what is especially important and that's where we are now spending a lot of time is to properly organize care with the GPs who work on a computer.* (Interview with H, project manager for the CVR project)

However, ICT systems were also seen as a barrier, in that the development and implementation of the systems is costly in both time and effort. Project leaders also spent time prioritizing and in some ways, limiting, the focus of the ICT system.

> *We have a lot of barriers. First barrier is with the ICT system. It's not already finished. . . It was a long step to come so far as we are now.* (Interview 1 with X, project leader with the CVR project)
>
> *The fact that the software builder couldn't deliver what they said they would deliver [was a barrier]. And still now we do not really have the perfect system and the perfect system does not exist, I know. But there are too many things that are really what we want.* (Interview with B, project leader for the diabetes project)
>
> *And you have the program, and it's sort of the same, and it works on the mobile phone. And E. thought that it would be a program that worked on the Internet and on the mobile phone. And there are two programs, but the content is different, so you have only prevention on the Internet or after care on the SMS. So there were all kind of technology things that had to be discussed before we decided what to do.* (Interview with M, mini-project leader for the eating disorder project)

Patients and clients, too, played a role in the development of an ICT system. Depending on the system, patients and clients were developed to interact directly with clinicians through a website or patient portal, clinicians at multiple locations were planned to have the ability to interface with a patient's record, and/or project leaders and clinicians were planned to be able to review the information of large sets of patients for patterns and quality control.

> *They [the patients] can choose their treatments. And all those steps we have laid out in our ICT scheme.* (Interview with X, project leader with the CVR project)

However, not all patients were expected to want to participate directly in an ICT system, or have the skills to do so at this time.

> *Well there are patients who say "I do not want that my information is put in the software system" so we have a form that they can sign if they do not what that.* (Interview with B, project leader with the diabetes project)

Integrating projects into the larger healthcare system

As the projects were funded for a short amount of time, the project leaders recognized the need to integrate the projects into the larger healthcare system if they want to make lasting changes to the delivery of healthcare. This effort to integrate projects into routine care often involved the development of program plans, budgets, the hiring of new staff, and/or the training of existing staff. Some project leaders saw the projects as an opportunity to expand the scope of the projects and create a system for the management of chronic disease in general at their sites.

> *The third step is to make the disease management program a multi-morbidity program. These steps are further integration into chronic care. The project is a model for all future chronic care programs. We don't believe in a system for separate projects for multi-morbidity... One program.* (Interview with V, project leader for the multi-morbidity project)

> *And the second thing there is trying to make it more a disease management than only one chronic care model. For COPD and cardiovascular, we know that we are going to introduce also the chain system, so we're trying to make the base ready for other chronic care systems.* (Interview with B, project leader for the diabetes project)

> *Other members of the project leadership team are working with clinicians to imbed the current changes into the current healthcare delivery system. So they have to integrate it in their daily work….in their practice. That's a very big step to get it implemented there and instruct all the other employees in the practices.* (Interview with R, outside expert at the COPD project)

However, project leaders found that working with clinicians to think beyond the project and beyond their currently defined roles could be a challenge.

> *That's the biggest challenge. Because we are all professionals at this moment. It's very difficult to connect the clinic with the outpatient clinic. Ah, I think that we are, as professionals, able to want to look further than our little business. It's the same old story with all the professionals in healthcare.* (Interview with K, project manager for the eating disorder project)

For the project leaders, the disease management programs are an iterative process, with ongoing efforts made to improve the programs and the care that they help provide.

> *The program is not the answer, only an answer. We have to have the courage to change again without always being on the move.* (Interview with S, department head at the eating disorders project)

DISCUSSION

In this study, disease management programs, as defined by the elements of the Chronic Care Model, were analyzed as a traveling technology. A traveling technology refers to the translations, adaptations, and expenditures that occur when an object or program moves from one location to another; traveling was more than the translation of the disease management projects, as it encompassed the translation of the disease management programs to the local setting, but focused on the travel expenditures and travel documents created in the process [27]. As a result, project leaders played an important role in this process, especially during the development and early implementation phases. It is important to note that the traveling expenditures of the programs were much more than financial, and include the social costs and changed expectations, the administrative effort, and the altered obligations for patients and staff; these traveling expenditures were often hidden and, in many ways, unexpected by the project leaders.

Through management and organizational work, the project leaders served as 'travel guides' for the programs, as they oversaw the expenditures of the programs, helped guide the travel of the disease management programs to an individual clinician's offices, assisted clinicians involved in the projects in the travel of the programs to and with patients, and connected the disease management programs to a global disease management community. Much of this work involved the creation and management of documents involved in each of the aspects of the disease management programs; these documents included framing documents, such as revised project plans, and communication documents, such as emails to clinicians and newsletters. Each aspect or theme of disease management (changing the healthcare system, patient-centered care, technological systems and barriers, and integrating projects into the larger healthcare system) involved the creation or management of documents or communications (including telephone and in-person communication) by the project leaders. As can be seen in the interviews, project leaders were frequently communicating with the clinicians and editing ICT plans to match the available computer programs. These documents traveled the technology, both literally (as a newsletter moves from the project leader to the clinician) and figuratively (as the documents house strategies and networks for the traveling of the programs).

While disease management programs have been widely touted as a method of reducing costs in healthcare delivery, research has shown that the implementation costs can have a large financial impact [28]. However, the costs of developing and implementing a disease management program were more than money and effort. These traveling expenditures included the making and managing of program documents, the developing and maintaining of relationships and networks, the re-shaping of roles and responsibilities of patients and clinicians, and the adapting and moving of regulations and policies [29]. In the five disease management programs, we saw that project leaders were aware of these traveling expenditures. This can be seen in the project leaders' statements about the development and implementation of ICT systems, as well as in discussions of clinician training. The time needed to refine and develop the programs, to manage the timeline of the programs in relation to the ICT system, and to negotiate relationships with software developers are all expenditures that the project leader must manage, even when many of the expenditures are out of his/her control.

While it might be assumed that as 'travel guides,' the project leaders were in control of the projects, this was not unvaryingly true. In fact, control and traveling of the programs shifted between the project leader, outside contractors, clinicians, and patients. In some cases, the project leader actively moved the control, such as by working to change the role of the patient to one that was more self-managed, while in other cases, both the control of the programs and its traveling moved in spite of the actions and desires of the project leader. This movement of control could be seen in the project leaders' statements about the development of ICT programs and in their thoughts on the challenges associated with the changed roles for clinicians in regard to patient self-management. However, while the project leader may have been (in title and in role) in charge of the project, the traveling of the disease management programs was also reliant on the actions (and inactions) of the local clinicians, patients, and outside contractors.

The disease management programs, in line with the elements of the Chronic Care Model, were implementing some form of computer-based health system. These computer-based health systems were designed to enable the flow of information between clinicians in multiple locations, connect clinicians and patients, and organize the work of the programs through communication and the posting of project plans and meeting notes. Yet computer-based health systems in general are still a work in progress for the technological developers and for the end-users [30]. Implementing computer-based systems was and is a major undertaking for healthcare organizations, needing support as well as organizational, cultural, and technical changes [31]; even when implemented, the computer-based system may not provide the improvement in care desired, but may increase mistakes in medical record documentation and medication dosing, and may, in fact, be more difficult for clinicians to use [32]. Developing and using computer-based systems to travel the program to and between healthcare providers, project leaders, and patients was not a simple task but was a 'mutual shaping' of expectations and goals [33]. This mutual shaping can be seen in revised project plans for ICT systems, as well as extended timelines.

Better care for patients with a chronic condition was one of the main goals of the disease management programs. Project leaders saw disease management as a patient-led journey (*it's the process of the client*) that focused on the needs of the patient (*the client knows best*) through self-management. Project leaders worked to travel, to move, both the patients to the program (*to move clients to the clinic*) and the program to the patients. In line with the traveling technology framework, project leaders used movement verbs when discussing patient involvement in the disease management program, highlighting the actions that the project leaders are taking to move the program to the patient. Yet, in line with literature on self-management [34], project leaders saw that self-management has challenges and limitations (*the challenge is to know who needs support and who can self-manage*). Through their understanding of these challenges and limitations, project leaders worked to find ways to travel the programs to the patient in a way that was appropriate and thought to be acceptable to the patients (*one is to provide adequate information but not in professional language but in language that appeals to teenagers, so anecdotally, but to provide information which is at least scientifically accurate*).

While traveling the programs to patients and to the clinicians involved in the programs, project leaders also saw their work as connected to a larger global arena. Globalized language was apparent in the projects (*all the professionals in healthcare, what worldwide they discovered*), tying the project leaders and the projects to a larger movement in healthcare. The project traveled from the global, as defined by the elements of the Chronic Care Model, to the local healthcare providers. Project leaders were aware of the influence of outside models, with some referencing the chronic care or the Chronic Care Model as an influencing factor, and were cognizant of the longer term implications of the projects (*The project is a model for all future chronic care programs.*). This awareness leads to broader efforts when developing the programs, as well as a willingness to be influenced by larger trends within healthcare (*look according to the Chronic Care Model*). The project leaders were responsible for traveling to and from the large global sphere.

Research on disease management programs and the Chronic Care Model is increasingly relevant, as healthcare systems are turning to disease management programs to treat the rising number of patients with chronic diseases. While other research has focused on the implementation of the Chronic Care Model in Belgium [35], where the care of patients with chronic disease was delivered in a primary care setting within a limited structure, this research focuses on the primary care setting in the Netherlands; in the Netherlands, the primary care setting is the typical setting of disease management programs for the care of patients with chronic diseases, including those studied in this article. Similar to the findings in this article (*I have to tell [the GPs] that it's just a project*), research conducted in one large healthcare organization implementing programs based on the Chronic Care Model found that physician engagement could be difficult due to lack of commitment, lack of time, and change fatigue [36]. Other researchers in the US have shown that while healthcare organizations using collaborative teams can make substantial changes in the delivery of care for patients with chronic diseases, these changes can be difficult to maintain at the same level of intensity [37]. As the research conducted in this article is during the planning and early implementation stages of disease management programs, it will be useful to observe the evolution of the disease management programs as a traveling technology over time.

This article presents information that could benefit project leaders of disease management in understanding the longer term implications of their work in both global and local arenas. This information could be especially useful to project leaders within the Netherlands or who are new to disease management programs. This data shows how project leaders adapt to and adopt new systems. The qualitative data on which this article builds give important insights into how project leaders, especially project leaders who are new to disease management programs, struggle with and overcome challenges involved in interacting with a traveling technology such as the Chronic Care Model. Understanding how project leaders struggle with and overcome these challenges will help facilitate the development of better supportive structures for disease management projects, as well as the development of more comprehensive project plans and budgets.

However, the paper is limited by the number of interviews. As the interviews were conducted in the early stages of the programs, only 11 interviews were available. In the case of the eating disorders project, where multiple mini-projects are being conducted as part of the larger disease management project, each mini-project leader was interviewed. As this research follows the project leaders and programs over time, this will be improved in future research and will show not only how project leaders work with and through the Chronic Care Model, but will also reveal how GPs and other clinicians adopt and adapt to the project leader's guidance. While the limited number of interviews may impact the conclusions, the use of these interviews is still relevant; the mini-project leaders serve a similar role as the project leaders at other sites, overseeing the projects, project staff, timeline, communication with patients and/or other clinicians, and the content of the mini-project.

CONCLUSION

This study has revealed that disease management project leaders serve as 'travel guides' when a disease management program is seen as a traveling technology, and adds to the understanding of how disease management programs are developed and implemented in the primary care setting. Through the project leaders' interpretation, translation, adaptation, and adoption of the tenets of disease management, as well as through the management of travel expenditures, the disease management programs traveled not only from global notions of disease management, but more importantly, the programs traveled within the network of the project teams: from the project plan to implementation, from the project leader to the clinicians, and from the clinicians to the patients.

As 'travel guides,' project leaders should be aware that the impact of their work is both deeper and broader than they may realize, as the disease management programs are traveling throughout their project teams. In many ways, project leaders set the overall tone of the project – the focus and the sentiments behind the disease management program. Their work not only guides the overall project, but impacts the interaction of one clinician with one patient, as well as traveling to the broader disease management arena through participation in research, through the development of care consortiums, and through the honing of standards and protocols within the Dutch healthcare system.

Understanding the beginning stages of implementing a disease management program (at the project leader level, as well as at the health systems level) can be helpful for other programs and health systems. Other healthcare clinicians can benefit from this work by understanding that the development and implementation of disease management programs is also the implementation and development of a traveling technology, with associated traveling expenditures and roadblocks. Through this, other project leaders can understand that their work has broader implications, both within their own program and as part of a larger disease management community. Much can be done at the project development phase to aim for smoother implementation, though every project will still face travel expenditures. Project leaders should pay more attention to the lasting effects of their work in all of the arenas it touches. This attention can come through more forethought on the implications of their project as a traveling technology, more research on the various elements involved in the project, such as ICT systems, and more funding allocated to project leadership and project leadership development during the development and early implementation phases of the project. Project plans can allow for more hours for project leadership, as well as a more flexible timeline to allow for overcoming roadblocks and overseeing traveling expenditures.

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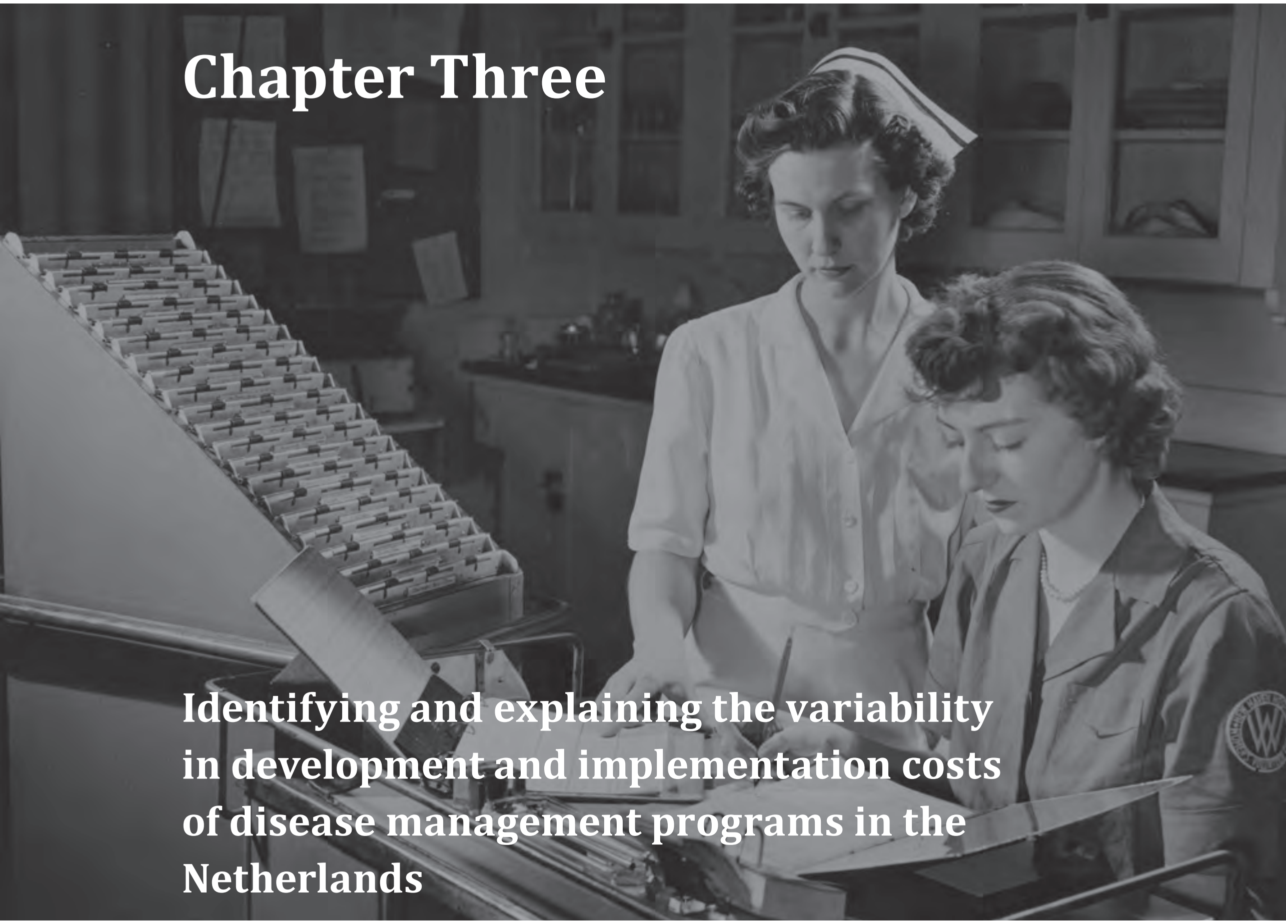

Chapter Three

Identifying and explaining the variability in development and implementation costs of disease management programs in the Netherlands

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ABSTRACT

Background

In the Netherlands, disease management programs (DMPs) are used to treat chronic diseases. Their aim is to improve care and to control the rising expenditures related to chronic diseases. A bundled payment was introduced to facilitate the implementation of DMPs. This payment is an all-inclusive price per patient per year for a pre-specified care package. However, it is unclear to what extent the costs of developing and implementing DMPs are included in this price. Consequently, the organizations providing DMPs bear financial risk because the development and implementation (D&I) costs may be substantial. The aim of this paper is to investigate the variability in and drivers of D&I costs among 22 DMPs and highlight characteristics that impact these.

Methods

The data was analyzed using a mixed methods approach. Descriptive statistical analysis explored the variability in D&I costs, as measured by a self-developed costing instrument, and investigated the drivers. In addition, qualitative research, including document analysis and interviews, was conducted to explain the possible underlying reasons of cost variability.

Results

The development costs varied from €5,891 to €274,783 and the implementation costs varied from €7,278 to €387,879 across DMPs. Personnel costs were the main component of development. Development costs were strongly correlated with the implementation costs ($\rho = 0.55$), development duration ($\rho = 0.74$), and number of FTEs dedicated DMP development. Organizations with large size and high levels of care prior to the implementation of a DMP had relatively low development costs. These findings were in line with the cross-case qualitative comparison, where programs with a longer history, more experienced project leadership, previously established ICT systems, and less complex patient populations had lower D&I costs.

Conclusion

There is wide variation in D&I costs of DMPs, which is driven primarily by the duration of the development phase and the staff needed to develop and implement a DMP. These drivers are influenced by the attributes of the DMP, characteristics of the target population, project leadership, and ICT involved. There are indications of economies of scale and economies of scope, which may reduce D&I costs.

BACKGROUND

In recent years, the healthcare community has been struggling to identify strategies to better manage the rise in the number of patients with chronic diseases. In the Netherlands, there has been a 17% growth in diagnoses of chronic disease and a 26% growth of patients with multiple chronic disease diagnoses in the past 8 years [1]. One possible method of managing the changes in healthcare that result from the increased diagnosis of chronic diseases is the D&I of disease management programs (DMPs), as has happened in the Netherlands. The Netherlands Organization for Health Research and Development (Nederlandse Organisatie voor Gezondheidsonderzoek en Zorginnovatie (ZonMw)) funded a research project to stimulate the implementation of DMPs and study their impact.

Twenty-two healthcare delivery sites were awarded funding to participate in the study by developing and implementing a DMP; the majority of the sites were primary care cooperatives. In exchange for funding and support, each of the sites agreed to participate in research and put a DMP into place. Disease management was defined by the funding organization as:

> *a broad programmatic approach to chronic diseases, and a comprehensive care chain of diagnosis, treatment and counseling, as well as prevention, early detection and self-management. The approach is based on multidisciplinary care standards and is organized around the patient and his condition, as much as possible, in conjunction with his surroundings.* (Call for proposals, page 7)

In the programs proposed by the care delivery organizations and in the literature about DMPs, patients' participation in the treatment and management of their condition is a key component of DMPs [2], as is the involvement of multiple medical professionals in care planning and delivery [3], and the development and implementation of information systems (most frequently computer-based systems) to support chronic disease treatment and management [4]. The development of the DMPs at the selected sites included interventions altering the existing organization of healthcare delivery (e.g. regular multidisciplinary meetings and regular monitoring of patients) and interventions that were implemented as new processes (e.g. case management, self-management support, ICT). A more detailed description of the interventions is given in elsewhere [5].

In addition to funding for research on DMPs, the Netherlands has implemented a new financing system that impacted care for those with common chronic diseases (an overview of the Dutch healthcare system is provided in Additional file 1). In 2010, a bundled payment scheme was introduced in the Netherlands [6]. Bundled payment is a single payment that covers the multidisciplinary care required by a patient for one particular chronic disease during a predefined period of time [7]. The aim of this payment scheme was to improve the access, comprehensiveness, continuity, and other aspects of quality of care for chronic patients and to control the increasing expenditures for healthcare for patients with a chronic disease. In the first year of this funding reform, only care for diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD), and cardiovascular risk (CVR) could be contracted in a bundled payment. Under the new payment scheme, chronic care is coordinated by groups of healthcare providers (called ‘care groups’). The bundled payment is negotiated between care groups and health insurers and includes 1) the costs of multiple caregivers in primary care (e.g. general practitioners, practice nurses, nutritionists, physiotherapists, and lifestyle counselors, but not medicines, diagnostics, and medical devices) as well as 2) the costs of care coordination, 3) information and communications technology (ICT), and 4) professional training and courses for healthcare providers. The latter three groups of costs can be seen as costs for the development and implementation (D&I) of DMPs.

Since DMPs involve a significant reorganization of healthcare delivery, they require substantial development costs (including but not limited to training costs, ICT costs, and costs of redesigning the care delivery process) and implementation costs (such as multidisciplinary team meetings, the costs of coordination between care-givers, the costs of monitoring and feedback). These costs are commonly carried by the organization that implements the program (i.e. care groups). To which extent the D&I costs of DMPs are included in the bundled payment is often unclear. This is despite recommendations to report these costs separately from the healthcare utilization costs and to include them in the price of implementing a DMP [8].

However, some insurers, including the largest one in the Netherlands, are not convinced about the benefits of bundled payment and do not provide this type of funding. Rather, these health insurers provide an add-on payment to cover the D&I costs, whereas the cost of healthcare is funded as before. It is not clear how this add-on payment is defined and to what extent it covers the D&I costs [9]. Considering this uncertainty and taking into account the substantial D&I costs of a DMP, care groups need to be able to correctly anticipate the D&I costs. Failing to do so could be financially disastrous for the providers of DMPs, and serve as a disincentive for the implementation of DMPs.

The aim of this paper is to investigate the variability in and drivers of D&I costs among various DMPs and highlight characteristics of the DMPs that may explain the variability in costs during the project period.

Study setting

The research for this paper was conducted as part of an evaluation of 22 Dutch DMPs spread across different regions of the Netherlands [5]. The DMPs were categorized in CVR (n = 9), COPD (n = 4), DM (n = 3), mental diseases (n = 3), and other (n = 3). The ‘other’ disease category includes DMPs for stroke, heart failure, and mix of CVR, COPD and DM. The Ethics Board of Erasmus University approved the data collection. All content has been anonymized.

METHODS

We used a mixed-methods approach to analyze data on D&I costs. To this end, we used descriptive statistical analysis to explore the variability in D&I costs, as well document analysis and interviews with project leaders, managers, and professional care givers.

Quantitative methods

All development and implementation costs associated with the 22 DMPs were systematically collected. We developed a template that was based on the CostIt instrument of the World Health Organization (WHO) [10]. This template was completed during face-to-face interviews with DMP managers. During these interviews we also asked managers whether they had additional financing to cover the specific elements of disease management. The development costs included all costs made during the preparation phase of DMPs, e.g. labor costs for brainstorming sessions, training costs, and ICT support costs. The implementation costs included costs of multidisciplinary team meetings, coordination between care-givers, monitoring, and feedback that occurred the year after the DMP implementation. We collected the development and implementation costs regardless of the budget holder for their financing; the budget holders could include care groups, health insurers, and/or government. The labor costs were calculated using the full-time equivalents (FTEs), duration of involvement in the project and the gross salary of medical, administrative, ICT, management and other personnel. Operating costs (including costs of professional courses, information/communication, licenses, and materials) were calculated based on volumes and unit prices as stated in the template. Capital costs (such as building and purchase of ICT) were calculated based on their volume (for buildings, that was square meters) and unit prices (for buildings that was Euro per square meter) and they were amortized over their lifespan as suggested by the WHO [10]. In the analysis, we included the development costs during the development phase, the annualized development costs, and the implementation costs in the year after implementation.

In addition to D&I costs, we also collected data about the duration of the development phase (in months), the number of patients participating in a DMP, the total FTEs available to the organization providing a DMP, and the FTEs dedicated to developing and implementing the DMP. The level of chronic care integration was also measured at the start of providing a DMP and a year later by using the Dutch translation of the Patient Assessment of Chronic Illness Care (PACIC) [11]. This questionnaire was distributed to participants of 19 DMPs (no data for the 3 mental disease DMPs was available). The mean PACIC value of the participants in each DMP was used in the analysis.

Descriptive statistics were used to investigate the variability in D&I costs among 22 DMPs. Pearson correlation coefficients and Spearman correlation coefficients were calculated for normally distributed and non-normally distributed variables, respectively. The normality was tested based on the Kolmogorov-Smirnoff test. We also performed an analysis of variance based on ANOVA and Kruskal-Wallis estimates to explore differences in the development and implementation costs among disease categories. We also performed an analysis of variance to investigate differences in D&I costs among different payment methods during the development and implementation phases. The payments were categorized in normal (e.g. for GPs this is a mixture of fee-for-service and capitation payment), normal plus add-on payment for D&I costs, and bundled payment. Considering the small number of observations (n = 22), we also looked into various associations using scatter plots and graphs.

Qualitative methods

In order to understand how various characteristics may influence the costs associated with the D&I of DMPs, we examined how program plans 'travel' from the grant proposal to the D&I of the DMPs [9], as well as what actually happened during the D&I phases of the program, by exploring and analyzing the multiplicity of D&I in practice [12]. This approach enabled us to gain a deeper knowledge of the activities implicit in DMPs, including activities that influence how programs develop, how programs use the provided finances, and how project teams overcame (or not) difficulties in the early stages of programs.

Document analysis was the first step of the qualitative data collection. The documents analyzed included the grant applications and project plans submitted by project leaders, the call for proposals (Diseasemanagement chronische ziekten), and care organization websites. The documents were analyzed inductively to gain a better understanding of the DMPs, project leaders, and care providers. The content of the documents informed the development of the interview guide, which focused on D&I of DMPs in practice.

Two in-depth case studies were selected for this paper, which highlight the different D&I costs in the DMPs; 15 interviews with project leaders and clinicians were conducted and used in the case studies presented in this manuscript. Questions about the history and contexts of the DMPs were asked. Interviews were digitally recorded, and detailed notes and observations were also made during the interviews. Interviews were conducted in Dutch or English and ranged from 30 minutes to 90 minutes. Interviews were transcribed and coded into themes. Quotes were translated by a native English speaker; the translations were later confirmed by a native Dutch speaker.

To better understand the variability in costs from a mixed methods perspective, the primary economic researcher (AT) and the primary qualitative researcher (BHW) met regularly and jointly reviewed the data. The economic and qualitative data have been integrated iteratively, after consensus by all authors. This was done through frequent meetings between the first two authors and the rest of the authorship team.

Ethics statement

The study protocol was approved by the ethics committee of the Erasmus University Medical Center of Rotterdam (September 2009). For more details see Lemmens et al., 2011 [5].

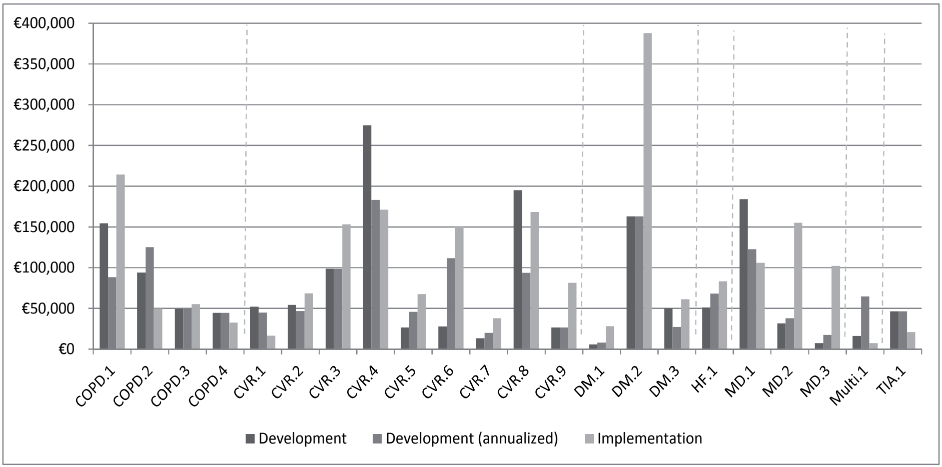
RESULTS

Adequate understanding of complex policy structures and the impact of their change requires multiple types of information. Mixed-methods research facilitates this by combining qualitative and quantitative research methods in order to identify, decompose, analyze, and understand complexities in healthcare [13]. Our research found a large variability in D&I costs between the researched DMPs. We uncovered three common characteristics of the studied DMPs that may explain the variability in costs between programs. These characteristics included attributes of the interventions, ICT systems, and the experience of the project leaders. The history of the programs, including personnel time invested and ICT systems already in place, may have also played an important role in the variability in costs and was an underlying characteristic.

Variability in D&I costs and cost drivers

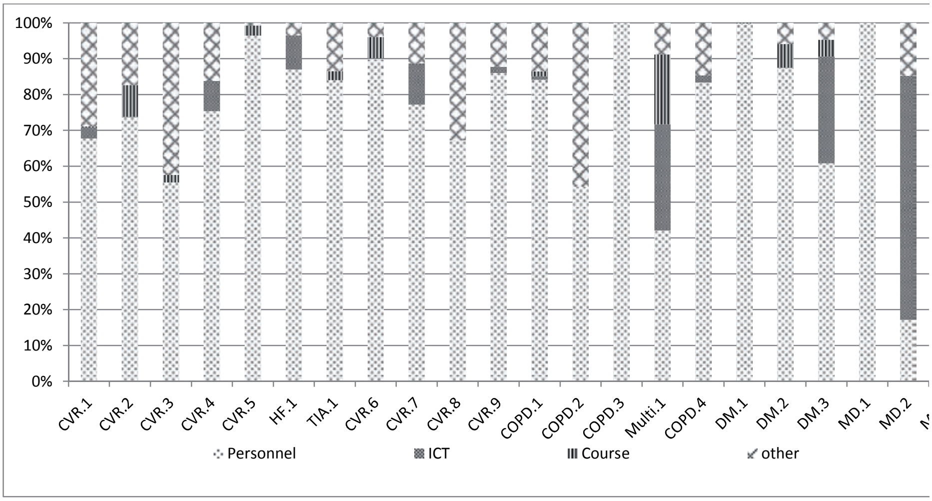
As Figure 1 shows, the development costs varied from €5,891 to €274,783 across DMPs, and the implementation costs varied from €7,278 to €387,879 across DMPs. There was also large variation in D&I costs across DMPs in the same disease category. In some cases the development costs were higher than the implementation costs and in some other cases not. In addition, the four DMPs with the highest development costs among all DMPs also had the highest implementation costs. When annualized, the development costs varied also largely between and within disease categories and were also positively associated with the implementation costs.

Figure 1. Development and implementation costs per DMP



Personnel costs were the primary component of development costs across 18 of 22 DMPs, accounting for more than 60% of total development costs (Figure 2). They were followed by ICT costs (maintenance and licensing) and the costs of professional courses as the main cost components of development costs.

Figure 2. Share of total development costs per cost component



The results from the descriptive statistical analysis are presented in Table 1. This table shows that our sample consisted of DMPs varying in the duration of the development phase (range: 3; 25 months), number of patients participating in the DMP (range 75; 3,400), total number of FTEs in an organization (range 1; 2,850), and number of FTEs involved in developing a DMP (range: 0.1; 2.5). The mean development costs were €75,832, the mean annualized development costs were €69,749 and the mean implementation costs were €100,827 across all 22 DMPs. The mean PACIC at implementation was 2.88 and a year later was 2.95. The Kolmogorov-Smirnoff test showed that the variables 'number of DMP participants,' 'organization FTEs,' 'development costs,' 'PACIC at implementation,' and 'PACIC a year later' were not normally distributed.

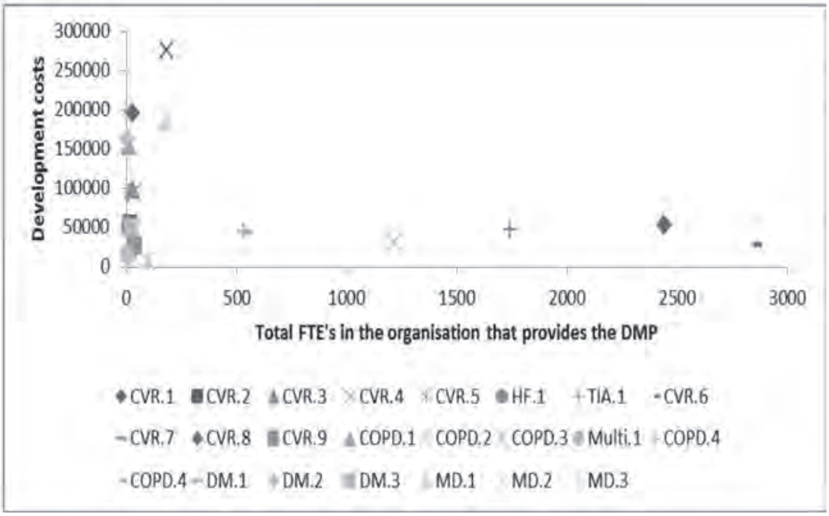
Table 1. Descriptive statistics

	Mean	SD	Median	Min	Max	IQR
Development duration (months)	12	6	12	3	25	6
Patients participating in DMP#	801	986	300	75	3,400	957
Organization FTEs#	433	841	33	1	2,850	256
DMP FTEs	0.76	0.58	0.60	0.10	2.50	0.63
Development costs#	75,832	72,727	49,972	5,891	274,783	85,917
Annualized development costs	69,749	47,807	48,141	7,855	198,188	66,704
Implementation costs	100,827	86,776	74,836	7,278	387,879	117,079
PACIC at baseline# (1-5 best)	2.88	0.29	2.81	2.25	3.60	0.35
PACIC at year 1# (1-5 best)	2.95	0.28	2.99	2.44	3.62	0.40

The Kolmogorov-Smirnoff test rejected the assumption of normally distributed data; SD: standard deviation; min: minimum; max: maximum; IQR: interquartile range (Quartile 3-Quartile 1); FTE: full-time equivalent; implementation costs accrued within the first calendar year of DMP implementation

The relation between development costs and the total number of FTEs in the organization that provides a DMP is illustrated in Figure 3. This figure shows that large organizations had relatively low development costs compared to small organizations. This relation remained between the annualized development costs and the total number of FTEs in the organization that provides a DMP (see Additional file 2: Figure S4).

Figure 3. Association between development costs and total number of FTEs in the organization



The relation between development costs and the total number of FTEs in the organization that provides a DMP is illustrated in Figure 3. This figure shows that large organizations had relatively low development costs compared to small organizations. This relation remained between the annualized development costs and the total number of FTEs in the organization that provides a DMP (see Figure 4 in Supplementary File 2).

Figure 4 illustrates the relation between implementation costs and the number of patients participating in a DMP. We see that there might be a small negative relation between the two variables.

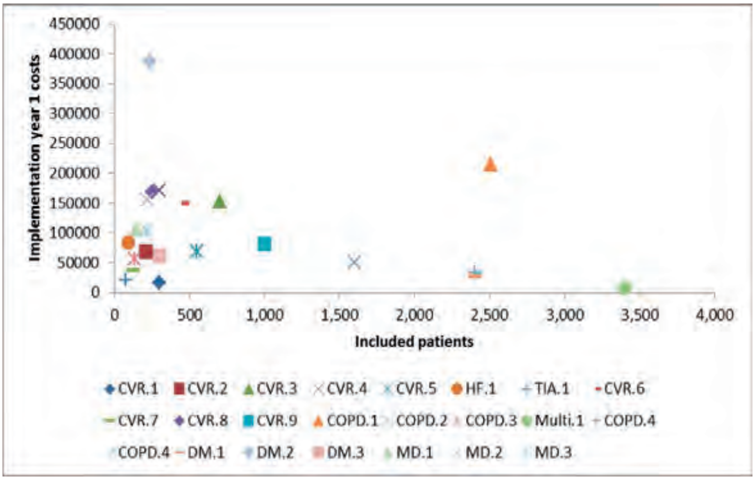
The results of the analysis of variance of D&I costs comparing different payment methods as well as different disease categories were not statistically significant. Figures illustrating these variances are presented in Supplementary File 2.

Table 2. Correlation coefficients

	Development costs	Annualized development costs	Implementation costs	Development duration	DMP participants	Organization FTE’s	DMP FTE’s	PACIC baseline	PACIC year 1
Development costs	1								
Annualized development costs	0.79 (0.000)	1							
Implementation costs	0.55 (0.008)	0.65 (0.001)[#]	1						
Development duration	0.74 (0.000)	0.24 (0.284)[#]	0.27 (0.228)[#]	1					
DMP participants	-0.12 (0.600)	0.02 (0.922)	-0.08 (0.707)	-0.09 (0.688)	1				
Organization FTE’s	-0.03 (0.887)	0.02 (0.940)	-0.00 (0.988)	-0.03 (0.880)	-0.14 (0.549)	1			
DMP FTE’s	0.54 (0.010)	0.52 (0.013)[#]	0.16 (0.482)[#]	0.49 (0.022)[#]	-0.04 (0.869)	-0.35 (0.110)	1		
PACIC baseline	-0.22 (0.366)	-0.02 (0.937)	-0.21 (0.388)	-0.24 (0.323)	0.21 (0.380)	-0.40 (0.095)	-0.29 (0.232)	1	
PACIC year 1	-0.27 (0.051)	-0.08 (0.049)	-0.24 (0.044)	-0.21 (0.396)	-0.23 (0.350)	-0.02 (0.932)	-0.28 (0.909)	0.64 (0.003)	1

[#] Based on Pearson correlations; FTE: full-time equivalent; in brackets are the p values of the correlation

Figure 4. Association between implementation costs and number of patients participating in a DMP



Characteristics of the disease management programs

While each of the practice sites had a different method of addressing chronic disease through the funded DMP, the qualitative research uncovered characteristics that help to understand the differences in D&I costs. These characteristics included attributes of the DMP, ICT systems, and the experience of the project leadership teams. Qualitative data from two case studies will illustrate these characteristics. The diabetes case (DMP number 17) had relatively low D&I costs, while the CVRM case (DMP number 10) had high D&I costs.

Case study: Diabetes (DMP number 17)

One of the project sites with a focus on adult-onset diabetes developed a DMP for clinicians and patients. The clinicians and project leaders at the site have invested time and effort in improving diabetes care for patients since 1999 by working in cooperation with the hospital and specialists, developing care protocols, and contracting with providers. Around 2006, the changes in diabetes care were formalized into an early form of disease management. The studied program was a continuation of a previously funded program. This site had two project leaders, the first of which was hired for the previously funded program to assist with the development of an electronic medical record and stayed on through most of the funded DMP. The first project leader was a professional healthcare consultant with a background in economics. The second (and current) project leader was the assistant of the first and took over the project leadership when the first project leader left, after a period of mentored transition.

Program attributes

For the disease management study, the project leaders worked with healthcare professionals to change how they thought about care and creating multidisciplinary care teams, implemented an updated networked electronic medical record system with a patient portal, and oversaw self-management education for patients.

The multidisciplinary care teams included nurse specialists, nutritionists, general practitioners (GPs), nurses, chronic disease specialist assistants, ophthalmologists, podiatrists, and/or internists; members of the care team were located in multiple GP and specialist offices throughout the region. The care team worked together, communicating with each other frequently.

> *I think that working closely with the nutritionist especially... We sit together, we discuss a lot, and we can call the GP or practice nurse, and yes, several people are looking [at the case].* (Interview with diabetes specialist nurse)

Communication was seen as key to coordinating care. It was common for the staff, such as doctors, nurses, nutritionists, and other clinical professionals, of disease management teams to sit together in a shared office and communicate about patients and care; however, this was not the only way that communication happened. The diabetes program had regular meetings with clinical professionals from multiples GP offices with the project leader overseeing the meetings. The project leader also sent out emails, reports, and posted information about the DMP online. Clinicians also communicated with one another through the networked electronic medical record. This system of coordinated care had been developed by investing in time for the project leader and clinician stakeholders over the years of the program.

One of the efforts of this disease management project focused on self-management through educating patients about diabetes. There were a variety of formal and informal educational opportunities for patients: group classes, clinical visits, and online. Patients could participate in voluntary classes, which were led by a nurse, doctor, and/or non-physician chronic disease specialist assistant. Clinicians were trained to lead by experts in diabetes education, an additional D&I cost-item which was hoped to be recouped in a reduced need for individual education sessions with patients. However, the classes were no longer offered as a result of lack of patient interest and attendance.

Information and Communications Technology systems

For the diabetes project, as is the case for many medical practices, the full development and use of an electronic medical record (EMR) was a complicated process. The GP offices involved in the diabetes project began working with software developers in 2006 to develop a more-limited version of an EMR. The project leaders, especially the first project leader, worked with clinicians and software developers to enhance the record. The newly enhanced record allowed for viewing the record by multiple clinicians (and the project leaders) at different physical locations, electronic referrals, and messaging between clinicians and between clinicians and patients.

Information and communications technology (ICT) systems, such as the EMR, have been seen as a remedy for the many predicaments in healthcare delivery and quality, one that promises more than is realized in most cases [14]. The implementation of ICT systems in healthcare delivery has been a lengthy process for project leaders and clinicians involved in the DMP, requiring planning, developing, implementing, and tailoring the system before the system can begin to meet the needs of clinicians and patients. At this site, the development of the ICT system began well before the program was funded as part of the study. By working with a previously developed system, this project leader and leadership team had the opportunity to gain the needed support from stakeholders, as well as work through the inevitable bugs and challenges in the system before the funded DMP officially began. These challenges included:

> *The fact that the software builder couldn't deliver what they said they would deliver. And still now we do not really have the perfect system and the perfect system does not exist, I know. But there are too many things that we want. But, there is no other software builder at this moment that DOES have it. The software builder itself has been in bankruptcy two times, once in 2007 and 2 months ago for the second time. Fortunately they worked together with another department who had been able to go on with the system, so that we were not cut off.* (Interview 1 with project leader 1)

As noted in the quote above, the investment of staff time and the hurdles that frequently occur in the early development phases of a networked electronic medical record occurred, in part, before the study and in the early phases of the study. Since the computer program had already been chosen, the time and effort needed to select a computer program and coordinate the program with existing record systems were not part of the study. As a result, much of the development work and growing pains of implementing an ICT system were not seen in the D&I costs for this aspect of the DMP.

One of the goals of the funded portion of the DMP was the D&I of a patient portal for the networked electronic medical record. While the project team was able to develop a patient portal in a timely manner, the development of the portal does not guarantee usage.

> *Yes, we do have that but no-one uses it. We have talked and talked to get people to look, [telling patients] you have your own care dossier, your own plan, we can agree on goals there, you can report on how it is going, you can also tell us what does not go well, or if you have questions. Really easy, you can do that from your chair at home, you don't have to come here if you don't want to. But people don't want that. It has cost money, because in order to offer the portal we had to expand our software package. Of the current 2700 people with diabetes I believe 15 now have a care plan.* (Interview 1 with second project leader, diabetes project)

While rates of patient participation in the portal were low, the numbers were expected to increase in the future as more internet-friendly patients are diagnosed. Though the usage remains low, this D&I cost is expected to have lasting impact well after the project period.

The networked electronic medical record has traveled from plan to action successfully in principle, in that the portal was developed in a timely and cost-effective manner, but not in the current day-to-day reality of the program, as very few patients used the portal at the time of the interview. This investment in future patients via a patient portal can be seen as a D&I cost. While the patient portal was successfully developed from a technical point of view, the implementation in practice will still require much effort on the part of the clinician, the project leader, and the expected future patients, who too must learn how to use the new system and whose time is frequently overlooked in accountings of D&I costs.

Project leadership

The cooperation hired an experienced project leader to oversee the diabetes DMP. Much like the groundwork done with the ICT system, the hiring of this first project leader occurred before the funding of the study. The project leader saw her role as giving support, both material and strategic:

> *And I think that a unique thing is that what I do is I'm able to give support on the strategic thinking… where do you want to go to, what are the goals, what's your mission, what's the gain of it. And the second is how can we achieve that. So it's not a consultant with only the advice but also what does it take to get there.* (Interview 1 with project leader 1)

The first and second project leaders led meetings, created reports from data extracted from the networked electronic medical record, and coordinated the efforts of the study team, such as sending out surveys. When the project leader resigned, she passed the role on to her assistant.

Effective leadership is crucial for bringing projects to life. In fact, in their seminal article on DMPs, Wagner et al. [3] pointed out that making the change needed for DMPs is "difficult, if not impossible, without strong leadership". Leadership support was (and, in general, is) needed for multiple aspects of the DMP: for the successful implementation of a health ICT system [15], to guide the vision of the improvements in chronic care treatment and management [2],[16], and to facilitate change in the healthcare delivery [17]. Yet project leadership skills and efficiency, in general, grow over time, as the project leader gains the trust of the clinicians, as the project leader is better able to understand the needs of the clinicians and patients, and as the project leader and the clinicians are able to adapt to one another.

Case study: Risk of cardiovascular disease (DMP number 10)

A DMP conducted in two GP offices focused on improving care for those with an elevated risk of cardiovascular disease. The project team consisted of two GP-researchers (one of whom served as a part-time project leader) and a nurse manager, who did the day-to-day management of the program and study. As written in the grant proposal, the key elements of the program were:

a) *a patient choice program to promote a commitment to the formulated treatment goals*

b) *a focus on reaching people with a low socio-economic status (SES)*

c) *the use of a web-based patient record* (Grant proposal)

This DMP was a newly formed project, developed by the GP project leader who had recently completed a Masters in Healthcare Management from a nearby university.

Program attributes

The disease management project focused on providing coordinated care with multiple clinicians to a challenging population: patients with an elevated cardiovascular risk and a lower SES.

> *We have many patients, about 20% of the patients in the GPs practices are known to the GP as having one form of elevated cardiovascular risk. That's a very big number of patients. Of those patients, about 8 or 9% are under regular control of the GP. And from those, a small part has a low SES. Especially patients at low SES do not follow our advice; you can see that as you look at the numbers. Most people, more people at low SES, dying of cardiovascular diseases, more people smoking… That's the most important start of our project. And we don't reach people with low SES, so we are looking at new methods of treatment of people with low SES.* (Interview 1 with project leader)

The patients with a lower SES were, and commonly are in healthcare, seen as a tricky population with multiple problems, less access to resources, and lower rates of literacy. Providing care and self-management education to this population was expected to be (and was) challenging for the project leadership team and clinicians, requiring a significant time investment. To be overcome, these challenges required effort on the part of the clinicians, patients, and project leaders.

Much of the investment of time for project leaders, in general, comes in the early stages of the DMPs. As time goes on in the course of programs, project leaders develop a better sense of the population and are better able to tailor attributes of the DMP to the needs of specific populations. This was the case in the CVRM program, as the project leader noted below:

> *Then we ask the patient, do you want to look at your own patient file on the internet? And when he says yes, he can open his own file and see his own cardiovascular risk profile on the internet. Because we suppose that not every patient with low SES has a computer at home or can look at his file on the internet. So that's why we ask this to every patient.* (Interview 1 with project leader)

This patient population required (more) time and effort from project leaders, clinicians, and medical office staff, as the patient population may not have had internet access, may have spoken limited Dutch, and may have had fewer economic and social resources for support. Accommodating this population to ensure good care required time during the clinical visit and, for the project leaders, time during the D&I of the DMP.

However, the challenges with the patient population were not the only challenges that the project leadership faced.

> *Well, you've got to separate the problems: content level and organizational level. Content, I think, it actually runs smoothly. We must, of course, continue to develop, but that is going the way we want. Organizationally we have some problems. [Primary care] practices are (...) very large organizations now. So before we begin, we have to convince everyone of the importance of the research. That takes a lot of effort. Plus the implementation of such a project, in practice is not simple because practices are large organizations where 30 people work. Plus there are other members of the care group that need to be involved: the physiotherapist, the nutritionist.* (Interview with the project leadership team)

Effort and accommodation, in the form of meetings, telephone support, and emails, was needed to assist the clinicians in implementing the changes needed for implementing a DMP and for conducting research on the program.

Information and Communications Technology systems

As was seen in many other projects, the D&I of the networked electronic medical record required much time and effort over the course of years; this effort included working with outside vendors, outside educators, and outside funding agencies, as well as working with clinicians and GP office staff. The effort did not stop; changes and further tailoring continued after the record was in place. The project leaders and manager were key in these activities.

> *And for the development of cardiovascular risk management, this is how far we are now: we have funding. We are now working with contract negotiations. And then we can start developing and the ICT supplier, if they are fast, can get us a beta version in three months' time. We hope that we can really start with ICT in March, February… well, of course it is a problem to get financing. A negotiation problem. Yes, but we are happy that we have had luck.* (Interview with the project leadership team)

Because health insurers provided some of the financing needed for the D&I of the networked electronic medical record, there was much coordination work needed. Health insurers required extensive plans, budgets, and presentations before financing was awarded. This was in addition to the work needed to develop the record, such as working with the developers and clinicians. Patient portals were included in the development of the networked electronic medical record, allowing patients to go online and access their record.

> *You can see here, patients with active risk. This is what patients can see at home. The treatment goal of this patient was weight reduction of 6 kg in 3 months. And you can see at this point, he has reached a risk reduction of 80% of his goal. ... Here is the plan and what he or she still has to do is treating hypertension and becoming more adher-*

> *ent for medication. But this patient has chosen for weight reduction in a first step for cardiovascular risk treatment.* (Interview 1 with project leader)

While project leaders hoped that the implementation of clinical information systems would improve care for those with a chronic illness, the D&I of the system to this point has come at a significant time–cost in both sites. As Wears and Berg noted, while electronic medical records are often thought of as a panacea for the ills of medical documentation, this is often more dream than reality [14]. To meet the goal of including patients into the patient portal of the new record system, additional time on the part of the clinician and of the project leader was needed, time to tinker with the system, to tailor the system to the needs of the clinicians and of the individual patient, who may or may not have had computer access.

Project leadership

For this two-practice project, project leadership took the form of a team of two GPs and a nurse manager. The nurse's duties included interacting directly with staff at the practices, coordinating the research efforts, and aiding the practice staff as they adopted disease management principles. The work of the project leadership team started:

> *by organizing meetings. That's why we start with 4 meetings and why we start at practice level. Speak with the GPs and the nurses. And we have learned to start slowly, go slowly. I will not tell my GPs to start with 100 patients but will tell my GPs we will start very slowly. ... But if it works, we have to change the practice. I hope it works. But we have to wait for it still.* (Interview 1 with project leader)

Changing the practice was seen to need to begin slowly in order to gain support from clinicians and staff at the two GP offices. The project leader saw this coordination and background work as necessary before large-scale changes in patient care were implemented. While this work can be seen as an investment, it was likely a notable source of D&I costs.

Another significant challenge for the project leadership team was to work to procure additional funding for the DMP.

> *Step by step, we write down [the plan] for the insurance company. Because they will first look at the plan. After they will decide whether to give us some money. And when you are going to visit your GP, the GP will receive 9 Euros. But when you do the visit according to our rules of cardiovascular risk management, we think that the consult will take half an hour so we have asked to the insurance company not 9 Euros but 25 Euros.* (Interview 1 with project leader)

The complete implementation of the program goals cost more time at the patient care level as well as the time and effort invested at the project leader level to procure more funding.

DISCUSSION

The findings of this study show that large variation exists in the D&I costs of DMPs implemented in the Netherlands. This variation can be explained by the large variability in DMP development duration, size of DMP providing organization, and the level of care in the providing organization prior to the implementation of a DMP. The qualitative analysis showed that these characteristics were associated with the attributes of the interventions, project leadership, and the history of the ICT systems used in a DMP.

The DMP development duration was positively related to the labor intensiveness during the development phase and development costs. Considering that the development costs are highly positively correlated to the implementation costs, the length of the development phase was an important cost driver of D&I costs.

The research on the case studies and other qualitative research conducted in the remaining 19 sites highlighted that the D&I of an ICT system was an involved process. While previous literature shows that a well-developed ICT system is one of the main preconditions of successful implementation of bundled payments and DMPs in the Netherlands [6], the work required to develop and implement ICT systems was, at the sites, time-consuming and costly. In the diabetes case study, the majority of the development work involved in implementing the ICT system occurred before the study period, but, nonetheless, the work did happen; however, the cost for this work is not included in the financial data in the diabetes project. As the ICT work (and the costs associated) was included in the D&I period of the CVRM project, this may be an explanation for variation in costs. The D&I of adequate ICT is important for all stakeholders in chronic care. It is important for care groups with the aim of achieving lower D&I costs, for health insurers in order to contract chronic care at lower cost, and for public authorities with the purpose of controlling healthcare expenditure by supporting managed care for chronic diseases. As our data shows, this D&I requires time, financial support, and a flexibility of goals, targets, and timelines, no matter when it occurs or how the D&I is funded.

The qualitative research conducted at the sites revealed that the role of the project leader was an important one, with more established projects with experienced project leaders and managers spending less time on the early development of the programs. Project leaders were responsible for guiding the programs, working with clinicians, delegating responsibilities, and developing contacts with outside funders and vendors. In the studied sites, we saw that in projects with a longer history (and with a project leader with more experience in leading healthcare projects and in the DMP project in specific), the relationships needed for smooth, efficient project management were likely developed in the early years of the programs and the costs for these efforts have not been included in the D&I costs (as was seen in diabetes project). In the CVRM project, these relationships were in the process of being developed during the study in an incremental manner through meetings, developing project plans, and the slow introduction of changes. Project leadership, in general, was especially relevant in that organizational and management failure threaten the successful implementation of disease managed care facilitated by bundled payment in the Netherlands [6].

Project leaders had a fluid role and flexibility within the project, as meeting project goals often requires adaptation. Whether by offering new tools online or printing for patients who have limited computer access at home, this constant adaptation by project leaders and clinicians can be seen as "persistent tinkering in a world full of complex ambivalence and shifting tensions" [18]. Through tinkering, project leaders worked to meet the changing needs of patients, of the healthcare system, and of themselves. Yet tinkering was a slow and often invisible process, as was much of the work of project leaders when tailoring interventions, applying for funding, or working with researchers. This tinkering was constant during the study and programs, but as our data shows, appeared to be more prevalent in the D&I stages, as the project leaders are working with new vendors, systems, and care plans. This prevalence of tinkering in the early stages of a DMP may have resulted in higher D&I costs.

The specific DMP populations, too, may have had a significant impact on the D&I of the DMPs. The CVRM DMP was working with patients with low SES, many of whom were reported to be complex patients with limited access to resources. Accommodating the needs of this population may have required more tinkering, more effort from project leaders, and more time from clinicians. These characteristics could have played a role in the higher D&I costs for this site.

Our findings also suggest that large organizations providing DMPs are more likely to have lower D&I costs than smaller organizations. This indicates the existence of economies of scope where large organizations may have already established ICT systems, managerial knowledge, and available capital in other care (e.g. public health and prevention) and disease areas that can be also used in the development of disease specific DMPs. This is supported also by the negative relation between the existing level of disease managed care (as measured by the PACIC) in the first phase of implementing a DMP with D&I costs. This unveils existing synergies between projects within organizations. The economies of scope may appear financially attractive to DMP providers, since they might increase the profit margin of providing DMPs for different diseases. The provision of DMPs that could address different disease areas and multi-morbidity could also tackle the criticism of the current DMPs: that they are narrowly focused on a single disease, while chronic patients need broader care because they often have one or more other diseases (55% of the patients in our sample have more than one chronic disease). Such a development could also tackle the hesitations of health insurers in contracting DMPs.

Moreover, the minor, though negative, relation between the number of DMP participants and the implementation costs, as illustrated in Figure 4, may indicate the presence of economies of scale. The more patients included in a DMP, the lower the marginal costs of implementation. This can be attributed to fixed costs that are divided by more DMP participants. Capital and operating costs, which are included in the implementation costs, are known cost components subject to economies of scale. This financial advantage of large organizations may attract health insurers to purchase DMP from them, hoping for a lower bundled payment per DMP participant. However, as in all industries, the number of participants that lowers the marginal costs of DMP implementation should be investigated, because further inclusion can lead to higher costs.

Furthermore, we found no evidence of relation between D&I costs and DMP payment method. Similar to case two, many DMPs reported challenges to get additional financing for the provision of a DMP. However, this did not lead in all cases to higher D&I costs. A previous study found a positive relation between additional funding for disease managed care and healthcare utilization costs [19]. Therefore, care groups should be careful in setting the prices of DMPs when negotiating a bundled payment because that price should cover not only the costs of healthcare for the particular disease but also the D&I costs.

There was also no relation found between D&I costs and type of disease addressed by a DMP. That suggests that none of the diseases studied here can be characterized as “cherries” or “lemons” in the chronic care market with respect to D&I costs. This fact may enable the broadening of the scope of diseases that a DMP addresses by making every disease equally financial attractive to care groups.

The 22 DMPs are considered to be representative of the DMPs that have been implemented the last 3 years in the Netherlands because (a) they cover all diseases for which DMPs have been implemented, (b) they include DMPs in primary and/or secondary care (the most common settings for DMPs), (c) they cover a wide variety of diverse regions and geographic areas with different population density and (d) they differ in the attributes of the DMPs put into place and in the structure of multidisciplinary teams [5]. The study population per disease is also representative of the overall disease population in the Netherlands with respect to age and gender.

The findings of this study are relevant to primary care practices in the Netherlands as well as to health policy makers and primary care practices in other European countries that have implemented or are planning to implement DMPs to achieve integration of chronic care. The programs in this study represent a diversity of chronic diseases that can be addressed by DMPs, ranging from common chronic diseases such as diabetes, CVRM, and COPD, to less frequently addressed chronic diseases such as depression, eating disorders, and mental illnesses. The programs, while diverse, had features in common with other DMPs outside of the Netherlands: addressing the issues of chronic illness through coordinated care, through the use of ICT systems, and through the promotion and implementation of self-management education. This research also provides unique insights into the role of project leaders and of the impact of the history of the programs on D&I costs. Policy makers, DMP designers, and primary care practices in the Netherlands and in Europe can explore the possibilities to contain D&I costs at a minimum level by enhancing leadership and ICT in DMPs as well as exploiting existing economies of scope and economies of scale in the provision of DMPs.

CONCLUSION

The conclusions of this paper can be summarized into the following statements:

- There is wide variation in D&I costs of DMPs, which is driven primarily by the duration of the development phase and the labor intensiveness needed to develop and implement a DMP.
- The level of disease managed care in an organization prior to the provision of a DMP is negatively associated with the D&I costs of this DMP.
- Assisting care groups in developing adequate ICT systems for disease managed care is a win-win situation for all stakeholders.
- It is crucial to define the right mix of DMP interventions and target population and to incorporate these mixes in the planning and budgeting of the DMP development phase.
- There are indications of existence of economies of scale and economies of scope, which may reduce D&I costs. Care groups and health insurers should explore the potentials in exploiting them in a mutually benefiting manner.
- The work done before the sites are awarded study funding, especially in relation to ICT systems, saves time and money during the program and study.
- The experience of project leaders may play a fundamental role in the development and early intervention efforts of the DMP.
- Programs with a longer history, more experienced project leadership, previously established ICT systems, and less complex patient populations had lower D&I costs.

NOTE

Some of the results presented in this paper have been previously published in:

Cramm, J.M., Tsiachristas, A., Hipple-Walters, B., Adams, S., Bal, R., Huijsman, R ., Rutten-Van Mölken, M.P.M.H., Nieboer, A.P. (2013). The management of cardiovascular disease in the Netherlands: analysis of different programmes. International Journal for Integrated Care. 13: e028. Impact Factor of 1.75/SE2.

Cramm, J.M., Tsiachristas, A., Adams, S.A., Hipple-Walters, B.H., Bal, R., Huijsman, R., Rutten-Van Mölken, M.P.M.H., Nieboer, A.P. (2014). Evaluating Disease Management Programmes in the Netherlands. Sociaal-Medische Wetenschappen (SMW).

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ADDITIONAL FILES

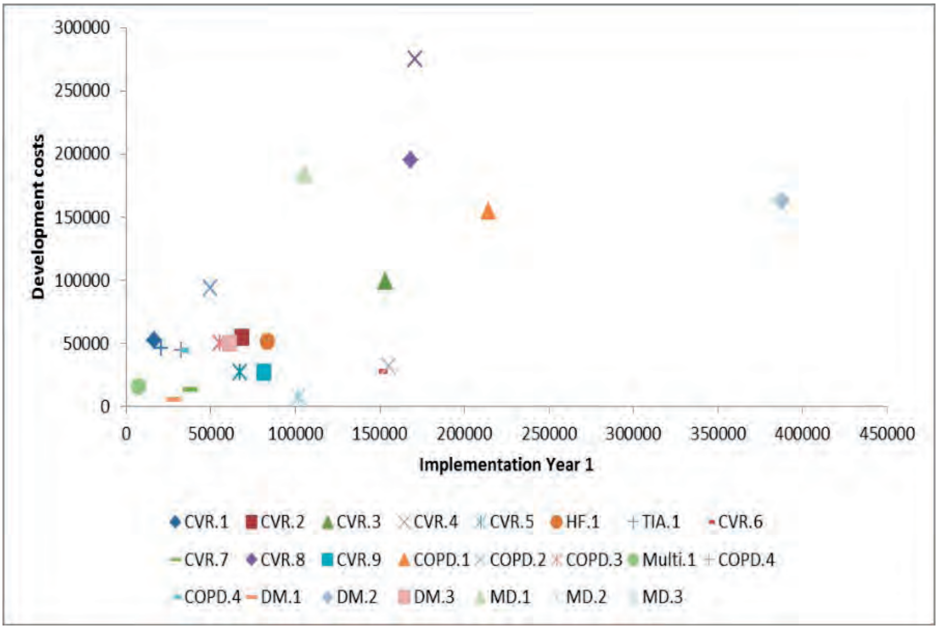
Supplementary (online) File 1: Background information about the Dutch healthcare system

Undoubtedly the dominant issue in the Dutch healthcare system at present is the fundamental reform that came into effect in 2006. With the introduction of a single compulsory health insurance scheme, the dual system of public and private insurance for curative care became history. Managed competition for providers and insurers became a major driver in the healthcare system. This has meant fundamental changes in the roles of patients, insurers, providers and the government. Insurers now negotiate with providers on price and quality and patients choose the provider they prefer and join a health insurance policy which best fits their situation. To allow patients to make these choices, much effort has been made to make information on price and quality available to the public. The role of the national government has changed from directly steering the system to safeguarding the proper functioning of the health markets. With the introduction of market mechanisms in the healthcare sector and the privatization of former sickness funds, the Dutch system presents an innovative and unique variant of a social health insurance system. Since the stepwise realization of the blueprint of the system has not yet been completed, the healthcare system in the Netherlands should be characterized as being in transition. Many measures have been taken to move from the old to the new system as smoothly as possible. Financial measures intended to prevent sudden budgetary shocks and payment mechanisms have been (and are) continuously adjusted and optimized. Organizational measures aimed at creating room for all players to become accustomed to their new role in the regulated market. As the system is still a “work in progress,” it is too early to evaluate the effects and the consequences of the new system in terms of accessibility, affordability, efficiency and quality. Dutch primary care, with gatekeeping GPs at its core, is a strong foundation of the healthcare system. Gatekeeping GPs are a relatively unusual element in social health insurance systems. The strong position of primary care is considered to prevent unnecessary use of more expensive secondary care, and promote consistency and coordination of individual care. It continues to be a policy priority in the Netherlands. The position of the patient in the Netherlands is strongly anchored in several laws concerning their rights, their relation to providers and insurers, access to information, and possibilities to complain in case of maltreatment. In terms of quality and efficiency of the healthcare system, the Netherlands is, with some notable exceptions (e.g. implementation of innovations such as day surgery and electronic patient records), an average performer when compared to other wealthy countries. It is too early to tell whether efficiency and quality gains will occur as a result of the 2006 reform.

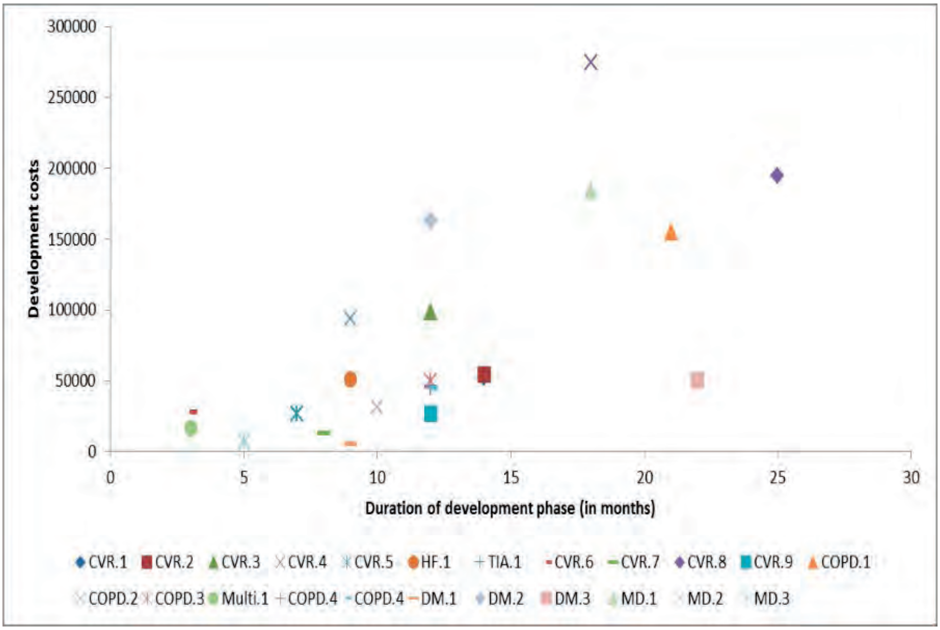
Text from “Schäfer W, Kroneman M, Boerma W, van den Berg M, Westert G, Devillé W and van Ginneken E. The Netherlands: Health system review. Health Systems in Transition, 2010; 12(1):1–229.”

Supplementary (online) File 2: Additional figures

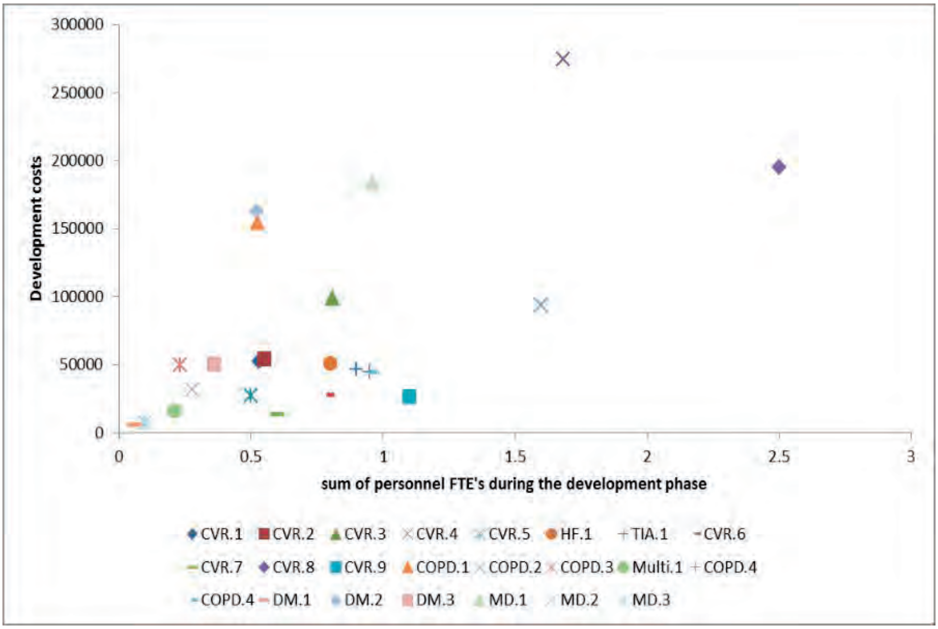
Supplementary Figure 1. This is the relation between development costs and implementation year 1 costs.



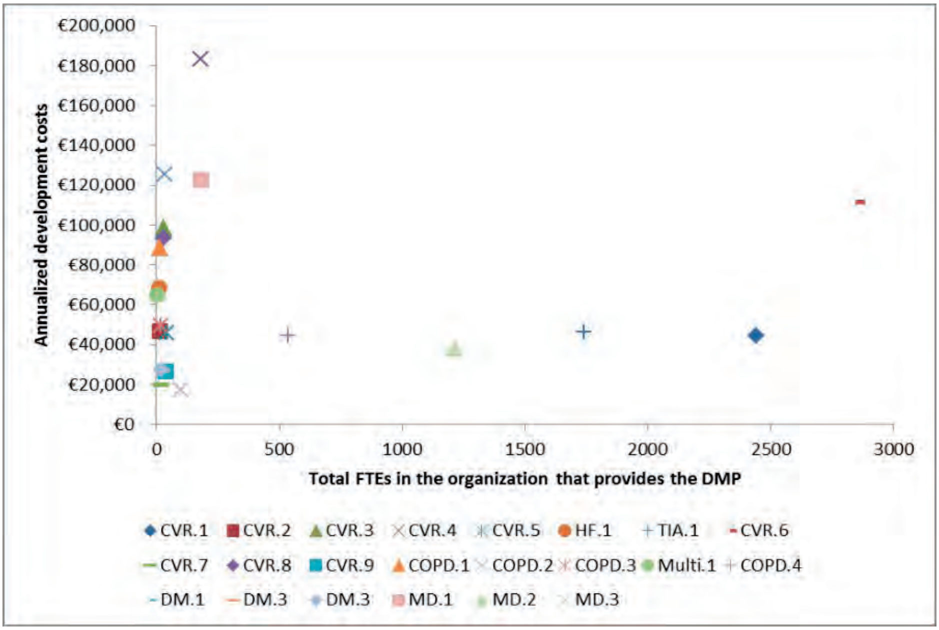
Supplementary Figure 2. Relation between the development costs and the duration of the development phase (in months).



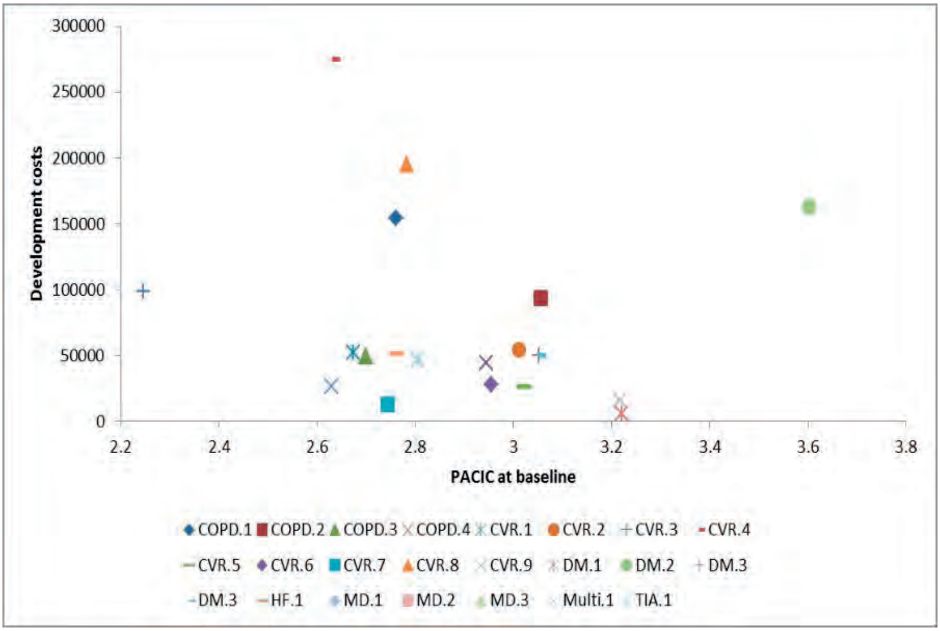
Supplementary Figure 3. Relation between development costs and the number of FTE's dedicated to the development of each DMP



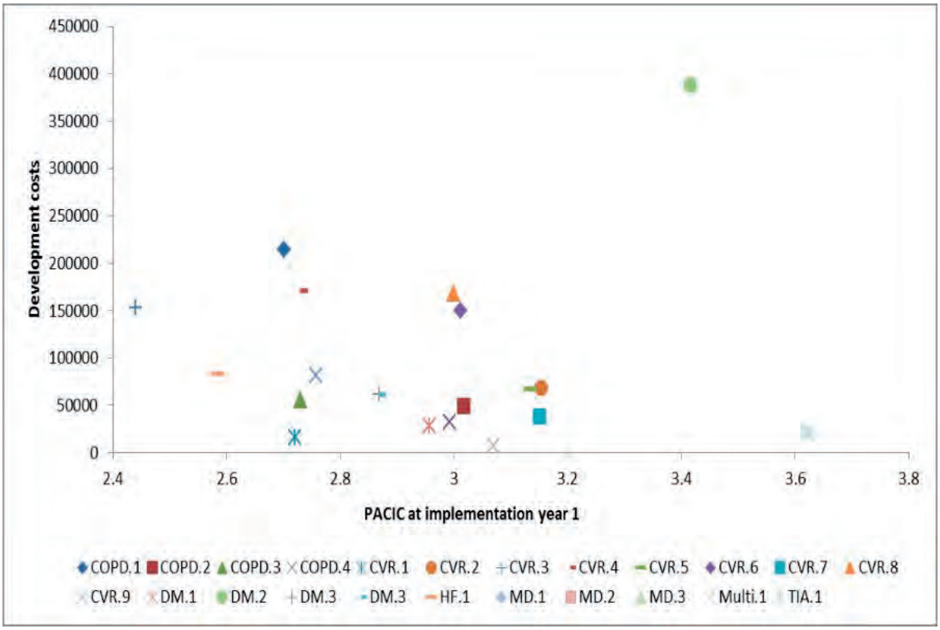
Supplementary Figure 4. Relation between annualized development costs and total number of FTE's in the organization



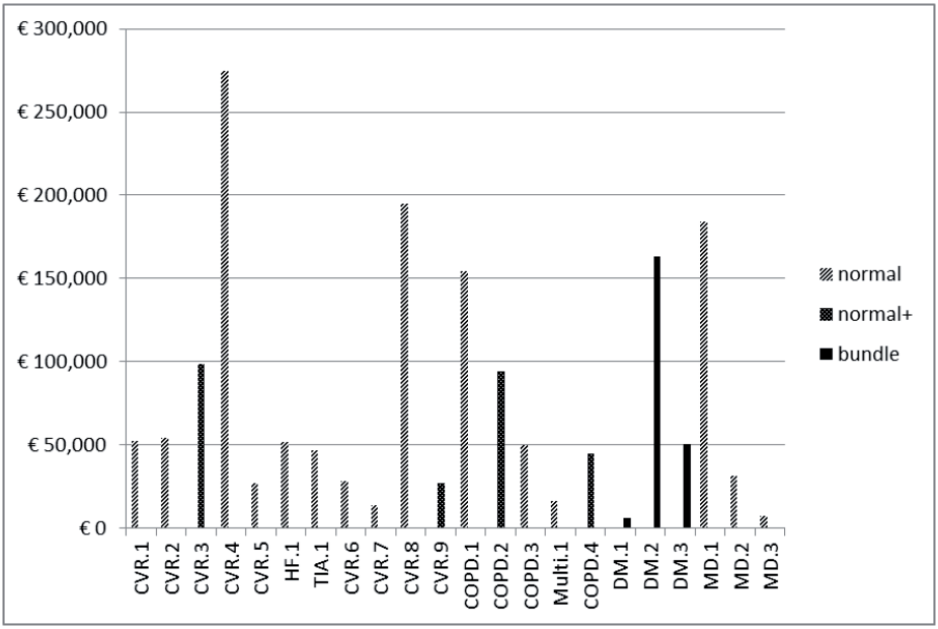
Supplementary Figure 5. Relation between the development costs and PACIC at baseline



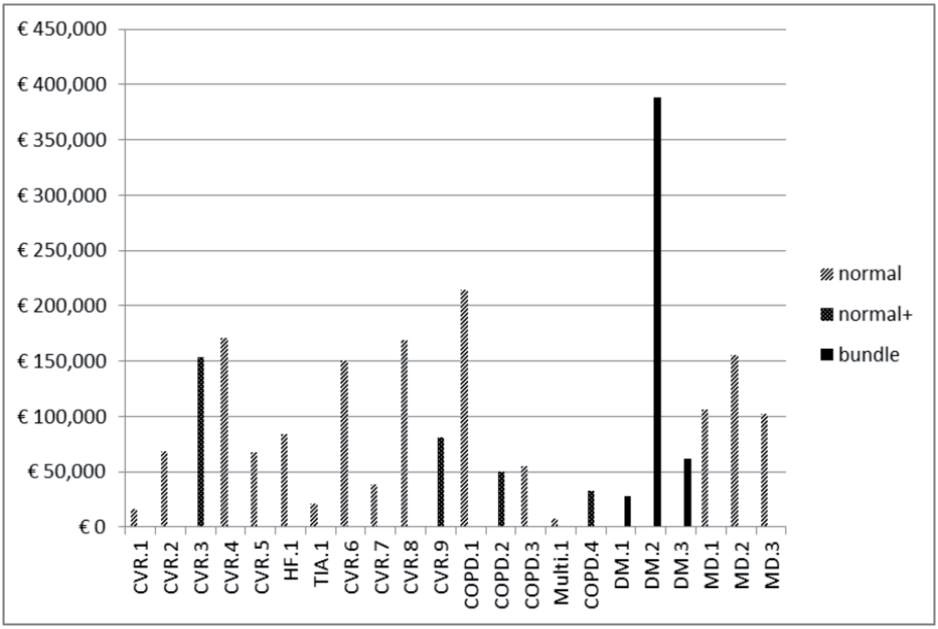
Supplementary Figure 6. Relation between implementation costs and PACIC at year 1



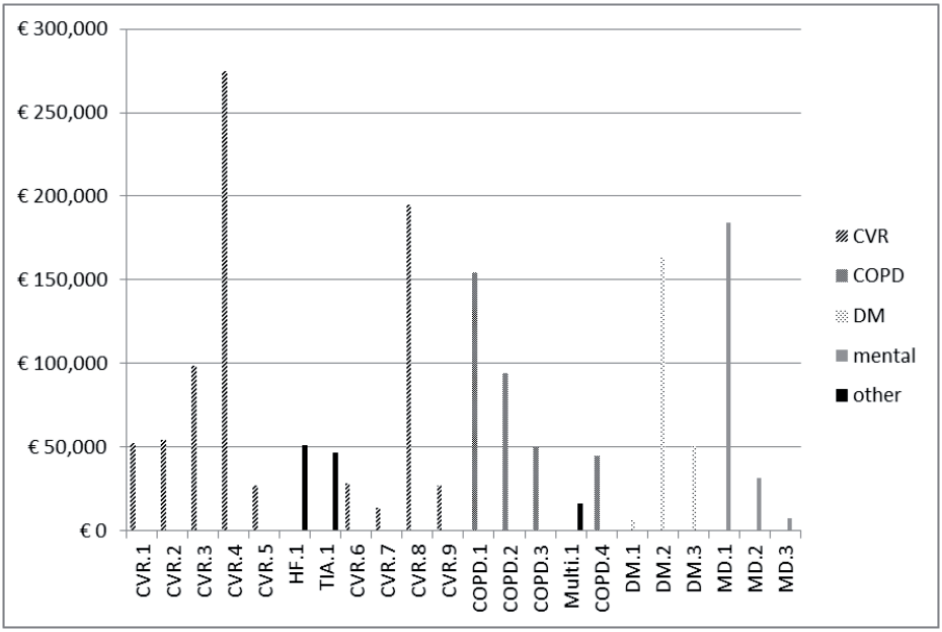
Supplementary Figure 7. Development costs by type of payment at the development phase



Supplementary Figure 8. Implementation costs by payment method at implementation year 1



Supplementary Figure 9. Development costs by disease category



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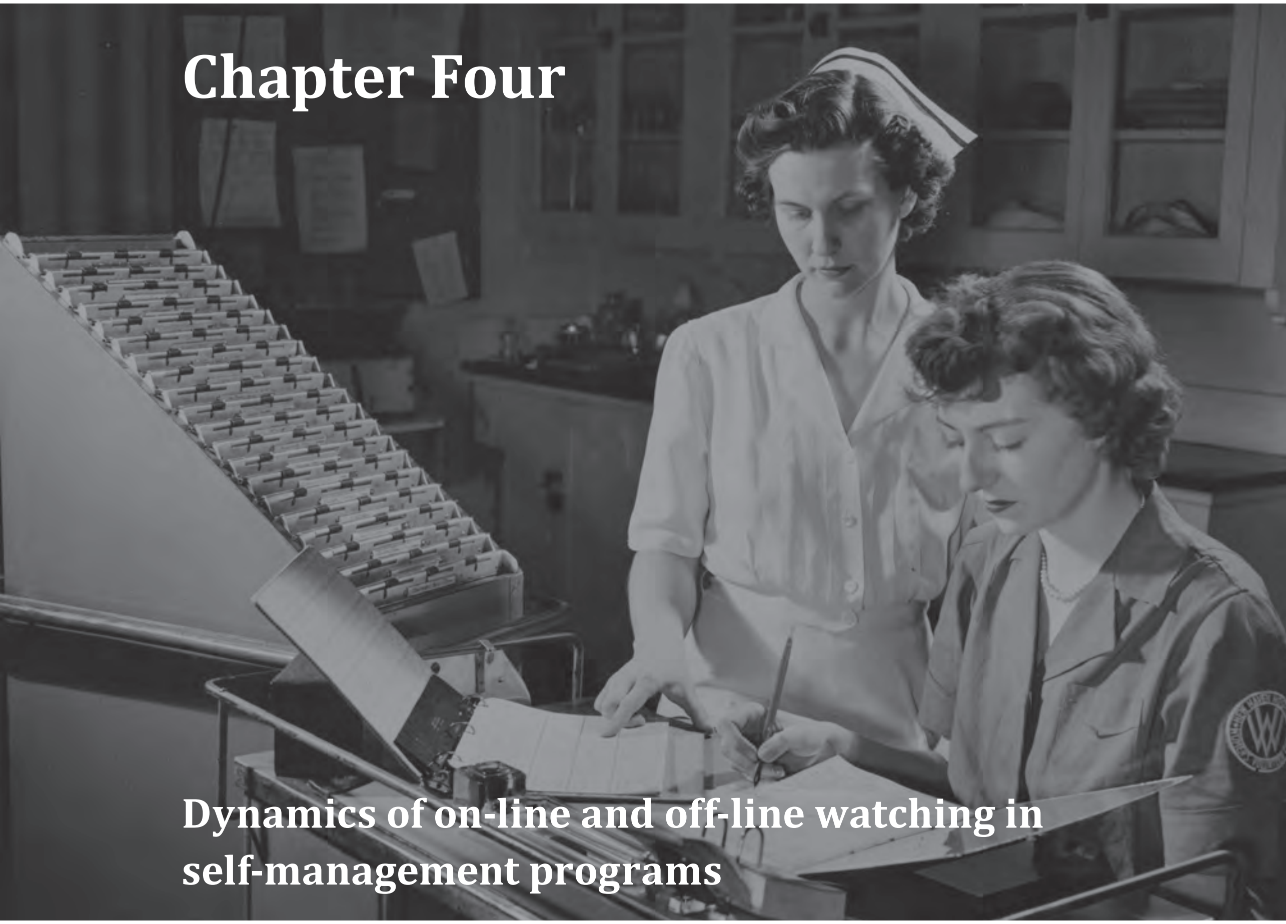

Chapter Four

Dynamics of on-line and off-line watching in self-management programs

Hipple Walters, B., Adams, S., & Bal, R. Dynamics of on-line and off-line watching in self-management programs. Submitted.

ABSTRACT

In this paper, we explore the multiple types of online and off-line watching involved in self-management programs for people with a chronic disease through data collection in two disease management programs. This paper builds upon Mann's new work on veillance, which is defined as watching from above (surveillance), watching from below (sousveillance), watching data (dataveillance), and watching everything (uberveillance) (Mann, 2013; Mann & Ferenbok, 2013); this paper expounds upon veillance to include watching each other (coveillance), watching one's self (self-surveillance), and the umbrella concept of webveillance (watching of and on the internet). We argue that these forms of veillance, as conducted through self-management programs, techniques, and technologies, impact the relationship between patients and clinicians, transform the allocation of medical responsibilities, alter the architecture of healthcare, and expand the places in which healthcare is performed. This has significant implications on online activities of patients and clinicians, as well as on how and by whom healthcare is conducted in the doctor's office, the home, and public spaces.

INTRODUCTION

Healthcare is filled with forms of online and off-line watching and observation. Observation is one of the primary means of understanding a patient's symptoms and illness, overseeing and tailoring treatments to patients, and comparing symptoms and signs between patients to create standardized notions of disease (Foucault, 2003). This trained and assessing form of watching is the medical gaze (ibid, pg 33). Foucault's notion of the medical gaze originated with the development of professional medical education, standardization of care, and teaching hospitals and other distinct medical spaces, like doctor's offices (also understood as *the clinic*). The medical gaze and the concept of the clinic have been expanding outside of these institutions, including online spaces (Patton, 2010; Bunton & Petersen, 2002; Lupton, 2013).

The medical gaze consists of multiple forms of observation and watching, better understood as veillance. Veillance is "a broad concept that includes both surveillance (oversight) and sousveillance (undersight), as well as dataveillance, uberveillance, etc." (Mann, 2013, pg 1). By including "etc." in his definition, Mann (2013) leaves the term open for development and the inclusion of other types of watching and observing, such as coveillance, self-surveillance, cyberveillance, infoveillance, and webveillance. While many of the other forms of veillance have been defined by others[2], webveillance is a new concept. We define webveillance as the multiple forms of veillance that occur in and as a result of the use of networked computer systems. In healthcare, these networked computer systems include websites, forums, smart phone and tablet apps, and/or networked electronic medical records that are viewed via the internet.

The concept of *veillance* opens up the medical gaze to include more types of relationship hierarchies, technologies, and actors interacting and reacting to one another. The medical gaze, made up of many forms of veillance, is neither singular nor unidirectional. It is distributed, relational, technical, and stretched out over time. Clinicians became archeologists of clinical information on websites and records, in person and by proxy, uncovering and bringing to light data that may have been relevant to self-management of these and other patients.

In the following paragraphs, we explore the concept of veillance and the implications of veillance in the self-management of chronic conditions, using type 2 diabetes and eat-

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[2] Coveillance is defined as lateral watching between peers (Mann, Nolan, & Wellman, 2003). Self-surveillance is the watching of one's own behavior, especially when one will be observed by others of the same or higher social position (Vaz & Bruno, 2003, pg 273). Dataveillance is the collection and review of personal data (Clarke, 1999), while cyberveillance is the collection and review of personal data from networked computer systems (Lyon, 2007). Eysenbach defines infoveillance as the "automated and continuous analysis of unstructured, free text information available on the Internet" (Eysenbach, 2011). Sousveillance is watching from below, in that those in positions of less power are observing those in positions of greater power (Mann, Nolan, & Wellman, 2003). Surveillance draws on the theory of the Panopticon, of the potential for omnipresent watching from above (Foucault, 1995).

ing disorders as case studies. Both conditions frequently entail changes in eating habits, significant lifestyle alterations, the obligation for patients to watch their activities and symptoms, and the collection of (bio)metrics. Both conditions require self-management outside of the clinic and interaction with multiple types of clinicians over a long period of time. Self-management is a useful lens for understanding veillance and the expansion of the clinic, especially online.

While research has been conducted on work, patient experience, and uni- or bi-directional surveillance in self-management (Sav et al., 2013; Pryce, 2000; Lorig & Holman, 2003; Walstrom, 2000), less research has been done on the broader concept of veillance in self-management, especially in regards to the multidirectionality and interactivity of the forms of veillance online and off. We explore what types of veillance are evident in self-management programs, techniques, and technologies. Further, in the findings and discussion sections, we analyze what these forms of veillance *do*. This analysis is an important addition to the fields of internet studies, online healthcare, self-management, and veillance.

Self-management

Treatment protocols for chronic disease rely heavily on patient involvement in the treatment and management of their condition through educating patients to self-manage (Bodenheimer, et al., 2002). Treatment strategies also include sharing and coordinating care between multiple medical professionals and using information systems to support chronic disease treatment (Wagner et al., 2001; Green et al., 2006).

Self-management efforts change the roles of patients and clinicians as well as how power moves between clinicians and patients. The clinicians provide structured support, guidance, education, oversight, and emphasis on patients' self-management responsibilities (Lake & Staiger, 2010). Clinicians coach patients to become the main care provider for their chronic disease (Holman & Lorig, 2004). Through self-management, patients are trained to become empowered, educated members of their care team and adopt duties to manage their chronic condition. A significant duty for patients is reporting their self-management activities back to clinicians. Patients report by talking with clinician(s) during appointments, through entering data online in their record or on a website, or through sharing their self-management activities (Moser et al., 2008; Winkelman, et al., 2005; Stone et al., 2003). Holman and Lorig classified these duties as medical management of chronic illness by a patient (2004), but reporting only represents a fraction of the work that a patient does and is expected to do. Having and being treated for a chronic disease is work and involves emotional adjustment, organization, making decisions about care, and cooperating with providers (Lorig & Holman, 2003; Bodenheimer et al., 2002). These activities have implications for veillance and for the power relationship between clinicians and patients. While self-management has been shown to improve patient outcomes (Lorig & Holman, 2003), these improvements are an effort for clinicians and patients (Rogers et al., 2005; Chodosh, et al., 2005).

This study draws on qualitative data from two different disease management programs with self-management components. The first case is an eating disorder treatment center near Amsterdam. At the time of data collection, the center had a four-fold disease management program that included a website to support and encourage (mostly) young women with eating disorders or eating problems, an online eating disorder assessment tool, a visiting nurse program, and an expert patient/support group program based in the center. The second case was a project based in practices of a large general practice (GP) group near Utrecht. The program focused on managing adult-onset diabetes through patient self-management and coordinated care between medical professionals, conducted via meetings, phone calls, and a networked electronic patient record. The program has been in existence for over 10 years, though it has further developed through recent funding. Patient self-management activities occurred through coordination of clinicians and through direct training of patients.

METHODS

We conducted this research as part of a larger study of disease management programs in the Netherlands, which was funded by the Netherlands Organization for Health Research and Development (Nederlandse Organisatie voor Gezondheidsonderzoek en Zorginnovatie (ZonMw)). The Ethics Board of the Erasmus University approved the data collection of the overarching study. We collected the data through interviews, observations, and websites from the two cases analyzed.

We conducted thirty-two interviews in total at the two case sites. The interviews focused on the development and implementation of disease management programs, with special emphasis placed on self-management. The interviews were recorded when possible; due to equipment failure, one interview was not recorded. Twenty-five semi-structured interviews were conducted with the project leaders, medical professionals, and communication specialists at the sites. Seven interviews were conducted with patients in the diabetes project and focused on the patients' experiences with diabetes and treatment. Data has been presented anonymously.

Data was collected from the eating disorder treatment center's website, primarily but not solely from the 'experience stories' portion of the website. The 'experience stories' are narratives written by young women about their eating disorder and treatment. Other data was collected from the privacy statement pages of the site, as well as from advice articles written by volunteers and/or staff of the website. All data was collected from pages available without a log-in.

Two half-days of observations of nurse specialist and nutritionist visits were conducted in the diabetes case. One morning of observation of the two-morning diabetes education course was also conducted. One GP cooperative meeting was observed, and two meetings at the eating disorder center were observed.

We analyzed the collected data inductively through close readings of the raw data and through coding based on themes found in the data (Thomas, 2003). In specific, the first author read the transcripts, observation notes, and data collected online; she then coded the data into themes that arose from the close reading by copying sections into separate documents, based on the themes uncovered (self-management, computer systems, financing, shared decision making, standards of care). The second and third authors approved the coded quotes selected for this article. The first author translated the quotes from Dutch and a native Dutch speaker validated them. The core meaning of the quotes was sought through the close reading, coding, and translation. When possible, interviewees reviewed and approved the quotes for use in this paper. Our chosen method of inductive analysis provided the opportunity to map the themes back to literature on disease management, veillance, and self-management (Creswell, 2012).

FINDINGS

Our data shows how the forms of veillance interact in and outside of the clinic, in the lives of patients, and in the delivery of healthcare. This proliferation and interaction shows that there has been a change “from understanding society as strictly an oversight system [to] one that has potential to be multi-channeled” (Mann & Ferenbok, 2013, pg 32). In self-management programs, this multi-channeled veillance system involved, as our data will show, multiple actors over time, with the circumstances of veillance altering as the programs, technologies, and actors changed.

Training, Coaching, and Accountability

Self-management relied, as noted by Tattersall, on a “sea change in attitudes among patients, and more importantly, healthcare professionals” (Tattersall, 2002, pg 229). Self-management and the associated veillance required significant changes in knowledge, skills, interpersonal behavior, and attitude for patients, clinicians, and project leaders. In the diabetes program, the first step towards changing the attitudes of healthcare professionals was education. Clinicians were trained through meetings and education sessions to deliver self-management support and education to patients.

In the diabetes program, education was often paired with data collected and reviewed from the networked electronic medical record. In fact, the data from the networked electronic medical record influenced the type of training offered. For example, when webveillance of the aggregated data in the records revealed a significant number of Muslims, an instructor was brought in train clinicians to address diabetes, Ramadan, and self-management. The project leader's ability to conduct webveillance changed how clinicians were trained about the needs of patients and, ultimately, how the patient population was treated. Webveillance altered healthcare online and off.

For patients, too, one of the first steps in conducting self-management was being trained to conduct self-surveillance. Self-surveillance is "usually understood as the attention one pays to one's behavior when facing the actuality or virtuality of an immediate or mediated observation by others whose opinion he or she deems as relevant – usually, observers of the same or superior social position" (Vaz & Bruno, 2003, pg 273). Self-surveillance is paying attention to behavior with the thought that someone else will be watching, too. In the self-management programs, these observers were clinicians, other patients, and project leaders. The behaviors were observed, often, by proxy through the data that the patients collected on their chronic condition (food diaries, glucose readings, etc) and through the patients' online and off-line reports of their lives with a chronic condition. Self-surveillance was a trained skill. Patients were trained by clinicians to conduct standardized self-surveillance using tools and approved methods. Patients were taught when, how and what to observe about themselves and their chronic condition. The resultant standardized data from multiple self-managing patients allowed broader dataveillance of the record across practices. The online and offline data collection created a common discourse that was used during the visits and linking patients and clinicians in the work that they conduct for self-management.

The trained skill of self-surveillance came, in the diabetes project, via one-on-one meetings between clinicians and patients and/or through voluntary group classes on diabetes self-management. It also, as will be explored later, happened online as the patients searched for relevant information.

> *Through two mornings (in group classes), patients are educated about diabetes, the risks, nutrition, medication. The principle is that you don't impose anything [on the patients] but if you make people responsible for their illness through self-management, it works better.* (Interview with GP; diabetes project)

Responsibility was another 'skill' that patients learned in the self-management components of the disease management program. Responsibility, though, meant a very specific form of responsibility: compliance with clinicians' recommendations, self-managing according to standard means, being and staying knowledgeable, using tools, knowing and reporting health metrics, being available for veillance. Responsibility was seen as the core of self-management and, as a result, self-surveillance. The information collected through self-surveillance provided patients the opportunity to self-manage through changing medication dosing, eating habits, and exercise based on their needs and to share aspects of their disease with their clinicians. However, as other research on self-management in these disease management programs has noted, patients were not necessarily eager to accept new responsibilities for their care, including the responsibility to look at their care plan and health information online (Cramm & Nieboer, 2015); while patients still conducted self-surveillance and reported data back to clinicians, it was most often done in person, face-to-face with a clinician. The data collected through self-surveillance represented (for clinicians) the chronic condition and the self-management of the condition. It represented the experience of a disease in tabulated numbers, written accounts of foods eaten, and changes in symptoms. This information also provided clinicians the opportunity to tailor care to the patient and the disease that the data represented, to add the data to a larger repository of data on diabetes, and to understand if their training of patients in self-management and self-surveillance had been effective for the needs of the patient and of the clinic. Self-surveillance changed the care provided online and off and inside and outside of the clinic.

There were a variety of reasons for clinicians to believe that the training and education in self-management had been ineffective. One of the primary ways was through interacting with the patients during the visit.

> *They [patients] know so little, they know so little… Why is that? I don't know. They come to me, and most people know so little. And then I think, 'you've been to the doctor, you've been to the chronic care provider, some have been to the diabetes nurse...' There is so little retention of what everyone has said.* (Interview with diabetic nutritionist; diabetes project)

The causes for the lack of retention weren't necessarily clear to clinicians, as it was not always in the record (available for dataveillance) or made apparent in the visit (available for surveillance). Rather, the veillance of the data in the networked electronic medical record showed that the patients had encountered many clinician educators, and had, in principle, many opportunities to learn how to self-manage. Patient education by clinicians, which was visible through veillance of the medical record, was not seen as enough for patients to become educated self-managers. Surveillance during the visit (of patients' lack of retention) and veillance of the online record (of the education that patients had been given) created a problem that clinicians would continue to try to solve by offering more education and support.

In line with the work of Henwood et al. and with other research conducted on these disease management programs, some patients in the diabetes project were (at least at some points during the course of their illnesses) reluctant to accept responsibility for the management of their chronic condition (2003; Cramm & Nieboer, 2015).

> *And also until now I have more or less waited till somebody said you have to do this or this. Because I missed two appointments with the chronic disease specialist assistant, very strange because normally I am very careful with appointments. I missed it twice, because simply either I didn't want to do it, internal resistance or at least it didn't live in my awareness that it was important.* (Interview with patient D; diabetes project)

The patient could not give a definitive answer for his/her own lack of participation in treatment, though self-surveillance revealed possibilities: the patient was not used to being responsible for his/her own illness management, the patient wasn't aware that the appointments were important, or he/she faced internal resistance. In short, the patient was not ready to 'do' diabetes as recommended through the self-management education by clinicians. As Mol noted in her work on diabetes, bodies (and chronic diseases) are something that people both *do* and *have* (Mol & Law, 2004). Doing diabetes, especially doing self-managed diabetes, meant the physical and mental work of living with a chronic condition, including dealing with the biological realities of the disease (such as the disorientation from low blood sugar, selecting food suited to the glucose readings, etc.) and the additional responsibilities of self-managing, or the work involved in doing diabetes in the ways suggested by clinicians through self-management education. Doing self-managed diabetes required a change that the patient was not ready to make at the moment. Rather, the patient avoided knowing and doing self-managed diabetes. The outward sign of lack of readiness was missed appointments. The missed appointment would show up online in the networked electronic medical record, prompting clinicians to explore the reason with the patient. Missing appointments and the associated missing data was a source of data for dataveillance aspects of webveillance. Missing data had the potential to shape care.

While numeric data played an important role in the self-management and veillance of diabetes, numbers alone did not always drive the visits. During an observation of a clinical visit between a diabetic specialist nurse and a patient, the patient's self-collected data revealed unusual and unhealthy trends in his/her blood glucose. The nurse, upon learning of the changes, asked why; the patient had recently quit smoking after a decades' long habit, and the change was reflected in the biometric data. Dataveillance of biometrics alone would have shown unhealthy data without revealing the health-promoting rationale. Once the rationale for the unusual glucose readings was found, the conversation turned to congratulations and methods of quitting smoking; there was no change in the course of treatment. The patient worked to improve his/her health by quitting smoking, even at the detriment of the numbers. The numbers were a catalyst for further discussion and surveillance during the visit.

The eating disorder project approached self-management in similar ways: through training, through shifting responsibility (and power) to patients, through working with patients outside of the clinical setting. However, the methods through which these self-management activities and the associated veillance occurred are different. In the eating disorder project, it is clear that before training patients, clinicians first had to surveil the patients to understand what knowledge and skills patients had, and to understand how the chronic condition might impact patients' abilities to self-manage and conduct self-surveillance, as seen in the quote below from the eating disorder project.

> *Oh yes. So now, during the intake phase, we try to work with the client to have them get more control over their own treatment plans. And the aim is that a kind of co-production will occur between clients and professionals. That's difficult ...Because the clients are so passive and they sometimes do not know. And their weights are too low, so sometimes*

> *they cannot think clearly about what they want or how it looks or what really is their request for help. They often do not know. So you have to help them, you have to teach them to figure out, what can we (at the clinic) really do for you?* (Interview with first project manager; eating disorder center)

While those at the eating disorder treatment center desired for patients to have more control over their treatment, patients were often seen as too thin and ill to be rational and know what they needed. According to those at the center, the patients' disease limited their ability to learn about self-management and conduct self-surveillance. The center's desire for patients to have more control over their treatment had to be balanced with care for the critical aspects of their conditions. This balancing act is especially tricky in the treatment of chronic conditions with a significant mental health component. Clinicians and patients struggle with how much, when, and over what aspects of treatment patients could or should have responsibility; some patients were seen as limited in their ability to have responsibility due some of the effects of their chronic condition. Similar to findings by Broer et al. (2010), the clinicians first removed constraints to autonomy and responsibility (in this case, constraints caused by the condition, as patients with severe eating disorders were not considered rational due to low weight as a result of their disease) and worked to learn patients' preferences. To do this, the treatment center provided an 'overdose' of treatment:

> *Rather, what we do now, the clients come to the clinic and they get an overdose of therapy. In particular, it's the basic groups that will be important. Those are important. There you [the patient] work on your eating disorder and clarify your request for help. Then you get a program comprised of modules, made up of the therapies you are going to follow.* (Interview with first project manager; eating disorder center)

This overdose of treatment had multiple functions, some of which were unspoken: to improve the physical condition of the patients and improve their cognitive processes by eating, to show the patients that they are supported in their treatment (what can we really do for you?), to observe the patients as they were being treated, to balance the patients' control over their treatment with the limitations imposed by their physical and mental conditions, and to show the patients what treatments were available for them to choose from. This overdose of treatments created the opportunity for sousveillance, watching the treatments and clinicians from below in order to see what treatments would work best for them, and an opportunity for self-surveillance as they were encouraged to think about and report back on which of the offered treatments would be most effective for them. The opportunities for veillance and the veillance conducted impacted what treatments the patients selected for their personalized treatment regime at the center.

Self-management training and coaching was also conducted via the center's website for young women with eating problems/disorders, who were not necessarily patients at the center. Interacting with the website users in a standard clinical setting was not possible; the website and wherever it was accessed were the locations of treatment. Self-management was facilitated by technology, which allowed for different forms of veillance to take place and impact self-management in different ways.

> *If I look at what our girls on [the website] do is that they take some here, take some there. Why not try to provide them with what I would call more self-management tools, but what you could also construe as smaller, individualized therapy modules or intervention or whatever… Just offer a food diary or just offer … a cognitive tool in which you can analyze your thoughts and restructure… Sort of take traditional treatment but cut it up into smaller components, offer those as self-management tools.* (Interview with project leader; eating disorder center)

The information about what the website users wanted came from their collective online histories. The users of the website reported what tools, education, and coaching they found useful by using them. The webmaster and the project leader conducted webveillance on the website by reviewing Google Analytics reports and looking at the postings of young women. The veillance of the project leader and webmaster was unseen – not quite hidden, as the website did state that it would collect data for quality improvement – but not directly observable by the young women; they did not know which of their postings would be read by the project leader or which of their page views would shape the project leader and webmaster as they changed the site. The veillance was unobtrusive, but influential. Through various aspects of webveillance, the project leader and webmaster observed the actions of the young women and tailored the offerings of the website accordingly. Veillance trained the clinicians in the needs of the users of the site.

Education and veillance, as the above section showed, interacted in different ways. Much of the education focused on teaching patients to self-manage through self-surveillance, which was effective to greater and lesser extents. Clinician surveillance, dataveillance, and webveillance resulted in changes in the education and tools provided. Patient self-surveillance resulted in collection of various forms of numeric and non-numeric data, which were then available for other forms of veillance and shaped care online and off. Patient self-surveillance also impacted what forms of care patients participated in and how. These forms of veillance interacted, shaping the education and care provided, impacting patients' and clinicians' perceptions of care, and altered how self-management was conducted and understood.

Observing and Monitoring

While much of the observation by clinicians of the patients' self-management was done by proxy (by the patients through self-surveillance, then reported back) or of the information in the record (by clinicians of their own data, the data of other clinicians, the data of patients, and of the data that was not there), some of the veillance was quite direct, quite visible, and quite personal.

> *One of my patients is now in the hospital due to underweight. This is primarily a somatic indication. And three times in the week, I sit with her for one of her meals... They say that the first bite is hardest; I know that being kind will not help her, so I'm a bit strict as far as the amount of food is concerned. I try to distract her with small talk about all sorts of things, except for food.* (Interview with nurse; eating disorder center)

The young woman with an eating disorder was not able to be responsible for the management of her own condition; she was hospitalized for very low weight, which (as an earlier quote pointed out) was understood to impact cognitive capabilities. The nurse and patient sitting together was 'veillance made visible'.

This direct veillance was part of the treatment, much as other forms of veillance are components of treatment. In this instance, the nurse watched her patient eat and, while watching, modeled mealtime behavior. This surveillance was intended, in part, to be seen and internalized by the patient, who would then, the nurse hoped, be able to eat without direct surveillance by nurses or family members. The sousveillance by the patient and the surveillance by the clinician was treatment for a condition that impacted the patient's ability to self-manage and was training in self-management for the future.

Sometimes veillance was about what should *not* be seen or recorded by whom. For young women with an eating disorder, eating and the physical impacts of eating, especially when weight gain was reflected in the numbers on a scale, could be distressing. However, this number was seen as sometimes necessary for self-management.

> *Blind weighing is a good option to break your relationship with the scale or not to restart an old one. [Someone else] can look and tell you only when there are notable increases or decreases. This can be done for example by standing backwards on a scale.* (Article on eating disorder support website)

Advice on the eating disorder support website suggested that the users seek out assistance in self-managing. This assistance would come in the form of surveillance and dataveillance by a trusted outsider, who would not reveal the collected data, merely trends; no joint dataveillance would be conducted. While the young women were potentially always seen and shaped (or disciplined) through various forms of veillance, they were also encouraged to limit what they veilled and to leave some things, especially their weight, unseen by themselves but monitored by others. Here, patients were hoped to self-manage the limitations that their eating disorder placed on their behavior and be disciplined *not* to look and not to conduct behavior that may have contributed to their eating disorder in the past.

In the diabetes program, what was seen and unseen was different. It focused on what was intentionally not surveilled by clinicians and not recorded in the networked electronic medical record, which could be accessed and edited online by multiple clinicians working with diabetic patients.

> *I put the weight when I weighed [patients]. You have to put the weight in the record; it's mandatory. Sometimes I do not weigh people because I don't think weight's important.*

> *Then I just put the old weight that was already there into [the record]. I occasionally look at the medical history and sometimes not; it depends whether I think it's important. And from my plan, I write my notes about what I think is important for GPs and practice nurses to know. What have I discovered? Yeah, that's actually the conclusion.* (Interview with nutritionist; diabetes program)

Using a technology for veillance (here, a scale) was seen as unnecessary for treatment by the nutritionist. The clinician chose not to *see* the weight and not to collect the data for the networked electronic medical record. While the clinician met with patients, the clinician did not always conduct all forms of veillance on patients: the clinician did not surveil body weights using a scale nor did the clinician always conduct dataveillance of the medical record. Rather, the clinicians focused on what they thought was important for the patient and for other clinicians who might view the data added to the record. Veillance was, in some ways, built (or not) through a series of choices that the clinician made; these choices had the potential to impact care during the visit and care at future visits through the record. This was also shown in the quote above: what was *not* seen and not recorded can be just as important to self-management programs as what *was* seen and was recorded. This is a contrast to the more Panoptic view of watching put forth by Foucault and others, in which those who watched are potentially *always* watched from above (Simon, 2005; Bunton & Petersen, 2002; Foucault, 1995). Veillance includes, but is not limited to, surveillance, which is understood to be a modality of control and a method of disciplining (Foucault, 1995). Through the self-management programs and the veillance associated with them, control, responsibility, and data were shared (or attempted to be shared) between patients, clinicians, project leaders and managers, and technological systems, such as websites and networked electronic medical records.

How data was shared and not shared played an important role in self-management. Patients shared the veillance of data through self-surveillance and collecting their own data, through sharing this data with clinicians, and through looking, with their clinicians, at their collected data in the networked electronic medical record:

> *I'll let patients look at the results on the screen, for example lab results. [The electronic medical record] will show a graph. For example, when glucose readings are taken, then there will be a very nice graph. So then I show the patient. I turn my screen and I show patients, 'look, this happens and it's good or it's bad'. I'll do that. Yes, yes. It is kind of educational, increasing the self-awareness of the patient. I always report what is Gly-hb. And therefore they often look at me in confusion and I spell it out again. Then I think, you heard about it sometime back, that Gly-hb is important, you should know this term, you know the term glucose, you should know the term carbohydrates. So I try to not talk in sugars or bad sugar, but when I talk, I say diabetes, carbohydrates, glucose. They just need to know these things to increase their awareness, like what are we talking about now. I think that is actually very important.* (Interview with nutritionist; diabetes program)

The clinician created the opportunity for joint dataveillance of the networked electronic medical record by turning the screen to share the online data. This dataveillance done together was an opportunity to bring the patient into the medically dominant care process through education on the correct terms used in diabetes care, through the emphasis on what the clinician considered important, and through increasing the patient's self-awareness. Patients and clinicians were responsible for the data and education, and it was the efforts of patients and clinicians that made the records and this combined veillance possible. This veillance was collective and both online and in-person, but done on the terms of the clinician with the goals of educating the patient and improving internalization of self-management principles.

Online

While both programs used web-based platforms to support self-management, they did so in different ways. The eating disorder center focused more on outreach to young women with their web-based efforts, including via a website for those with eating disorders. Participating in the website was voluntary for the website users. The website allowed clinicians to come to the patients to provide treatment, support, and self-management. The website blurred the border between home and clinic.

> *And that is why e-health is so important to us. You are immediately in someone's living room and that is why there is less of a barrier for him/herself.* (Interview 1 with second project manager; eating disorder project)

Those who used the site may have had no other treatment for their eating disorder, becoming, through their use of the site and the veillance that the site facilitated, online-only patients. As the site was open to the general public, the use of the website expanded the clinic and included the online-only patients in the medical gaze. The website served as an online personal health record for the young women, open to the review of themselves and/or their peers. As an open health record, the posted histories became self-management tools for those who viewed them and wished to learn from the experiences of others, as well as histories for the young women who wrote the postings. The records became an online communal medical record which was open to the webveillance of others, including clinicians.

As archeologists of clinical information, clinicians and webmasters conducted veillance on more than the words and pictures posted online, but also of the data that the website kept. This was, as others have noted, a form of governmentality, which "operates on particular groups, using the gathered information with statistical analysis, financial reports and population registers" (Rajagopal, 2014). This governmentality through webveillance, at times, revealed illicit information, such as names of diet drugs, body weights, and pro-eating disorder messages; such information was removed, and repeat offenders were blocked by IP address and/or username. This webveillance, including cyberveillance, shaped care in the living rooms of website users and on the structure of the site but did so differently for the diabetes site and the eating disorder site.

In the diabetes project, internet-based efforts included a website, a monitored forum for clinicians, and a networked electronic medical record. The website was for the entire GP cooperative, with a special section about the diabetes program. While the website had self-management information, there was little data to suggest that patients or clinicians used the website frequently. Rather, (some) patients went to other online and offline locations for information.

> *Of course I already know a lot already, because I've also searched a lot on the Internet and also received information from the doctor and I was just curious what ... if they still might add something. Any information you can get is important.* (Interview with patient C; diabetes project)
>
> *What I did notice is the nutritionist is very nice, but she does not have a very good feel for teaching…I went to her before as a nutritionist and I quit, because I just couldn't get the bigger picture. I went to the internet and I got everything I wanted in one package. And what I need more with a diet is the motivation to do it. And for that I have to have a clear mental picture and I think this is giving me that… Yeah I think I went to a hospital in xx. There they had a pamphlet; they had everything I needed to know… And then, suddenly, all the pieces came together.* (Interview with patient D; diabetes project)

Sousveillance changed how patient D collected information on his/her chronic condition. As the patient observed that the nutritionist was not a good teacher and motivator for him/her, the patient went online for information, downloading educational materials from another hospital. While this patient was not motivated to change his/her diet, the patient was motivated to learn more. The internet provided educational materials and a work-around for poor patient-clinician match, as well as the opportunity for another form of veillance. While the clinicians at the diabetes program did not know what the patient had downloaded, the hospital from which the patient downloaded the information did – through the webveillance of their site[3]. The sousveillance of the clinician had a ripple effect in how this patient (and possibly future) patients inside and outside of the diabetes program were educated in diabetes and self-management.

Other online tools included the networked record, which played an important role in the delivery of self-management support and education online. The record contained various forms of information and biometric data, allowing clinicians to tailor their advice, prescriptions, and education based on historical trends for patients. The record was accessed online.

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[3] The patient gave the name of the hospital, which has been removed for anonymity. However, the disclaimer page of the hospital's website stated that the website uses Google Analytics to understand how the site is used.

> *Yeah, so in principle, I can (write) in the whole file and in the diabetic file. And I can open up the diabetes file for other clinicians: the optometrist, the nutritionist, the podiatrist, the physical therapist, the diabetic specialist nurse… And that is pretty easy; it gives patients a bit of security that their private information (and) their privacy is well respected. Otherwise anyone anywhere can look in.* (Interview with practice nurse; diabetes project)

The staff at the GP's offices had the ability to limit veillance on the record. The record was a site of dataveillance (when the clinicians looked at the records through the local program in the office) and of webveillance (when the clinicians used the online interface to view the records). Reduced access limited the dataveillance and webveillance that were possible. This reduction possibly shaped self-management education and support, as not all clinicians had a holistic overview of a particular patient's health (not just their chronic condition). The clinicians at the GP's office valued patient privacy over having all data available to veillance by all clinicians involved in the care for a patient's chronic condition; data open to veillance was seen as a tool to be used by certain people in defined circumstances.

Patients in the diabetes program had the option of viewing parts of the networked electronic medical record through a patient portal. The majority of patients had not chosen to access their records at home. Some of the reasons included a desire to learn from their clinicians, lack of access to the internet, lack of interest in the record, or lack of ability to read the record. While it was frustrating for clinicians to see the lack of participation in the patient dossier, it was not unexpected:

> *But we must realize that only a certain percentage of the diabetes patients will really work with that (online system). But that's what we also said, that's for now because not everybody works with a computer yet. And not everybody is well-equipped enough to use it.* (Interview with first project leader; diabetes project)

Even though it was anticipated, this lack of participation impacted the veillance in the diabetes program. By electing not to use the portal, for whatever reason, the patients were electing not to interact with their clinicians in the record system, not to conduct webveillance on their own patient data that was in the medical record, not to add data that would be webveilled by clinicians, and not to participate in this aspect of self-management. Patients were doing more than not using a computerized communication tool; they were also opting out of the self-management and veillance systems around that specific computerized tool. Opting out of the patient portal of the networked electronic medical record had the potential to impact care at the group level (as there was less data from the patient portals available for reports on care over the project), at the clinician level (as clinicians had less information available about the patient), and at the patient level (as patients had one less way of interacting with clinicians, relying instead on calling clinicians and visiting the clinic).

However, opting not to use the patient portal did not mean that patients did not use other electronic methods, such as insulin pumps and glucose meters with data collection capacities, to collect and record their data. Veillance through electronic means changed how people *did* their bodies and their chronic diseases:

> *Well you have all the tools, I mean you can even simply transfer all your readings to your computer, you get nice graphs of how it is going, and it helps that you have a visual. I think that started when you got the USB stick. Because when you see it on a graph, visually, yeah that is a lot more confrontational than just a list of numbers.* (Interview with patient D; diabetes program)

Technology altered how the patient did diabetes; this technology became a veillance tool for the disease for the patient. The monitor stored the collected data and had the option of dataveillance via graphs on a computer, rather than in a notebook, on the screen of the clinician, or in the patient portal of the networked electronic medical record. The ways in which he/she *did* diabetes altered the veillance structure; the patient limited the amount of webveillance that could happen by not adding data to the record, the patient limited the surveillance possible by skipping appointments, the patient chose technological means of self-surveillance that provided graphs similar to those that clinicians provide, and the patient came to group trainings, which allowed for surveillance and veillance in a group setting. Doing diabetes, for this patient, did not mean that he/she followed the self-management instructions of his/her clinicians exactly. Rather, it meant that he/she selected the best features for how Patient D wanted to do diabetes in his/her body, which altered how the patient was watched, how the patient watched himself/herself and how the patient watched others.

Clinicians and patients used and opted out of a variety of technologies that were used (primarily or secondarily) for veillance. The technological tools associated with self-management changed the locations of self-management and of veillance, blurring the boundaries of the clinic. Many of these technologies were online or had online components that could be used outside of the clinic by clinicians and patients, such as the website for young women with eating disorders and the networked electronic medical record. Through the use of these technologies, we can see the mutual relationship between veillance and self-management; the ways in which these technologies were used/not used impacted the veillance possible.

DISCUSSION

Multiple forms of online and off-line veillance were apparent in the self-management programs. These forms of veillance were multifaceted, architectural and built into the structure of the self-management programs, multidirectional, and conducted via multiple technologies and tools. While, in principle, the types of veillance are easily distinguished and distinct, the types of veillance blurred, in practice, for those who were using them. Those who were watching may not have known what kind of veillance they were performing at any one given time and were, in all likelihood, conducting multiple forms of watching simultaneously. The various types of veillance were impacted by and impacted how self-management was conducted; this could be seen, for example, in how what the girls used on the eating disorder website shaped the site, as learned through webveillance by the webmaster and project leader, or in how the clinicians at the diabetes site shaped their message to the individual, based on the information learned through the veillance of the record and through the direct surveillance of the patient in front of them in the exam room.

The veillance conducted, however, did not always give a complete picture of how a chronic condition was being managed by patients, clinicians, and project leaders; understanding *why* certain actors performed in such a way was not always clear to others or even to the actors themselves, such as Patient D, who skipped appointments and was not exactly sure why. Some self-management activities were outside of the view of others in the self-management team, such as aspects of their eating disorder that the young women did not post online on the eating disorder support website; others were intentionally hidden from view, such as when those at the GP's offices in the diabetes program restricted access to parts of the record. Since the activities of patients never were (and never are) completely visible to external veillance and the rationale for their own behavior was not always clear to patients, training patients to internalize the messages of clinicians about self-management and to conduct veillance on themselves was one means of overcoming this incomplete picture. If patients were trained to manage their chronic condition in ways that the clinicians approved of and to conduct their own veillance, the clinicians' incomplete picture became less important and less potentially harmful for patients. Training, however, was rarely completed to the satisfaction of clinicians and patients, and met multiple forms of resistance from patients.

As our research showed, veillance and self-management were intrinsically linked through the interactions of patients, clinicians, project leaders, and technological systems such as glucose meters, websites, and networked electronic medical records. This linkage, as will be explored in the following section, impacted what both veillance and self-management *did* in patients' lives, clinical practice, and project management.

Veillance as a clinical tool

Through self-management programs, the clinical tool of veillance was used by patients as well. As a clinical tool, veillance worked at different levels through different technologies. This included how veillance impacted and was impacted by how patients self-managed; how clinicians treated patients at the individual level, the group level, and at the aggregated level; how care was managed; and how chronic disease programs were funded and studied.

One of the key features of self-management education was training patients to become more responsible for their own chronic condition according to recommendations of the clinicians. Patients were educated in various ways to be their own clinicians; this included education on how, when, and what to self-surveil. Responsibility for self-management and self-surveillance was not handed over without restrictions but was transitioned over gradually through education sessions with multiple clinicians, through group classes, through exams, and/or through websites.

Self-management programs relied on clinicians training and supporting patients to monitor, document, and to care for their chronic disease outside of the direct view of the clinician. However, as other research on the self-management aspects of these disease management programs shows, patients were often seen as hesitant to take up self-management of their chronic disease (Cramm & Nieboer, 2015). Whether or not the patients took up self-management duties, supervision was potentially ever-present through patient self-surveillance and the possibility of clinician surveillance and dataveillance; clinicians and patients (as part of the same self-management team, though reluctantly at times) controlled the body and the chronic disease. In the eating disorder project site, this education and shift of responsibility came through the website, through the initial 'overdose' of treatment that made those with an eating disorder aware of the treatment options that they could select, and through the act of a nurse watching and training a patient to eat one bite at a time. In the diabetes program, patients were trained in self-surveillance and to be their own clinicians through various technologies such as glucose meters and food diaries, through using the 'correct' medical terminology, through retaining (or not) the knowledge passed on. At both sites, patients were trained, too, in what not to watch – their own weight. For those with an eating disorder, this lack of self-surveillance was active; the young women were told not to watch their weight to avoid a relapse or a worsening of their condition. However, in the diabetes program, this education on what not to self-surveil was passive; when patients saw that the nutritionist didn't weigh them, they learned that weight wasn't always important for them to surveil too. In both projects, self-management was primarily defined and steered by the clinicians, who taught patients to be responsible for their condition and watch themselves in various ways, as if they were clinicians themselves. As others have shown, the emphasis on learning and expertise for patients can focus on the biomedical model of care to the detriment of other understandings and ways of doing and having a chronic condition (Fox, Ward, & O'Rourke, 2005).

Being their own clinician and responsible for their condition meant that those in the program needed to internalize the medical gaze. Clinicians, patients, and project leaders were disciplined into internalizing the gaze. This disciplining occurred through education, through the ever-present potential of supervision, through steering by others, and through controlling the body (Foucault, 1995). Without the expectation of internalized discipline, self-management would not have been possible. Discipline (through coaching and education, through constant observation by patients and clinicians [by proxy], through controlling the chronic condition) was internalized by patients (to greater and lesser extents). Internalization of discipline made self-management possible and expanded the realm of the clinic outside of the doctor's office or hospital.

Case Comparison

The two programs provided an interesting lens through which to understand how the types of veillance interacted and impacted patients' lives, clinicians' actions, and the delivery of healthcare. The two cases had different patient populations: the diabetes population was significantly older than those being treated for an eating disorder; many of the young women at the eating disorder site were online only patients or were in-patient, in contrast to the diabetes patients who lived at home; the patients with diabetes were thought to be less computer literate than the average population. The differences in the populations impacted how and what types of veillance occurred. As the eating disorder center had many more patients online, webveillance played a larger role in the delivery of care than in the diabetes program; through webveillance, the clinicians and website managers observed what the young women used on the site and tailored offerings accordingly. As the patients in the diabetes program saw many clinicians at multiple locations over a longer period of time than those were seen in the eating disorder program, dataveillance of data in the networked electronic medical record played a role in tailoring care to the patient and to groups of patients as a whole. The types of veillance used and the self-management techniques promoted were impacted by the types of patients seen.

Both those with diabetes and those with an eating disorder were taught how, what, and why to eat; patients from both groups were taught to use tools for veillance, such as food diaries, glucose meters, and scales, and report the data that they collected back to clinicians. In both sites, clinicians focused on shifting responsibility for the chronic condition to patients, on self-surveillance, on veilling patients at the individual and group level, on collecting and analyzing data to better tailor care. Patients at both sites watched the actions of clinicians (either directly or by coveilling the experiences of others) and changed their behavior accordingly. Neither patient group had full responsibility over their disease, despite the efforts to shift responsibility towards them: the young women with eating disorders were seen as too physically weak to have full responsibility over their eating disorders while those with diabetes were seen as too passive and too computer-illiterate to have full responsibility for their records, their diseases, and their bodies.

The prevalence of webveillance

While surveillance and dataveillance on the internet have been well-researched (Lyon et al., 2012), veillance online is much broader. Webveillance is an umbrella term for watching that is conducted in networked computer systems such as the eating disorder website and the networked electronic medical record, which was accessed via the internet. Webveillance includes multiple types of veillance, such as infoveillance, cyberveillance, dataveillance, surveillance, coveillance, and sousveillance. These aspects of veillance may be conducted individually, but are more likely to be conducted collectively, with clinicians (or patients or website users or project leaders) looking at multiple sources of information at the same time for slightly different, but interacting reasons. As Rich and Miah note, while early concepts of the internet saw it as a non-corporeal space, it is increasingly seen as a "medicalized cyberspace within which the virtual and corporeal are enmeshed" (2006, pg 1). The self-management programs revealed this enmeshment; the data doubles of the body (in the networked electronic record, on a forum, on the eating disorder support site) and the bodies themselves impacted and were impacted by the self-management programs. The data doubles created a different patient altogether, one that existed in the records kept by the clinic, in the data kept (or not) by patients which was entered into the records, and on the website. These data doubles contained information about patients' chronic condition that was disembodied, done in the data rather than in the bodies and lives of those with the conditions. These data double patients were ill in their data only, managed in their data only, and their data, though incomplete, was available to be veilled separately from their bodies.

While webveillance is a broad term created from many aspects of veillance, it is a useful one. The term webveillance allows us to describe how the different forms of veillance interact in a networked space, but are still related by the nature of where veillance is taking place: a networked computer environment. The distinction between online and offline blurred in care and in veillance. As seen in the eating disorder website, care (especially self-managed care) was increasingly provided online; the veillance followed the care, as the clinicians watched the patients and the patients watched the clinicians both online and off, noting their experiences of offline care in an online environment. Web-based information was only a part of the information taken into account when healthcare decisions were made, including those related to self-management. Webveillance also showed how the boundaries of the clinic and of care blurred. In the diabetes project, clinicians were no longer limited to viewing the record in the office (or bringing records home), while patients were given the opportunity to view the record on their own, rather than the lens of their clinicians. As noted by Marwick, "technology blurs the boundaries between formerly strict categories," such as clinical spaces and non-clinical spaces, clinician and patient, online and offline (2012, pg 386). As we show in the following section, non-clinical spaces became spaces in which healthcare and veillance were conducted.

Veillance and the clinic

In both projects, the power and responsibilities for caring for chronic conditions were shared between clinicians, patients, and sometimes patients' families, with some researchers claiming that sharing responsibilities embodies effective chronic illness management (Thille & Russell, 2010). Patients at both sites were given responsibility for self-managing their chronic condition outside of the doctor's office, with the additional responsibility of reporting data back to the clinic for veillance. This reported data changed the ways that care was provided during the visit, during future visits, and, potentially, outside of the exam room by the patient conducting self-management activities.

The expansion of the clinic and associated veillance could be seen clearly in the growth of web-based self-management activities. For those visiting the website of the eating disorder treatment center, there may have been no physical clinic, yet self-management occurred just the same, assisted by the counseling sessions on the site, the peer-to-peer relationships formed on the site, the tools provided for clinicians, and the ability to post for help. Without veillance, this expansion would not have been possible. Users of the site watched themselves (self-surveillance), their peers (coveillance), and the clinicians (sousveillance) to self-manage, while the clinicians and webmasters on the site watched what the young women wanted in terms of self-management (surveillance, dataveillance), monitored the postings on the site for unhealthy behavior (surveillance) and responded to the needs of the online community. At the diabetes site, the expansion of the clinic via online activities can be seen in the networked electronic medical record, the website for patients, and the forum for clinicians. Patients, too, could access their own data and records via the patient portal of the networked electronic medical record. This webveillance of their health information allowed them, in principle, to alter their self-management activities conducted outside of the clinic based on their medical history, and to observe the digital world of their clinicians. Clinicians, too, had opportunities to interact outside of the clinic. Clinicians were able to interact (and coveill) each other through the monitored forum. The clinic existed online, accessed in the home, offices, and internet-friendly spaces by patients, clinicians, webmasters, and project leaders. No matter where the clinic was virtually visited and where self-management was conducted, it was a site of veillance. While veillance could not capture all of the ways in which veillance was *done* by the activities, thoughts, and data related to a chronic condition, veillance was (potentially) constant in the lives of patients, clinicians, and project leaders.

Veillance of and by others

While this paper has focused on the veillance conducted by project leaders, clinicians, patients, and website users, it would be shortsighted to assume that these are the only actors conducting veillance on and in the self-management programs. In order to study the programs and ultimately write this paper, we (and the other researchers on the team) conducted veillance on the programs: surveillance when we observed meetings and clinical visits, webveillance as we explored the eating disorder support site, and dataveillance as we reviewed survey and economic data about the programs. Researchers were not the only external actors conducting veillance on the programs; others included, but were not limited to, health insurers, the ministry of health, and technical consultants. You, as a reader of this study, are also conducting veillance by observing the interpretation of the self-management programs, reading the quotes and agreeing (or disagreeing) with the analysis. Your reading, too, has power; you have the power to cite the article and to recommend (or not) the article to others. In the self-management programs, watching was not limited to one particular time or to those listed in this paper, but grows over time, as the self-management programs continue, as the articles about the programs get read, and as the funded sites grow and seek more funding, writing about their programs in funding proposals. While veillance is thus a layered concept, this paper has explored some of the specific effects that different types of veillance produce in clinical settings, producing specific types of patients and clinicians as well as the relations between them. Through our exploration of self-management programs, it is possible to see how veillance was a powerful force in care delivery in the clinic and beyond.

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Chapter Five

Proud2Bme: exploratory research on care and control in young women's online eating disorder narratives

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ABSTRACT

Illness narratives have been studied to understand the patient’s point of view. These narratives are becoming more prolific, accessible, and specialized, thanks to the improved Internet access and the growth of health-specific online communities. This article analyzes illness narratives posted on a Dutch eating disorder website hosted by a treatment center. Specifically, we look at ‘care of the self’ and ‘control’. The young women wrote about controlling situations with disordered eating as a self-care tool, about being controlled by the disorder and about regaining control over the disorder. The website, with the opportunity for constant, unseen supervision, coercion through comments, and steering through edits and comments, revealed various modalities of control. While issues of control and eating disorders have been explored by others, little work has been done on how the control experienced by the young women (coercion on the individual, the body as the object of control, and the modality of pressure and supervision) interact, how control is presented in stories for a recovery-focused, monitored website, and how the website directs the content. As the recovery-focused, therapist-led website is likely to continue growing, understanding how and why young women talk about care and control in the context of such websites is an important topic.

INTRODUCTION

> *I especially want to make it clear in my story that I have muddled along with all my problems for many years. That's why I am so pleased with Proud. If I had had such a website when I was a teenager, it all might have turned out differently. No one had heard of BED [Binge Eating Disorder], even nutritionists and doctors knew nothing about it, and here [on the site] you can get lots of information from professionals. You can get so much support from the users and from the experienced experts; it takes you out of that damned isolation.* (Story 12)

Why do people tell stories about their lives, including the stories of their illnesses? Where and why do people tell these stories? What does it mean when the stories are written and posted online on a recovery website, rather than spoken to a therapist or researcher? What do the stories tell us, beyond the stories themselves?

This paper explores these questions through the study of an online eating disorder support community hosted by a treatment center. Specifically, we analyze the discourse that the authors used when writing stories of their eating disorders, especially with regard to how different manifestations of control and discipline impact their lives, eating disorders, and participation in their online community. We also look at how the stories themselves are steered and disciplined by the structure of the site, site participants, and staff from the hosting eating disorder treatment center. For the purpose of this paper, we analyze the stories using Foucault's definition of discipline, which is comprised of multiple modalities of control: "subtle coercion" on the individual, the body as the object of control, and "uninterrupted, constant" pressure and supervision (Foucault, 1995). We analyze the different forms control takes in and through the stories, especially but not solely focusing on the role of control in eating disorder illness narratives.

Background

In the Netherlands, as a recent review of research has shown, rates of anorexia nervosa have increased to 7.7 per 100,000 in 1999 from 7.5 in 1985; young women (15-19 years old) make up 40% of all cases of anorexia, with young men representing less than 1 per 100,000 (Smink et al., 2012). Rates of bulimia nervosa dropped in the same period, from 8.6 per 100,000 in 1985-1989 to 6.1 in 1995-1999; however, the data also revealed that the age of onset (or diagnosis) of bulimia nervosa has been dropping as well, with diagnosis occurring at ages 15-25 rather than, as was previously, 25-29 (ibid). Less information about rates of Eating Disorders Not Otherwise Specified (EDNOS) and Binge Eating Disorder (BED) is available for the Netherlands; in the case of BED, an article by Preti et al. revealed a lifetime prevalence of 1.9% of women in six European countries, including the Netherlands (2009). Despite the relatively high prevalence, few Dutch young women with an eating disorder ultimately receive mental health treatment (van Son et al., 2010). Many young women delay treatment for their eating disorder due to shame, waiting lists, or poor treatment center match (de la Rie et al. 2006; Hayaki, Friedman, & Brownell 2002; Escobar-Koch et al. 2010). Early identification and treatment for eating disorders is highly desired by the eating disorder treatment community. Alternative methods of reaching and treating young (wo) men with eating disordered behavior, such as recovery websites, are a means of reaching this population.

Eating disorder treatment centers, recovery advocates, and young women supporting eating disordered behavior have been developing websites for those with an eating disorder. Pro-anorexia and pro-bulimia websites have been developed and visited by (primarily) young women who want to continue or are continuing in their disordered eating (see Norris et al., 2006 amongst others); recovery/support websites include those hosted by eating disorder treatment centers (as was studied for this article). As Rich (2006) found in her study of anorexic patient narratives, young women with eating disorders often feel most understood when interacting with others with an eating disorder, whether online or in-person. This interaction comes in the form of participating on message boards, reading postings, writing poetry, sharing photos, and/or storytelling, such as sharing their experiences with illness, treatment, and/ or recovery using a traditional story arc (having a beginning, middle, and end; chronological; intended for an audience) (Greenhalgh & Hurwitz, 1999).

(Online) illness narratives

Storytelling is communication of lives and experiences, of impressions and interpretations. The importance of narratives, as Hyden illustrated, “lies in its being one of the main forms through which we perceive, experience, and judge our actions and the course and value of our lives” (1997, pg 49). When people tell the stories of their illnesses, especially of chronic or long-term illnesses, they are using it as a means to understand, explain, and interpret their illnesses in relation to their life and life history (Williams, 1984). These stories are a potentially fertile source of research data; when reading and interpreting unsolicited illness narratives researchers, clinicians, and policy makers have the opportunity to understand the patient experience when it is not directed towards a clinician, possibly revealing a more unfettered story of illness, treatment, and/or recovery (O’Brien & Clark, 2012). As Greenhalgh and Hurwitz noted, illness narratives invite interpretation by the readers, whether those readers are others with a similar illness, clinicians, or researchers (1999). In research, illness narratives can help to focus on patients’ needs, confront prior knowledge, and help form new theories and hypotheses about care, treatment, and patient experiences (Greenhalgh & Hurwitz, 1999). Yet benefits of illness narratives to research are not limited to these points. As will be shown in our research, analyzing and interpreting online and unsolicited narratives can also substantiate research conducted in other ways (such as interviews, surveys, and observations), allow researchers to gain information about vulnerable, hard-to-reach, and/

or hidden populations with little impairment to that population, and conduct research in and on new locations of healthcare (websites, YouTube, Twitter).

Formal illness narratives have been traditionally part of medical history taking as an attempt to understand patient experiences with illness, especially chronic illnesses (Bury, 2001; Greenhalgh & Hurwitz, 1999). Websites and forums provide fresh spaces for individuals to gather social support through the telling of their experiences, as seen in research on online eating disorder forums (McCormack, 2010) or in social networks (Juarascio, Shoaib, & Timko, 2010), as well as in research done on online weight loss support groups (Hwang & Ottenbacher, 2010), HIV/AIDS online communities (Mo & Coulson, 2008), and infertility sites (Malik & Coulson, 2008). In the eating disorder literature, it is clear that writing is a form of personal interpretation and analysis of the causes and recovery from eating disorders, whether guided by therapists (Schmidt et al., 2002), for oneself (Hay & Cho, 2013), or for a community of peers online (Dias, 2003; Riley et al., 2009; Darcy et al., 2010). (Online) writing allows for the creation/manipulation of the self and personal histories in a public forum, as seen in work done on online gender presentation (van Doorn et al., 2007), for personal empowerment (Pitts, 2004), for accountability (Leggatt-Cook & Chamberlain, 2012), and for self-disclosure.

Internet-based resources provide flexibility for people to learn how to tell the story of their illnesses and to seek support through reading others' stories; researchers suggest that this online storytelling has implications for how people understand health (care) and implications for the new politics of disease and of the body that emerge in online communities of practice (Ziebland & Wyke, 2012; Akrich, 2010). By posting stories online, the users form part of online communities, gaining and offering support, setting community norms, educating others, forming and shaping identities, and sharing experience. For many members of online communities, the distinction between online and offline worlds is blurred, with online activities impacting offline ones. Online stories offer the possibility to understand online communities, site dynamics and norms, and the issues behind the illness narratives, including those of control.

Control and eating disorders

While the term 'eating disorders' encompasses a variety of physical and mental health problems (such as BED or excessive exercise), two of the more commonly researched eating disorders are anorexia nervosa and bulimia nervosa. Control is expressed differently in the minds and bodies of those with bulimia or anorexia. As research on young women with anorexia shows, the women saw themselves as attempting to control and process their lives by reducing food intake (Skårderud, 2007). Other work with young women with anorexia revealed that bodies were seen as the only thing that women could control by not eating, but noted that these behaviors quickly spun out of the women's control to the point where the anorexia became an identity (Malson, 2004). The disordered thinking was embodied, manifest in the young women's physical forms. Young women with anorexia were aware that they were controlling their bodies due to personal unhappiness, yet took pride and found joy in the control that they exerted; control over the body and emotions was found to be more important than changes in appearance (Dignon et al., 2006; Malson, 2004). Young women with bulimia reported feeling out of control of their eating and sought to regain control through purging (Fairburn & Harrison, 2003), as well as literally and figuratively ridding themselves of bad feelings by vomiting or using laxatives (Polivy & Herman, 2002). For those with anorexia, bulimia, binge eating disorder, or EDNOS, what the young women were feeling and thinking impacted their bodies (and vice versa).

Sex and gender play strong roles in eating disorders and issues of control. While growing numbers of young men are developing eating disorders, eating disorders are thought to predominantly impact young women in the Netherlands at this time (Smink et al., 2012). It is important to keep in mind that female bodies are disciplined differently than male bodies; eating disorders reflect this social and personal disciplining of the female body. As King noted, the "female body exemplifies Foucault's arguments about discipline," in that the female body is frequently disciplined into socially acceptable forms in ways specific to women (2004, pg 30). This disciplining has happened over time, Bordo wrote, as women's bodies have been historically subject to more cultural manipulation of bodies than those of men, whether through physical manipulation of the body through eating disorders or through the limiting of education and career opportunities (1997).

The language of control is pervasive in discussions of eating disorders; this discourse is found in research on eating disorder treatment, on pro-anorexia sites, and on the experiences of young women with eating disorders (Bell, 2009; Bemporad, 1996; Claes et al., 2012; Gremillion, 2003; Malson et al., 2008, 2011; Riley et al., 2009; Roth & Armstrong, 1990). This discourse is also present in eating disorder narratives in culture and media as well, including in the Netherlands; journalist Maartje Laterveer wrote, in the June 2014 issue of Dutch Vogue, "I thought that I had everything under control. But I had long relinquished control to an eating disorder that I did know about, if I was honest." (Laterveer, 2014, pg 154). While control, eating disorders, and young women have long been associated, there are gaps in this understanding. Less is known about what types and how the different modalities of control act and interact in young women's written, unsolicited illness narratives.

In this study, we used a novel method of data collection to gather and analyze how users of an eating disorder support website wrote about control in the stories of their eating disorders and what the impacts of control were on the authors, their illness narratives, and the treatment providers. As the illness narratives analyzed here were posted on a monitored eating disorder recovery website, the research presented in this study is an opportunity for readers to understand how the online community, the recovery support website, and illness narratives (inter)act in regards to the modalities of control, as well as to understand how the data collected online fits with the larger literature on eating disorders and control. As less was known about how online communities form a new arena for discussing, exerting, and tinkering with issues of control, this research shed light into the growing world of monitored online illness communities. In addition, this illustrates a deeper understanding of how the types of control interact and serve, ultimately, to discipline the lives of authors, the stories that they tell, and the website that they participate in.

THEORETICAL UNDERPINNINGS

The theoretical underpinnings of this article stem primarily from the work of Foucault on the technologies of power and, secondarily, on his work on the technologies of the self. As Foucault noted,

> *technologies of power… determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject, [while] technologies of the self … permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality* (Foucault, 1988, pg 18).

For a better understanding of technologies of power, we refer to Foucault's work on the penal system; *Discipline and Punish* explored how bodies and minds are shaped to internalize discipline by external actors, including the people in and the architecture of schools, prisons, hospitals, and churches (1995). This shaping comes via initially external forms of discipline, which are exercised through different modalities of control: discrete coercion and steering through e.g. creation of daily routines, the creation and discovery of the body as a subject of power such as through medical and prison structures, and (seemingly/potentially omnipresent) surveillance through panoptic physical structures (Foucault 1995). As seen in the literature on online narratives and in the literature on eating disorders, one of the more remarkable ways in which the technologies of power can be seen is through surveillance (Conrad, 2009; Dryburgh & Fortin, 2010; Leistert, 2012; Rich & Miah, 2009; Walstrom, 2000). This surveillance stems from multiple origins: the change towards new forms and implementations of surveillance within healthcare, especially in non-acute illnesses (Armstrong, 1995), the use of surveillance in eating disorder treatment in specific (Gremillion, 2003), the self-surveillance inherent in having an eating disorder (Bell, 2006), and the surveillance and governance of online activities, including those related to healthcare (Walstrom, 2000; Eysenbach, 2011). Gender plays a key role in the surveillance and control of bodies, thoughts, and activities. As feminist scholars have pointed out, women's bodies are watched (and, resultantly controlled) in different ways than are those of men – by their families, society at large, the medical profession, and themselves (Bordo, 1997; Conrad, 2009; Corones & Hardy, 2009; Gestaldo, 1997).

The watching of one's self is a form of self-care and an aspect of technologies of the self. Technologies of the self, understood simply, is working on one's self, often for self-improvement and taking care of one's self; without observing and knowing oneself, it is difficult, if not impossible, to care for the self. Here, writing plays a key role. As noted by Foucault:

> *Writing was also important in the culture of taking care of oneself. One of the main features of taking care involved taking notes on oneself to be reread, writing treatises and letters to friends to help them, and keeping notebooks in order to reactivate for oneself the truths one needed* (1988, pg 27).

Writing and re-reading illness narratives provides one with the opportunity to take care of the self, to self-improve, and to communicate those lessons learned about self-improvement to others. This writing is not, as Foucault showed in the *History of Sexuality*, necessarily done in isolation, but is conducted as part of a self-improvement culture (1988). The self, in many ways, is developed through care, whether through writing, self-care activities, or interacting with others. The technologies of power and the technologies of the self are interwoven in the lives and stories of the authors. While writing allows for the further care and development of the self for oneself and for/in one's community, this writing is not just a technology of the self, but is a technology of power as well. As our research will show in the following sections, the self is cared for and created through the online writings and postings of the young women.

METHODS

The stories reviewed in this research were posted on a Dutch eating disorder support website called Proud2BMe. The Clinical Director at the Ursula Center for Eating Disorders, other professionals at the Ursula Center for Eating Disorders, and patients helped to develop Proud2Bme in 2008 to fill a gap in educational and supportive services, including providing an alternative to pro-anorexia (pro-ana) sites, for the growing number of young women with eating problems.

As a currently active online support and education center, Proud2Bme promotes positive self-image, healthy eating, and treatment for eating disorders through participation in forums, chats with nutritionists and psychologists, news on eating disorders, inspirational messages, beauty and fashion pages, blogs written by site participants, and stories about living with eating disorders. While the website states that it is a resource for everyone, most of the postings focus on information of interest to women in high school and at university, such as healthy eating and team sports, eating disorders and school stress, and advice on how to tell parents, teachers, and friends about an eating disorder. The site's look and feel is also directed towards young women, featuring photos and vector images of younger-looking women on a pink background. These cues, as well as a statement on the webmaster's

‘About’ page, have led us to believe that the site was (and is) targeted towards youths and young adults. Some of the articles are directly written to family members of those with an eating disorder or are tagged with the tag ‘parents’. While the site contains information about eating disorders with formal diagnosis criteria, such as anorexia nervosa, bulimia nervosa, and binge eating disorder, much information is also provided about sub-clinical eating disorders or problems, atypical disorders such as excessive exercise or orthorexia, and other issues with food, body image, and mental health, such as cutting or depression. According to the site’s ‘About’ page, over 200,000 unique visitors access the website each month; over twenty volunteers work on the website, as well as two website editors who have experience in eating disorders, two other part-time employees, and various psychologists and nutritionists from the center. The website has been advertised in the media, has active YouTube, Instagram, Pinterest, and Twitter accounts, has an app, and is linked off of multiple mental health and lifestyle websites. The website has spawned a US version as well.

The stories were divided into four categories on the site: experience stories, interviews, famous and special people, and the psychology of… (www.proud2bme.nl)[4]. As the site was and is primarily targeted to young women and their families, we have assumed that the majority of the stories analyzed were written by young women (which we define as high school and university-aged). The ‘experience stories’ were and are stories written by young women about their life with an eating disorder, including the development of the disorder, revealing the eating disorder to adults in their lives, treatment paths, relapse, and current circumstances. Some, but not all, of the analyzed stories contained photos of the authors, supporting the assumption that the majority of the authors were young women; one story out of the reviewed stories had a photo of a young man as the author, while the remaining had photos of young women, of nature scenes, or of inspirational messages. While some aspects of the site require the user to create and use a log-in, much of the site, including the stories analyzed in this manuscript, was and is open to the public.

These data were gathered as part of a larger study. The Ethics Board of the Erasmus University approved the data collection of an overarching study. For this study, we specifically focused on the Proud2Bme website. We took various steps to ensure ethical data collection, following the example of other internet health researchers (Murray & Sixsmith, 2002; Robinson, 2001). For this paper, data were collected exclusively from the public pages of the website. As the stories were posted on the public pages of a frequently visited website, we assumed that the authors did not solely write for a private community (as might be inferred in some forums and sites that require a log-in), but were writing for an audience. As Hookway noted about blogs, “blogging is a public act of writing for an implicit audience” (2008). In addition, the center’s director approved data collection on the Proud2Bme website. The quotes from the stories, which were frequently anonymous when posted on the site, have

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[4] While the stories are still available on the website, the categorization has changed.

been further anonymized, with no reference to the title of the story or locations. Translation from Dutch to English provided a further level of anonymization. While issues might arise from translation, as the focus is on narrative, efforts were taken to reduce these issues; translation was done by the first author (a native English speaker) and verified by a native Dutch speaker. Translation also allowed for the checking of quote relevancy and coding.

Procedure

We reviewed all ‘experience stories’ and the comments that were written between November 4, 2009 [the first story posted on the site] and July 11, 2011 and collected data from the stories, which were coded into themes. However, the comments were not analyzed for this paper, as we were mainly interested in the presentations of the young women on this site at this time, rather than in the interactions on the site; as well, we were concerned about the anonymity of the comments. As the comments were tied to user names, which were used for any comments that the website users posted, the comments were less anonymous than the stories and not included in the analysis.

To be included in the study, the stories had to be written for and posted on the public section of the site as ‘experience stories’; while the website had much more content and grows continuously through the postings of website staff and users, we limited the data collection to these stories, as the stories were on the public part of the website, were written by users of the website, and were (in principle) written as complete narratives. This resulted in the collection of 94 ‘experience stories’. One of the 94 stories collected focused on self-harm, rather than life with an eating disorder; this story was not included in the analysis for this study. One of the included stories was written by a young man; based on pronouns, names, gendered words (such as daughter, school girl, etc), photos of the authors, and the fact that eating disorders were and are more common among young women, we assumed that the remaining authors were young women.

While it was not fully possible to know exactly who each of the authors were (e.g. in terms of class, age, background) and knowing that this can present challenges in terms of how we were to read the data, the data were taken at face value. Taking the data at face value allowed us, as researchers, to read what other users of the site were able to read, including those who do not have a log-in. This was a useful attribute to our research; we researched what the authors wanted to share with the public through writing and posting their stories. However, this can also be a limitation. As the stories were posted anonymously, it was not possible to contact the authors for additional information or clarification; just as the users of the website were, we were left with the information that the stories revealed, educated estimates of demographics rather than precise data on education, age, location, and unanswered questions. As we analyzed the stories as they were posted online (rather than stories of the young women told to us directly), further information and clarification was not needed for our analysis. Since the young women wrote in Dutch on a Dutch website, we were able to make a few important assumptions: that the young women had access to health insurance, as coverage is mandatory in the Netherlands and in Belgium (two locations where Dutch is commonly spoken), that the young women were writing for a Dutch-speaking audience of primarily young women, and that the young women were writing for an audience that was interested in eating disorders and eating problems, as the site where the stories were posted promotes support for those with an eating disorder or eating problems.

By collecting data from a public support site for those with an eating disorder, we were exploring control by using a fairly novel methodology: online only data collection from illness narratives. This exploration allowed us to understand how young women posted about control, what they considered important aspects of their stories, and how the young women wrote for a monitored community; it also allowed us to be unobtrusive (yet ethical!) researchers on a very sensitive physical and mental health issue.

Data analysis

The remaining 93 experience stories were analyzed deductively as well as inductively; upon reading the stories, we realized how ‘control’ was one of the main themes in the stories and, as a result, decided to focus on this theme more in detail using thematic analysis. All stories were first read closely to establish general knowledge of the data. Each story was then reread and coded into themes by the first author, based on the discourse and content of the stories. A memo sheet was made in Word by the first author for each theme and references to original material representing that theme were recorded under each theme. The major themes uncovered in the stories were present in the majority of the narratives in various ways; however, how these themes were presented by the authors and analyzed by the authors varied based on the context of the stories. The data were iteratively analyzed and reflected upon by the first author and the co-authors throughout the coding, translation, and writing processes.

FINDINGS

Eating disorders and control

The young women used a variety of discourses when writing about control and their eating disorders or problems, including disordered eating behavior as a tool to control a disordered life, eating disorders that took control of life, treatment for eating disorders and control, and regaining control while recovering from an eating disorder. This was a major theme in many of the illness narratives and was often quite explicit in the narratives. The eating disorder was sometimes described as a tool, as the young women wrote of using disordered eating behavior to govern their lives, circumstances, and/or emotions; these tools were a technology of the self, even if the self-care was often registered as self-harm by others.

> *The only thing I could do outside of my mom's control was eating. I longed to have something of my own so much and it's just sad that apparently eating was my only way out.* (Story 1)

> *I took up weight loss again, skipped meals, threw up and took laxatives. I was searching for control, control that I couldn't find in my life, but I found it in weight loss.* (Story 2)

The young women wrote of using eating behaviors as methods of self-care and independence from the direction and manipulation of others; they were governed by "the control, guidance, sway and mastery of others" (Rose, 1999, pg 16). Control was highly sought after, whether control of eating or of body weight, as the second quote reveals. This control can be understood as the ways in which their bodies were the objects of control, as enacted by themselves to manage difficult situations. Eating/not eating/purging was their 'own' and was the control that was unavailable in other arenas of their lives.

This was a battle, however. Parents were often described as controlling the young women and pushing young women into less eating disordered behaviors. As a result, the young women's bodies and behaviors "became the issue of a conflict between parents and children" (Foucault 1980, pg 57). The young women wrote of seeing their behavior as tools for controlling difficult circumstances and emotions, while family, friends, or clinicians were reported to have seen the behavior as an illness in need of medical attention, thus creating a conflict over bodily control. This conflict, in some cases, continued throughout treatment, as the young women wrote of resisting the efforts of parents, teachers, and friends to take part in treatment.

Writing, eating disorders, and control

The young women's stories followed a common narrative trajectory, starting with disordered eating behavior as a tool for controlling an unruly life, followed by awareness of the behavior as an eating disorder, and an exploration of how the eating disorder took control.

> *Weeks go by and it's getting worse, until I go to the doctor in a panic. I couldn't take it anymore. I wanted to be myself again and it wasn't working. The control over my own life was dominated by something inside me and at that moment, I came back. The control that I thought I had appeared to be no control at all.* (Story 3)

What had been a set of tools to manage difficult situations was reclassified by the young women on a public forum as a disorder; at times, this reclassification was seen as coming from parents, rather than from the young women themselves. The authors of the narratives frequently used discourses of subjugation when writing of the disorder. The disorder 'dominated' them, despite their efforts and without their full knowledge. As seen in the quote above, the disorder steered the young woman; the author wrote of 'not being herself'. This narrative and others revealed that eating disordered behavior was deeply internalized, yet remained external to identities.

The narratives described the various paths the young women took toward recovering from their eating disorder and recovering their identities, including via mental health treatment and support from friends, family, and members of the online community. Sometimes, the writers noted that the path toward recovery was not chosen by the young women, but was chosen for them.

> *I had to go into mental health care. Every week, sometimes twice a week, I had to go there and every time I was weighed and measured. I thought it was awful. My mother also weighed me and I almost started to hate her for that.* (Story 4)

The young women's stories revealed various sources of monitoring, often through observations of the metrics and behaviors associated with eating disorders; whether the young women chose therapy or were pressed into it, this theme was common throughout the narratives. As a result of this monitoring and observation, the young women interpreted their bodies as the objects of external, clinically-driven control.

This external monitoring and regulation of their bodies through weighing and measuring was conducted by multiple actors, making the body the object of collective control. The young women's written narratives also documented how they were (not so subtly) coerced into less disordered behavior and their frustration with this process of coercion. As was seen in the stories that the young women wrote for the recovery website, the bodies and minds of the young women were shaped by the various processes of control, even if the result was the young women 'almost hating' those who controlled and measured them. These modalities of control shaped young women's identities, which are "the products of a relation of power exercised over bodies, multiplicities, movements, desires, forces" (Foucault, 1980, pg 74). This imparted a deeper understanding of how the young women framed control and their eating disorders, treatment, and recovery for their online community.

The website and control

The website impacted the stories the young women wrote about their eating disorders; this theme was an undercurrent in all of the stories. In Foucauldian discourse, the possibility of being watched shapes behavior; the guard does not need to be seen in the Panoptic tower to change how prisoners act (Foucault, 1995). The eating disorder recovery website, with its blinded watching, provided an excellent example of how observation and monitoring changed what the young women wrote. This potential for constant observation was a process of control on the stories that the young women wrote; it was built into the architecture of the website through monitoring by healthcare professionals, trained volunteers, other users of the site, and through Google Analytics, which collects metadata on the registered site users, pages visited, and time on the site. The site's data collection policy was stated on the site's privacy page, which was viewable without a log-in. In principle, the architectural nature of surveillance was made clear to the authors, but the users had no way of knowing if, when, or how their stories were read. The stories and comments themselves were monitored by one of the founders of the site, clinicians, and/or site volunteers, with all mentions of weights, diet pill brands, and pro-anorexia websites replaced with ‘xx’.

> *When I eventually lost weight again, they said that when I weighed xx, I had to be tube fed.* (Story 15)

> *At school, I didn’t eat any more; I didn’t find breakfast so necessary. So I actually ate 1 meal a day, took xx, and exercised a lot.* (Story 16)

By replacing weights and diet pill brands with xx, the stories were edited, removing aspects that may have been significant to the young women. While the removal of taboo content was clearly demarcated with ‘xx,’ it was not possible to know who removed the content. The content may have been removed by the site administrators, who monitored the discourse on the site to ensure body-positivity and to ensure the stories followed the site standards; the young women who wrote the stories may have removed the content themselves to meet the site norms and support the recovery of the other site users. However, this editing controlled the stories to the point of removing content that was relevant to more deeply understanding the young women’s narratives.

The editing and steering of the stories was a continuous process. The stories did and do not end after the young women has posted them, but were/are continually changed through the comments sections, through adjustments in the location on the site, and through edits by the webmaster. The information posted on the website created a record, available to be viewed at any time. As Nicoll noted in an exploration of e-learning environments, through this online record, the website users and their information were more open to observation, correction, and tracking (Nicoll in Nicoll & Fejes, 2008). This correction came, in part, through the redaction of banned information, which also served as a public warning to others about the types of information deemed appropriate for the site.

Observation of online posting and activities by staff and users helped form the community, as young women wrote of finding the stories of others as a useful and supportive feature of the site. Through reading the words and looking at the photos of others, the young women were able to present information directly to their community to thank other users, present missing information, or to support others. While this was implicit in many of the stories, some of the young women explicitly addressed their reasons for telling their stories in their illness narratives.

> *The reason that I tell my story here? People often think that when you have an eating disorder, you are severely underweight. But you know, that is only a small part. Lots of people have struggled unnoticed and died. It has nothing to do with how you look on the outside – fat, thin, tall, short; anyone can struggle with it. I hope that people can come to see that you don’t only have an eating problem when you can count your ribs, that it’s about what is in your head. I hope that there is more understanding for people like me.* (Story 9)

> *The fact that there are so many girls and boys on Proud2Bme that fight to get better made me realize that I can also do it and more than that, I want to. I´m now stronger than before. I have control back, the real control. When I look in the mirror, I see myself as I am again. I have a handle on myself again*. (Story 10)

The young women shared the lessons learned in their care of the self with the hope of training others to care for themselves and to inspire others. No matter the intention when posting the stories, the stories and identities expressed through the stories were (and still are, as the stories are still available online at the time of writing) being controlled, "manipulated, shaped, trained" by the potential for comments, community norms, and surveillance by multiple actors at different times (Foucault, 1995, pg 136). Whereas the use of the word manipulation suggests a negative connotation, in this case it was seen by the authors as a positive force, protective, and supportive. This control was welcomed by the young women; research on weight loss blogs revealed that comments from readers can serve as an important source of motivation and collaboration (Leggatt-Cook & Chamberlain, 2012). The young women posted their stories to be read, to be observed, and were (to a degree) aware of the potential for shaping that posted stories possessed.

While the rationale for posting their stories was implicit in many of the narratives, a few of the young women stated explicitly that their reasons for posting on the public forum of the site was to support others and to try to influence (and perhaps steer the direction of) external systems.

> *With this petition, I hope that I can really achieve something, so that everyone who comes after me can get better treatment. I am grateful to Proud for giving me the chance to talk about the petition.* (Story 11)
>
> *I've had to come a long way to be able to write these words and share with you guys. I hope that with my story I can make the way to help and make recognition of the illness somewhat more traversable for those who have felt incomprehensible and alone because of cultural differences.* (Story 14)

As research about an online community for the discussion of SARs shows, online writing can serve as a form of cultural and political resistance (Gillett, 2007). The online platform of the eating disorder website was an opportunity to point out and publicize the faults and gaps that they perceived in society and/or the current healthcare system, whether it was faults seen in the lack of treatment options available, the impact of cultural issues on bodies, treatment, and emotions, or in the treatment that they have personally received. Similar to what was seen in Akrich's work on online communities for pregnant women (2010), the young women who were part of the community formed a type of activist group, collecting and sharing knowledge about the condition, mobilizing others, and forming an epistemic community, producing new types of knowledge about their diseases and bodies. These young women were working, through their illness narratives, to steer the future of eating disorder support, treatment, and recovery in their online and offline communities through attempts at coercion of those in power, as can be seen in the efforts to influence policymakers through a petition.

DISCUSSION

While eating disorders have long been associated with control, this work presents additional insights into the current research on control and eating disorders, as well as research on illness narratives; this research reveals the different manifestations of control apparent in young women's stories about their eating disorder, such as control manifested in and over the body, control and steering from outsiders including parents and treatment providers, control over the stories on the website by various actors, and control through oversight and supervision of the young women's bodies and stories. Through this work, we can see how young women wrote about control, about how these modalities of control impacted their lives, and how the stories were shaped by the website. While the illness narratives revealed many of the issues of control and eating disorders that were previously uncovered by researchers, this manuscript adds to the literature by exploring the modalities of control, as well as by using data written by young women for other young women. Through this research, it is clear that the modalities of control were key features in eating disordered behavior, eating disorders, treatment and recovery for young women, even when the young women were writing for themselves and for their recovery-oriented community. As online support communities are growing in number, this research can provide insight into how control and stories intertwine to create disciplined illness narrative authors.

Storytelling and control

Writing an illness narrative for an online community gives people the opportunity to explain their illness to themselves and to others (Hardey, 2002); in the case of the young women who wrote for the site, explaining their illnesses, offering support to members of the community, and clarifying myths related to eating disorders were stated rationales for writing and posting the stories. The process of writing, however, may not have been simple. As was seen in the young women's stories, there was a crafting to written autobiographical stories, a pattern that was followed, a language that was used, an intentionality of what was revealed and what was kept back. The posted stories, like the young women who posted them, were weighed and measured. As bell hooks noted:

> *Unlike therapy, where anything may be spoken in any manner, the very notion of the craft suggests that the writer must necessarily edit, shape, and play with words in a manner that is always subordinate to the desired intent and effect* (1999, pg 14).

The act of writing an illness narrative allows, in general, for interpretation and re-interpretation, framing, targeting to an audience, reframing, and tinkering until a desired portrayal of the self and of their story is reached. This is especially true online, where the writing and rewriting of self-narratives is common (Hardey, 2002). This is in contrast to posting on forums (such as on pro-ana sites), which often serve as quick message boards between users and do not often reveal complete narratives.

By telling their stories as participants of an online community, the writers were developing and strengthening relationships; as Frank wrote, storytelling forms, reforms, and elaborates the relationships between the storyteller and the audience (2000). In the studied stories, this recursive relationship relied on writers, readers, and the hosting institution to develop. The development of the relationship between the writers and the readers could be seen in the stories themselves, as the authors of the stories addressed their community directly for support, with gratitude, or with further insight into the disorder. Much as Foucault stated, the young women were writing for themselves to care for themselves, as well as for their community; the stories posted online were the modern “treatises and letters to friends to help them” (Foucault, 1988, pg 27). The relationships formed through storytelling helped shape the online community with its own norms, expectations, surveillance structure, and language, including the language used when discussing the different modalities of control associated with disordered eating, an eating disorder, recovery, and posting stories online.

Control and eating disorders

The stories that the young women wrote for the eating disorder website were not linear tales of how the young women got sick and then got better, but were highly complex illustrations of lives (and the stories of these lives) in transition. Though control was often characterized as a singular entity by the young women, the stories revealed that control was not singular, nor enacted by one actor at only one point in time. Through what the stories said and where they were (and still are) posted, it is clear that different modalities of control, multiple actors, and various forms of oversight impacted the authors’ lives and stories. The narratives revealed that a complex network of relationships between writing, agents, actions, and control was formed; this network was, as Foucault noted, a “highly intricate mosaic” (Foucault, 1980, pg 62). This mosaic included the actors such as the young women, the externalized eating disorder, their families, their treatment providers, the members of the online community, the actions of treatment and recovery, participating in the website, writing and posting their stories, and the ways in which control was acted out in and around the young women’s lives and stories. The mosaic was not static, but was a complex, moving network of actors and actions interacting in multiple ways over time in the stories and in the young women’s lives.

The segments of the stories about treatment revealed the mosaic of actors, actions, and the processes of control most explicitly. Treatment was described as involving the body as an object of control, coercion, and near-constant monitoring. Through treatment, the external, treatment-led modalities of control (such as weighing the young women, monitoring what they ate, and restricting access to the bathroom to limit purging) created discipline, which was exercised on the young women and their stories. In the young women's stories, this interplay of various modalities of control (coercion of the individual, the body as the object of control, and that of pressure and supervision) was conducted by different agents, with some actions revealing multiple modalities of control. For example, with the insistence that the young women ate defined amounts of foods, the bodies became objects of control and the young women were pressured to learn how to eat, and were supervised by nurses, parents, and others until they ate. Sometimes, the young women wrote, there was a struggle against the supervision by others to eat and coercion of the eating disorder not to eat. As was seen in the young women's narratives, treatment was an effort to discipline bodies and minds in order to improve the health of the young women.

Care for the self played an important role in the disciplining of the young women, as the narratives reveal. Eating disordered behavior was often begun in an attempt to care for the self, though the care of the self was seen as misguided by those around the young women and, often later, by the young women themselves. However, as this technology of the self was understood to be more harmful than helpful, the young women were often forced to seek outside help in caring for themselves. Treatment and recovery-focused activities were some of the primary technologies of the self, as one of the goals of these activities was an internalization of the lessons learned from therapists, friends, family, clinicians, other users of the site, and others with an eating disorder. These lessons often focused on new ways to care for oneself, such as through healthier eating habits, connecting with others on the recovery-focused website, and maintaining a healthier weight (for those who struggled with extremely low weight). The young women wrote of being disciplined into care of the self by treatment, recovery-focused activities, and by participating on the website.

In general, this discipline is not limited to eating disorders, but can be seen in other programs intent on the modification of women's bodies, as research by Cressida Heyes revealed. In her exploration of a commercial dieting program, the article exposed the supervision of the body inherent in weight loss programs, through the shifting of authority from the body to the mind and through the disciplining from both internal and external sources, such as weigh-ins and calorie logs (2006). This observation and coercion was also true for the treatment of eating disorders, as the stories from the young women revealed and as was shown in the literature (Bell, 2006; Malson, 2004; Gremillion, 2003; Warin, 2005). This literature, much like the young women's stories, revealed that treatment was situated within discourses of class, culture, and gender, impacting young women's bodies, lives, and, in turn, illness narratives in very specific, normalized ways. Much like research on diabetes has shown, the bodies and actions of the disorder, the treatment, and recovery were embodied (Mol & Law, 2004); eating/not eating, as shown in the example above, was how young women both did their bodies, disorders, and stories, and were their bodies, disorders, and stories. Bodies and control were always present in the stories.

The notion of control that is pervasive in the literature on eating disorders was, through the analysis of the stories, more nuanced and clarified; through this analysis, it was possible to see that there are many versions of control (controlling what, by whom, through what mechanisms) that compete, overlap, and influence the young women's lives and stories. The young women's illness narratives, intentionally or not, reflected the language of and the literature on the controlling and disciplining nature of eating disorder treatment. Whether this was due to the pervasive language of control surrounding eating disorders or a manifestation of the language of control of the online community was impossible to tell and, in all honesty, may not be that important; as Mol noted, attuning and adjusting is needed, as control is an illusion and the elements involved in lives, in treatment, and in bodies are constantly moving (Mol, 2009). In this case, the attuning happened in the young women's lives and was reflected in their stories. What is important was that the young women wrote of how treatment disciplined them. The origin of the notions of control in the stories is less important than the fact that it was important in the young women's lives and stories.

INSIGHTS FOR CLINICIANS AND THOSE WITH AN EATING DISORDER

For young women with an eating disorder, this research presents an opportunity to understand how the academic community understands the issues of control surrounding an eating disorder, storytelling about eating disorders, and the impact of posting said stories on a recovery website. This analysis also provides those with an eating disorder the chance to see how others with an eating disorder present their stories and interact with others on a recovery site. The translation of the quotes allows for those who do not read Dutch to see how others in another culture experience an eating disorder. The manuscript also shows that insights from the stories posted online are valuable not only to those with an eating disorder, but to a wider community, such as clinicians and researchers.

Clinicians and webmasters of recovery websites can benefit from this research by reading the narrative reproduction of the lived experience of those with an eating disorder, especially how those with an eating disorder experience control. As many young women with eating disorders were (and are) subject to treatment involuntarily, it can be useful to see how those with an eating disorder viewed the control exerted by treatment, whether this control was steering to make healthier choices, the physical control over the body by coercing eating, or the control by family assisting in treatment. It is also useful for clinicians to see how those with an eating disorder recovered from the control of the eating disorder with help from a virtual community, allowing the clinicians to see that there are other, less traditional resources available to help. Webmasters can see how such a website played a role in recovery and assisting those with an eating disorder in regaining control of their lives, and how the monitored nature of the sites (indeed, the controlling of the stories) influenced the recovery-positive nature of the website. Through this research, webmasters and volunteers gain insight into the pathology of the disorder from the point of view of those with the disorder, as well as how the stories posted on the website fit into larger understandings of eating disorders and recovery.

INSIGHTS FOR RESEARCHERS OF INDIVIDUALS WITH EATING DISORDERS

This research and article provide insights for researchers of individuals with eating disorders by showing ways in which researchers can access the stories of those with an eating disorder: by looking at the illness narratives that those with an eating disorder post online on a recovery website. Collecting data from illness narratives provides researchers with the opportunity to review the complete story that the authors want to share. By analyzing illness narratives posted online, the researchers have the opportunity to collect data about personal experiences with an eating disorder outside of a research setting. Through this method of collecting data, there is less research burden on a vulnerable population, as well as the ability to collect data in an asynchronous manner. However, ethical steps for online data collection should still be taken.

The analysis of control in the online eating disorder narratives also provides insights for researchers on aspects of control and discipline. While control is often treated as a singular issue, our research reveals the benefits of nuancing the types of control, as well as understanding how these types of control interact and discipline. By taking a more nuanced understanding of control, researchers have the potential to explore under-researched or ignored aspects of control. This more nuanced look at control also benefits researchers through giving them the possibility of deeper insight into how discipline is created and enacted through different modes of control. Looking at control in this way may help researchers, for example, to analyze how disordered eating can be a form of self-care and how treatment (in a broad sense) can function to change the ways that different modes of control play in the lives of people with eating disorders.

CONCLUSION

Through this work, we laid a foundation for future endeavors concerning control, especially in regard to online illness narratives and eating disorders, as well as showed that the findings gathered through the novel data collection method of analysis of online eating disorder illness narratives conforms with the larger eating disorder and control literature.

This research illustrated the technologies of power and of the self in how the young women and their stories were shaped by themselves, by the externalized eating disorder, by parents and treatment providers, by the structure of the website, by the website readers, and by members of the eating disorder treatment center. This coercion was not unidirectional; as the stories revealed, some of the young women used their stories to raise recognition of cultural issues and eating disorders and to reduce gaps in knowledge surrounding less common eating disorders such as BED (as seen in the quote at the beginning of this article). The research also revealed the different ways young women wrote of their bodies as objects of control for an audience of their online peers. In addition, we can see that the structure of the website supervised and surveilled the stories through Google Analytics and through the constant availability of the stories; the young women who wrote them did not know when, if, or by whom their stories were read. These modalities of control served to discipline the young women and their stories into acceptable forms.

One of the important findings of this research is that the processes of control put forth by the website had a large impact on the young women's stories and lives. As online support communities are growing for those with eating disorders, understanding how the processes of control impact the lives and stories of those with an eating disorder has the potential to improve care both online and off.

LIMITATIONS

This research has a few limitations. As the data were collected from anonymous stories on the public portion of a website, it was not possible to contact the authors for further information and clarification. The stories were posted by Dutch authors and were written in Dutch; however, the analysis revealed that the analyzed data posted on the site was in line with data collected by other means (interviews, document analysis, focus groups) and with data from young women from other countries, such as the UK (see, for example, the work of Helen Malson, especially her book *The Thin Woman*) and the US (e.g. the work of Helen Gremillion in her book *Feeding Anorexia: Gender and Power at a Treatment Center*).

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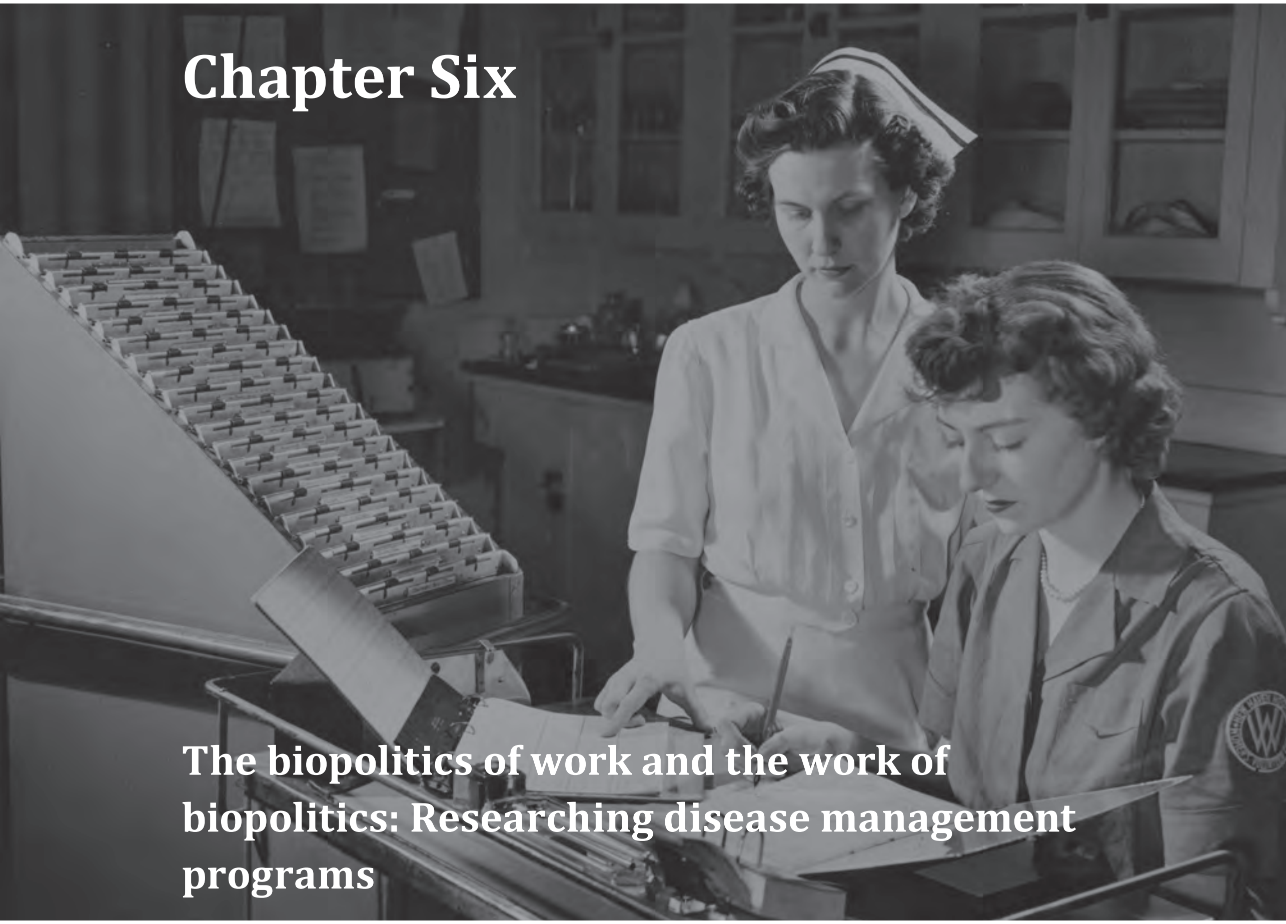

Chapter Six

The biopolitics of work and the work of biopolitics: Researching disease management programs

Hipple Walters, B., Adams, S., & Bal, R. The biopolitics of work and the work of biopolitics: Researching disease management programs. Submitted.

ABSTRACT

In the popular press and medical journals, a crisis of chronic disease is brewing, especially in developed, industrialized countries. The 'solution' to this crisis often takes the form of disease management programs and research studies. In this paper, we analyze the forms of work and the biopolitical implications of this work in disease management programs and studies. Data was collected through interviews with project leaders and document analysis; the analysis of the collected data was influenced by Strauss's scholarship on work, Foucault's work on biopolitics, and Epstein's explorations of the biopolitical paradigm.

The disease management programs and studies required much work and watching. This research found that watching and work are a micro-politics of power and a method of governing of populations through the changes in healthcare delivery. Biopolitics required work to happen. The notions of work, as developed and explored by Strauss and others, revealed the types of work done by project leaders. These types of work enacted specific versions of care, of patients, of project leadership, and of biopolitics.

INTRODUCTION

According to the popular press, Ministries of Health, and study data released in medical journals, there is a crisis of chronic disease brewing, especially in developed, industrialized countries. A quick search of *Lancet*, *JAMA*, and the *New England Journal of Medicine* revealed titles such as 'Preventing chronic diseases: how many lives can we save?' (Strong et al., 2005), 'The neglected epidemic of chronic disease' (Horton, 2005), and 'Rising to the global challenge of the chronic disease epidemic' (Quam et al., 2006). In the Netherlands, the number of diagnoses of chronic diseases increased by 17% from 2005 to 2013, and is expected to continue rising (RIVM, 2013). Contesting these numbers is not the goal of this paper. Whether these numbers signify a tangible increase of chronic disease or are, rather, the effect of specific politics of disease, including the marketing strategies of the pharmaceutical industry (Greene, 2006), is not a question that concerns us here. Rather, we analyze how this 'epidemic' influences the work done by patients, clinicians, and (project) leaders and managers. We specifically examine the different types of work that impact disease management programs and studies.

Disease management programs, especially those based on the Chronic Care Model, are commonly designed for the coordination of care for those with chronic illnesses on multiple levels, such as the community, the health system and self-management support (Wagner et al., 2001). Through such programs, care for those with a chronic disease is shared between multiple clinicians, project leaders, and patients; self-management is emphasized; and new information systems are (often) put into place. Disease management programs are used for a variety of chronic conditions[5]. The programs are intended to be flexible, changing with the needs of the population and the healthcare practice, while attempting to improve care and reduce costs.

Disease management programs are often funded as experiments, whether by state entities as research studies or by health insurers as innovative and potentially cost-saving mechanisms for chronic care delivery. These forms of funding, and the strings attached to the funding, require changes to care, which are made through the work of multiple actors. Studies involve data collection through surveys, interviews, data extraction from records, and/or billing information. Through the work of research, clinicians and researchers are creating 'evidence' to be used in the future delivery of evidence-based medicine (Nielsen & Jensen, 2013). While other research has focused on the work of patients with a chronic disease (Sav et al., 2013; Holman & Lorig, 2004; Corbin & Strauss, 1985; Langstrup, 2013), of lay caregivers for those with a chronic disease (Freydberg et al., 2010), of clinicians treating chronic disease (Lake & Staiger, 2010; Oudshoorn, 2008), or of patients and clinicians in

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[5] See http://www.improvingchroniccare.org/index.php?p=Chronic_Care_Model_Literature&s=64 for examples of disease management research projects.

self-management programs and studies (Ross Winthereik & Langstrup, 2008), less research has focused on the work of participating in the study of disease management programs or of the work done by project leaders in disease management programs and studies.

The empirical core of the research in this paper is the evaluation of a large-scale Dutch disease management program conducted by the Erasmus University Rotterdam. The evaluative research and individual disease management programs were funded by the Netherlands Organization for Health Research and Development (ZonMw)[6], with two healthcare consulting organizations (PICASSO for COPD and Vilans, a long-term illnesses and chronic care knowledge institution) contracted to support the sites in program implementation.

In this paper, we analyze the forms of work encountered in these programs, as well as how these forms of work impacted the enactment of biopolitics in the disease management programs *and* their associated research studies. We first explore the definitions of work and biopolitics, then explain our methodological approach. We examine our empirical data in terms of types of work and conclude with a discussion of the biopolitical implications of the work of creating, collecting, using, and communicating disease management program and study data.

Biopolitics, work, and illness

One way to understand the work involved in disease management programs is to analyze the programs and studies from a biopolitical framework. According to Foucault, biopower and biopolitics are technologies that focus on how, why, and to what end people are governed for certain goals, such as collecting statistics on birthrates and improving access to birth control if the birthrate is considered problematically high. Biopower “determines the conduct of individuals and submits them to certain ends or domination, an objectivizing of the subject” (Foucault, 1988). Foucault’s early conceptualizations of biopower focused on the “administration of bodies and the calculated management of life” to solve issues associated with “birthrate, longevity, public health, housing, and migration” (Foucault, 1984, pg 141). The collection of data and statistics created these problems by making them visible, easily transmissible to others, concretely quantified, and, as numbers, analyzable as data, an entity separate from people and their bodies.

Biopower creates a window of opportunity for biopolitics[7]. While biopower creates and illustrates the problems, biopolitics finds ways to deal with and work through these new problems, forming “the set of mechanisms through which the basic biological features of the

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[6] The principle backers of ZonMw are the Ministry of Public Health, Welfare, and Sport and the Netherlands Organization for Scientific Research, which is under the responsibility of the Dutch Ministry of Education, Culture and Science.

[7] While the distinction between biopower and biopolitics is rather binary, it is a false distinction for the sake of clarity; in practice, it’s difficult to delineate the border between creating and solving a problem.

human species became the object of a political strategy" (Foucault, 2009, pg 1). Bodies (and the lives connected to those bodies) become objects of political and social power dynamics through biopolitics. *Biopower* is a way of looking at populations; *biopolitics* is the ways and means of systematically reviewing and governing the populations that biopower has created.

The strategies of biopolitics include the surveillance of bodies and the creation, often through aggregation of data, of the standard body[8], the actions of making people and their bodies steerable, and the steering of non-standard bodies. However, the power of biopolitics is not unidirectional, but is a process in relationships between bodies and the state, with bodies directing the attention of the state and the state steering the bodies of the population through various political strategies (Mills, 2004). These relationships entail a significant source of effort for all involved.

An interesting example of biopolitics and work can be seen in the relationship between research, biomedicine, and the state. Termed the biopolitical paradigm by Epstein, this is a "framework of ideas, standards, formal procedures, and unarticulated understandings that specifies how concerns about health, medicine, and the body are made the simultaneous focus of biomedicine and state policy" (Epstein, 2010, pg 67). Through the workings of the biopolitical paradigm, bodies are sorted into niche standardizations through scientific and biomedical processes for easier management by the state, by biomedical institutions, by those providing healthcare in national healthcare systems, and by other governing authorities. These bodies are studied, standardized, and sorted into categories, some of which are smaller niche standardizations of larger categories, i.e. African American women *with* heart disease (Epstein, 2010). This sorting enables the management of these niche groups to improve the health of these groups.

In chronic disease healthcare delivery, different types of work can be seen as components of biopolitical strategies. Strauss et al. (1985) categorized the work done in treating chronic illness as machine work, safety work, comfort work, sentimental work, and articulation work. While Strauss took a fairly performative view of work, we analyze the nuances of different forms of work in terms of the specific forms of biopower they enable. Machine work, safety work, comfort work, and sentimental work are most commonly conducted at the care delivery level. While these types of work are important in understanding the biopolitical paradigm, they were not the focus of our study. Rather, we focused on the work of project leaders and managers. Articulation work, cooperative work, and information work provide better understanding of the types of work that project leaders do.

Articulation work, defined as work "done to assure that the staff's collective efforts add up to more than discrete and conflicting bits of accomplished work" (ibid, pg 151), is work done behind the scenes, but is necessary for the success of a given endeavor. In healthcare,

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[8] See the work of Epstein for a larger discussion of the creation of the standard body through biomedical research.

this work is often done by nurses, by other non-physicians, and by those leading projects (Bowker & Starr, 2000; Strauss, 1988; Allen, 2015). By doing this work, project leaders and nurses make sure that standard operating procedures and care protocols run smoothly in the face of changes, that interruptions are dealt with quickly, and that routines are established or continued (Strauss, 1985; Star & Strauss, 1999; Strauss, 2014).

Cooperative work is also a large component of the work done by project leaders in disease management programs. Cooperative work "interleaves distributed tasks" and people (Star & Strauss, 1999, pg 10). Cooperative work done by project leaders includes the coordination of tasks (such as trainings) and people, organizing the work of multiple clinicians involved in the disease management programs (Cramm & Nieboer, 2012), and organizing efforts with research teams (Clark & Sinclair, 2008).

Much of the work conducted in chronic disease programs and studies is done around the creation and coordination of information and data. Also called information work, this work focuses on creating and gathering numerical data; staff information; collecting, cleaning, and sharing budgets; reviewing and documenting processes; and gathering literature with which to make informed decisions. Project leaders watch, create, and gather information that shapes programs, work to meet (or game) performance indicators (Jerak-Zuiderent & Bal, 2010), and set standards for the programs and share this information with those in the programs (Thevenot, 2009; Bowker & Star, 2000). Information work is also involved in being part of a research study. Project leaders coordinate the development and collection of multiple sources of data for the study team, participate in research planning, and provide research data themselves (Clark & Sinclair, 2008).

Combining the perspectives discussed here, this paper focuses on the kinds of work done to perform biopolitics in the context of disease management programs, with a specific focus on the work done by project leaders vis-à-vis clinicians, patients, and researchers. We explore and analyze the following questions:

- What types of work are being performed?
- What types of problems does biopower uncover?
- What are the implications of the work and biopolitics performed in and through disease management programs and studies?

METHODOLOGY

This paper is based on semi-structured interviews with project leaders and/or managers and document analysis in the context of a disease management program in the Netherlands. The first round was conducted mid-way through the research project period, and the second round of interviews was conducted near the end of the projects. Sixty interviews were analyzed from 19 of 22 sites; the data from the 3 sites that focused on mental healthcare were excluded due to a different structure of the programs and research.

Document analysis was a crucial component of the research conducted for this paper. The documents analyzed include study protocols, applications, reports and other documents associated with the supporting agencies (Lemmens et al., 2011). They formed the backbone of the funding, research, and programs participating in the study.

Sites

The selected healthcare organizations included hospital departments, GP cooperatives (groups of GP offices that worked under one board of directors), healthcare centers, and specialist treatment groups. The chronic conditions addressed by the programs included diabetes, cardiovascular risk, COPD, depression, stroke/TIA, schizophrenia, and multi-morbidity (for patients with multiple chronic conditions). While each program was unique, they shared similar aspects: education and motivation for patients on how they can manage their chronic illness themselves (self-management, motivational interviewing); implementation of new or existing disease-specific care standards; development or enhancement of electronic medical records (EMRs); substitution of care from physicians to nurses and chronic disease specialist assistants; and the creation of chronic disease care teams of GPs, nurses, chronic disease specialist assistants, nutritionists, physical therapists, and/or internists[9].

Each disease management program had a ‘project leader’ aligning with the roles described by Solberg et al. (2006). Project leaders were responsible for leading and overseeing the changes in healthcare related to the implementation of the disease management program, coordinating data collection, attending the required training and information sessions, and writing reports. The project leaders had diverse backgrounds, ranging from clinicians to external consultants to GP staff.

Ethics

The Ethics Board of the Erasmus University approved the data collection of the overarching study. Consent was obtained at each interview. All data is anonymous.

FINDINGS

To understand the types of work involved in disease management programs and studies, we first describe the work done *before* the programs and studies begin. We then examine the work of and in the funded disease management study after program implementation, as well as other types of research conducted outside the funding program and how the work

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[9] A complete outline of the interventions proposed can be found in *Appendix 1* of Lemmens, et al (2011).

for this research plays a role in the biopolitical processes. Finally, we analyze the work of disease management programs themselves.

Preliminary work

Leaders from the healthcare sites prepared for their programs by applying to be part of the national disease management program and study. They hoped to acquire funding for the programs, though applications were written with no guarantees of financing. The application process involved writing proposals about how the site planned to change care delivery to match the conceptualization of 'disease management' outlined in the funding call.

> *By disease management, we mean a broad programmatic approach to chronic diseases, and a comprehensive care chain of diagnosis, treatment and counseling, as well as prevention, early detection and self-management. The approach is recorded in multidisciplinary care standards and is organized around the patient and his condition, as much as possible, in conjunction with his surroundings. Disease management requires appropriate management and funding structures, as well as innovation support.* (Call for Proposals)

The funder's goals steered project leaders even before funding was awarded and contracts were signed. To develop the proposals, the project leaders first had to conduct information work for the proposals. This work included learning the numbers of patients expected to be impacted by the proposed programs and the budget needed to complete the changes in care via the disease management programs. In some cases, the project leaders had access to EMRs and used them to gather practice data. In other cases, project leaders needed to conduct more intensive research to uncover who in their patient population was already diagnosed (or potentially could be diagnosed) with a certain chronic disease. In these cases, creating a population of people with, for example, COPD was the first step of their program. Project leaders were uncovering and creating niche populations of patients with chronic diseases. By creating, then problematizing these populations, they simultaneously demonstrated the need for state-level funding and exercised a degree of biopower over individual patients by categorizing them as needing intervention.

To write the proposals for funding, the project leaders needed to cooperate and coordinate between the various potential clinical settings, with insurance companies that might provide additional funding, and with the institution that issued the call. While the project leaders of the proposals did the majority of the work, clinicians and office staff also worked by cooperating to provide needed information, such as the number and type of staff expected to be involved in the programs. Clinicians provided feedback on the programs, such as ideas for patient education. In essence, to receive funding and support, the project leaders were developing biopolitical strategies (the disease management program) to address the problems uncovered and created through information work, cooperative work, and coordination.

Implicit in the *Call for Proposals* was the work that participating in the disease management programs and studies would bring about if funded. This can be seen in the broad goals for the programs:

> 1. *Initiating (local/regional) experiments in disease management, including self-management, from which, through sound evaluation research, knowledge can be obtained for spread and implementation (e.g. reimbursement)*
> 2. *Stimulating knowledge development on applications of disease management in providing care for people with a chronic disease.*
> 3. *Stimulating the use and insights of successful projects in healthcare practices.* (Call for Proposals)

The goals of the *Call* revealed points that were thought to be the primary issues impacting care for those with a chronic disease, e.g. facilitation of knowledge transfer. The implementation of a research study on disease management programs in healthcare organizations was seen as a solution for this problem. The close tie between research and practice was to be mediated through various forms of work done by project leaders, as was the implementation of the disease management programs.

After submission, a committee of academics, healthcare policy makers, and patient advocates reviewed proposals and selected twenty-two programs[10]. The state, working through and with ZonMw, had an interest in the practice change achieved through the disease management programs and in the data on the bodies and actions involved of patients in particular, but also the actions of clinicians and project leaders. When deciding which healthcare organizations would be funded, this committee was also selecting who and what would be governed by the projects. The chronic disease biopolitical paradigm was embedded in the *Call,* in the proposal writing process, and in the selection of sites.

Work of and in the funded disease management study

As part of the funding contract, in order to receive funding and support, the projects were required to fulfill certain requirements (described below). This placed project leaders in close contact not only with local clinicians but also ZonMw, PICASSO for COPD and Vilans, and researchers from Erasmus University. One requirement for all project leaders or managers was attendance at so-called 'Inspiration Days':

> *Vilans organized an 'Inspiration Day' targeted at practice projects. Best practices, challenging questions, and a soapbox were the ingredients of an afternoon full of inspiration.* (Vilans newsletter)

The Inspiration Days were intended to facilitate knowledge-sharing between projects, and presenting early research findings. As biopolitical agents, project leaders and managers were

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[10] While this meant different types of work for the selection committee, it is excluded from our analysis.

educated through the 'Inspiration Days' and tasked to change how patients' bodies were governed.

Project leaders were also required to complete annual reports on patient populations and changes in care. These reports to ZonMw were surveillance mechanisms used to oversee the project work, creating different types of work for project leaders.

> *Project leaders draft a yearly progress report, which might be discussed in a meeting between all project groups. At the end of the project, a report of the program content and final financial report is drafted.* (Call for Proposals)

One goal of the intermediate reports is closely tied to what Armstrong calls 'surveillance medicine' (Armstrong, 1995); this report, based on created and collected data, was "an efficient technical tool that both measured and reaffirmed the extensiveness of morbidity" in relation to the ongoing disease management program (ibid, pg. 397). Reporting data reflected supervision of the activities of patients, clinicians, and project leaders (Foucault, 1995). The report was evidence that work was being done, that the work met expected standards, and that the work was in a reportable form in the timeframe desired by the funders and the research team. For the reports, patients were, once again, sorted into categories through biopower to be more easily cared for and governed through the disease management programs by clinicians and by the state, who received the report.

The project leaders were contractually required to assist with the creation and collection of study data. This data was created through information work and cooperative work in conjunction with the researchers at Erasmus University, where it was cleaned, processed, and made public. The programs were studied using quantitative, qualitative, and economic methods to evaluate the programs[11]. The data was collected to learn about the impact of the programs on healthcare delivery, patients' health status and satisfaction, the costs associated with the programs, how the programs changed care delivery, and the processes of implementing disease management programs. One way this data was collected was through surveys:

> *We used the Assessment of Chronic Illness Care Short version (ACIC-S) to investigate professionals' assessment of chronic care delivery ... The ACIC-S consists of 21 items covering the six areas of the chronic care model: healthcare organization (n = 3), community linkages (n = 3), self-management support (n = 3), delivery system design (n = 3), decision support (n= 3) and clinical information systems (n = 3). Additional items integrate the six components, such as by linking patients' self-management goals to information systems (n = 3).* (Final evaluation report)

The elements of the biopolitics of the disease management program can be seen as underlying this data collection. The state funded the studies to learn about changes to the bodies of

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[11] A complete listing of the quantitative measures proposed can be found in *Table 1* of Lemmens, et al (2011).

those with chronic disease, and the changes to the processes of care delivery to understand how disease management programs governed. The state had not only redesigned the care practices of the participating sites, but created the evidence desired before making broader changes to healthcare in the Netherlands.

The project leaders had a crucial role in data collection, as both subjects and data collectors. As subjects, project leaders completed surveys, participated in interviews, and aided in economic data extraction. At the same time, project leaders and researchers were collecting data from clinical staff and patients. This data collection included the very fundamental work of thinking about and finding a place for patients to fill out the survey.

> *Yes, because it was a place where patients could fill in their survey in peace. And if you need to complete the survey in the waiting room, you can be distracted. And certainly after a stroke, you can have trouble with stimuli, so that is more difficult.* (Interview with MM)

Project leaders and managers dealt with the concrete issues of coordinating data collection with clinicians, patients, and the research team. This work was a hybrid of cooperative work (interleaving distributed tasks) and articulation work (managing the consequences of this distribution) (Star & Strauss, 1999). The disease management programs were conducted in multiple healthcare cooperatives which were comprised of doctors' offices, care centers, hospitals, online, and ultimately, in patients' homes, as patients managed their chronic disease wherever they went. Clinicians, patients, and project leaders, then, were steered by the research on the disease management programs, even to the level of where to sit to complete a survey or where to conduct an interview.

Work of other practice-based studies

Project leaders were also responsible for coordinating and gathering data for health insurance companies, for research conducted as part of other studies, and for the formal study of the disease management programs funded by ZonMw (of which this paper is one product). These types of work governed the project leaders and the programs that they oversaw. Project leaders collected data on the number of patients impacted by the disease management programs, the number of patients who attended courses, or the number with improved biometric data, in the hope of getting more funding or proving that the funding was effective. This information and coordination work had strong biopolitical implications: research conducted at the behest of health insurance companies could directly impact (extra) funding. The reports compiled influenced what sort of funding and healthcare the health insurance company provided for those with a chronic disease, as well as how much, for how long, and why.

Other research was conducted at the sites. Project leaders conducted their own internal research or coordinated internal research at the request of the healthcare organizations, with the goal of learning more about the care processes from the clinicians' and patients' points of view.

> *We had a number of separate focus groups composed of patients and professionals. Through this method, we got a lot of information that we have used for the development of improved care. The findings of the patient are very valuable in order to detect obstacles and to be able to improve patient care.* (Interview with M)

As the research for health insurers and/or ZonMw did not provide the information desired by the healthcare organizations, project leaders had to do more work. Conducting or coordinating the multiple, often simultaneous forms of research was a challenge and an example of information work, cooperative work, and articulation work, as the project leaders interwove the different forms of information gathering and the research subjects while making sure that the studies *and* care delivery ran smoothly.

> *You [the research team] don't realize this, but there is a lot of data collection going on all the same. And there is always more, never less. And then we get the insurers saying 'yeah, great that [two insurers] have their questionnaires, but now we have our own' and then we have to get data [other insurers] and, God forbid, we have to send out new questionnaires again. It can drive you crazy.* (Interview with G)

While the project leaders were driven 'crazy,' the evaluation was, in part, a tangible justification for their jobs and their authority as actors in the biopolitical paradigm. Without the programs and studies, there would be no need for project leaders, as there would be no information to gather, no services to coordinate, no people, programs and studies to smoothly hybridize through articulation work. Project leaders led projects – programs *and* studies – and conducted the work associate with leading projects.

As noted by Broer et al. in their study of mental health quality improvement programs, the projects served as a means of producing power, enabling project leaders to take the authority to get things done and the responsibility of getting things done through the various forms of work that they engaged in (Broer et al., 2012). This power allowed the project leaders to discover and then govern patients with chronic conditions through the work of clinicians in the disease management programs. The project leaders were a crucial component of the biopolitical paradigm through their work of sorting bodies through scientific and biomedical processes for easier management by clinicians in the healthcare organization, health insurance companies, and by the state, through the data collected for the funded research study (Epstein, 2007).

Work of the disease management programs

The disease management programs focused on methods of improving treatment and management of a variety of chronic diseases. The project leaders worked to improve care in ways that were related to the disease management programs. Changes in care included learning which EMR was best suited to their healthcare organization, setting up patient health education programs, coordinating care between clinicians, and establishing clinician education programs on different facets of disease management.

Leading disease management programs required much effort from the project leaders, especially finding staff that met the needs of the healthcare organization.

> *For me, the big line in the project was that at the start we made the big mistake of hiring a project manager that was also meant to execute the program. That didn't go well. The person we hired was good in executing the program but she was an inexperienced project leader and she didn't have the required distance from the project. I tried to train her from an inexperienced project leader to an independent one by having weekly sessions, but that didn't work. I have myself to blame for that.* (Interview with G)

Project leaders smoothed the way for other administrative workers, while (trying to) ensure that the work on disease management programs and studies continued. Project leaders often sought outside personnel, such as trainers from the software company (when implementing EMRs) or managers who had experience with the program. Project leaders then arranged trainings or transitioned the new manager into their role, while trying to ensure, through articulation work, that the disease management programs and studies continued. Putting electronic medical records into place influenced how clinicians interacted with patients and patient data, easing the extraction and categorization of this data.

Articulation work and information work were especially important for project leaders. Much of the information work involved sorting clinicians and patients into categories. Project leaders collected information on the patient populations and, with this information, created categories of who had (or was at risk of) a disease or condition. These categorizations were often based on (inter)national disease standards. However, standards change over time and require the assessment of the patient population at multiple points in time, as other scholars have shown (Nicholls, 2013; Bowker & Star, 2000). Existing biopolitical information about disease categories impacted the projects, which (in turn) created more data that could be used as a tool for surveilling and governing the bodies of the population.

> *We did a questionnaire that we did not do much with, but we did get a picture [from the survey]. Some of the patients were at the lung specialist and we didn't interfere as they were already being treated in multi-disciplinary ways. But some seemed to fall between the cracks and ... We detected that they had no treatment at all. As a result, we had the opportunity to start an appropriate treatment ourselves ...* (Interview with VDP)

> *We didn't have all patients in view and we used the electronic medical record system to call them in. We took care that patients were well coded so that they would be easier to trace. They don't notice themselves. We also broadened the consultations.* (Interview with G)

Though this information and articulation work was time-consuming for project leaders, reviewing the data to better understand the patient population was a moment for reflection.

Project leaders appreciated such reflective moments, as they allowed having ‘all patients in view,’ to find those who had fallen ‘between the cracks,’ and to learn how project leaders and clinicians could improve care. The project leaders were able to target the disease management program to the characteristics of the population with the chronic disease, such as education on how to stop smoking when data revealed that those with a risk of cardiovascular disease (CVR) had high rates of smoking.

Project leaders worked as researchers and research subjects, program coordinators, staff managers, program information workers, finance officers, comforters, and (sometimes) as clinicians. To understand the changing needs of the population, project leaders conducted information work through reviewing the electronic medical record, cooperative work through meeting with clinicians to learn from them and to present them with findings from the project leader’s record reviews, and articulation work to make sure that the work of the programs continued. The work that project leaders did impacted the programs during the project period and beyond by changing the focus of the programs, by adding or removing training, by changing the electronic medical record, and by offering new connections, such as patient support websites. In this way, the bodies of patients were governed by clinicians for the state’s biopolitical goals of learning, for example, which factors improved management and care for chronic diseases. Governance came through clinician oversight of patients, changed expectations of patients’ behavior, surveillance of patient and clinician data, and project leader oversight of clinicians’ care provision (Hipple Walters et al., 2015).

DISCUSSION

The analyzed data revealed that the disease management programs and studies were technologies of power. In the disease management programs, these technologies of power were biopolitical, defined as the “specific strategies involving contestation over the ways in which human vitality, morbidity, and mortality should be problematized” and what, how, and when solutions should be implemented (Rose, 2009, pg 54). Biopolitics was reliant on multiple, blended forms of work. By analyzing these forms of work, we can understand the biopolitical impact that the project leaders had and continue to have in the organization of disease management programs in the Netherlands.

Threaded through all of these forms of work done by the project leaders were observation, monitoring, and surveillance. These forms of watching and oversight were inherent in all of the work done by project leaders, and shaped the project leaders from the first efforts towards disease management. As Foucault (1995) noted, watching serves directly and indirectly to shape and govern. To implement specific strategies for the treatment of chronic disease, chronic disease had to be created as a problem. Information work was integral to the creation of a solution for this problem; policy-makers reviewed the existing literature on chronic illnesses and formed a disease management program and study around the literature. The program was further defined by clinicians and project leaders at the site, based on the needs of the patient population, the capacity of the site, and the goals of the practices.

The study of the disease management programs required information work (collecting data). The collected data served as a proxy, outlining the symptoms, diseases, and care practices in an easy-to-read fashion. Project leaders reviewed the disease management programs to identify necessary changes in care, such as population-specific self-management education. Yet this data collection was shaped by a pre-existing notion of a problem – chronic disease care. Project leaders collected and sorted *certain* data, based on the project's goals. Data was shaped by the call; by the project leaders, as they collected or created data; and by the researchers, as they cleaned it. The singular category of 'chronic disease' was created through information work, and a biopolitical solution of disease management programs was tested. Data collected had lasting implications which changed care delivery during the programs and beyond, as the data was intended to shape policy.

Watching and work were a micro-politics of power and a method of governing of populations (patients, clinicians, and project leaders) through the changes in healthcare delivery. While this problematization, creation of a problem, and research on the newly created problem has also been seen in research on long term mental health care (Broer et al., 2010) or asthma (Ross Winthereik & Langstrup, 2008), less research has been done on this issue in the field of disease management programs and studies. In the disease management programs and studies, these strategies and solutions were done through different types of work at the state and local level, at the level of national funding decisions and during the interactions between one patient and their clinician.

The work of research and the work implementation of care programs were interwoven. The work of research impacted the work of care, which impacted the research outcomes and the potential for future funding. The research, as others have noted, was creating evidence for current and future care delivery (Ross Winthereik & Langstrup, 2008). The work for and of the research and the programs helped define the norms of sickness and wellness in relation to chronic disease, created niche standardizations of patients, altered future research agendas, and informed local and national policy decisions. The research on the programs shaped the timelines for the changes in care in the disease management programs, governed the interactions between patients and clinicians (as clinicians knew that the patients were part of a disease management study which could influence funding decisions by the state and health insurers), and impacted the changes in care provided to meet the guidelines set by the study. Much of the work of the disease management programs and studies, directly or indirectly, flowed through the hands of the project leader. The project leaders and managers tried to align and balance the needs of the researchers and the funding agencies with the needs of patients and clinicians.

This research reveals several important issues about disease management programs and research. While other research has shown in various ways that chronic disease management programs are a significant source of work for those involved (Coleman et al., 2009; Freydberg et al., 2010; Kaziunas, Ackerman, & Veinot, 2013; Timmermans & Freidin, 2007), less work has been done on the types of work that disease management programs *and* studies entail, especially for project leaders. However, for the project leaders, much of this work was related to *studying* the disease management programs for the state-funded study, for health insurers, and for the healthcare organizations' own quality improvement desires, such as organizing focus groups or crafting and distributing surveys. Research, while understood as necessary, was enough to 'drive a person crazy.' While biopolitics and the biopolitical paradigm were made possible through the work of many, it was the work of project leaders in both the study and disease management program that was crucial to the process. Without the project leaders coordinating, managing, cooperating, and conducting information work, the research would not have been possible, nor would the programs have run as effectively and efficiently. The work of project leaders shaped the programs within the micro-political environment of a single doctor's office, changing how patients and providers interacted, and changing what information clinicians collected for what purpose.

CONCLUSION

This article set out to analyze and bring to light three questions related to work and biopolitics in disease management programs in the Netherlands: *What types of work are being performed? What types of problems does biopower uncover? What are the implications of the work and biopolitics performed in and through disease management programs and studies?* The last question is, clearly, the most informative for researchers, health policy makers, and project leaders.

Through the work of participating in disease management programs and studies in the Netherlands, project leaders became biopolitical actors. Their work of collecting data, sorting, cleaning, determining categories, and asking people again and again to complete surveys has (potentially) lasting implications as funding decisions are intended to be based on the data that they submit. Their articulation work and cooperative work done towards making sure that patients received the best possible care, from clinicians who were well equipped in the best possible way to treat chronic disease, shaped care at the doctor's office, changing the interactions between a single doctor and his/her patient. The biopolitical implications of the work that project leaders *did* were both macro (impacting state funding and policies) and micro (impacting care at the local level). This role of biopolitical agent was one that was taken up in all the work that the project leaders did. It was a huge role that project leaders struggled to fill, driven crazy by conflicting demands, limited time, and minimal funding. This is not to say that the project leaders did not do an honorable job, but that it was quite the job to do and to do well.

Many articles (our own included) end with a call for more research on a subject. While more research is a worthy goal, originating from the desire to better understand the complex processes in place in healthcare systems, research should not be undertaken lightly by funders, researchers, and the practice-based research settings. Research is, as our data shows, a significant commitment of time, resources, and energy for all involved, even when the research is seen as useful by all actors. The work and the types of work involved in research programs were not fully known before the studies begin, despite the efforts of funders and researchers to outline the expected work.

Nonetheless, while research should be undertaken thoughtfully, our work shows that research on practice changes (such as the disease management programs) provided project leaders an opportunity for reflection. Building room and time for reflexivity and insight into research studies on disease management programs can be beneficial for project leaders, clinicians, patients, and the external research team. By promoting reflexivity and insight as a component of research, project leaders had, as our research shows, the opportunity to more deeply understand the roles that the disease management programs could play in practice. Project leaders appreciated the pretext and the time to reflect on their healthcare organizations' practices and population, allowing them to make changes in a prudent and insightful manner. Research that incorporates space for reflection and introspection may provide room to answer questions about how disease management programs work in practice, how bodies and minds are shaped by both the research on the programs and the programs themselves, and how all of the work that goes into disease management programs and research is part of a large biopolitical paradigm.

It proved difficult for project leaders to balance the work and demands of the disease management programs, the external research, and the internal studies, while thoughtfully reflecting on their own activities, the care provided by clinicians in their healthcare organizations, and the needs (as uncovered by information work) of the patient population. Making room and space for reflection for the project leaders very clear in the *Call for Proposals* may aid this balancing act. Project leaders would have the opportunity to think more deeply about the changes that they are promoting and putting into place, as well as to think about the broader organizational and biopolitical ramifications of their work. The work that project leaders undertook, whether it was information work, articulation work, or cooperative work, had ramifications for the biopolitical sphere well beyond their individual healthcare arenas. The impact of the project leaders' efforts warrants designated and protected time to think, to plan, to daydream, and to reflect before, during, and after large-scale studies.

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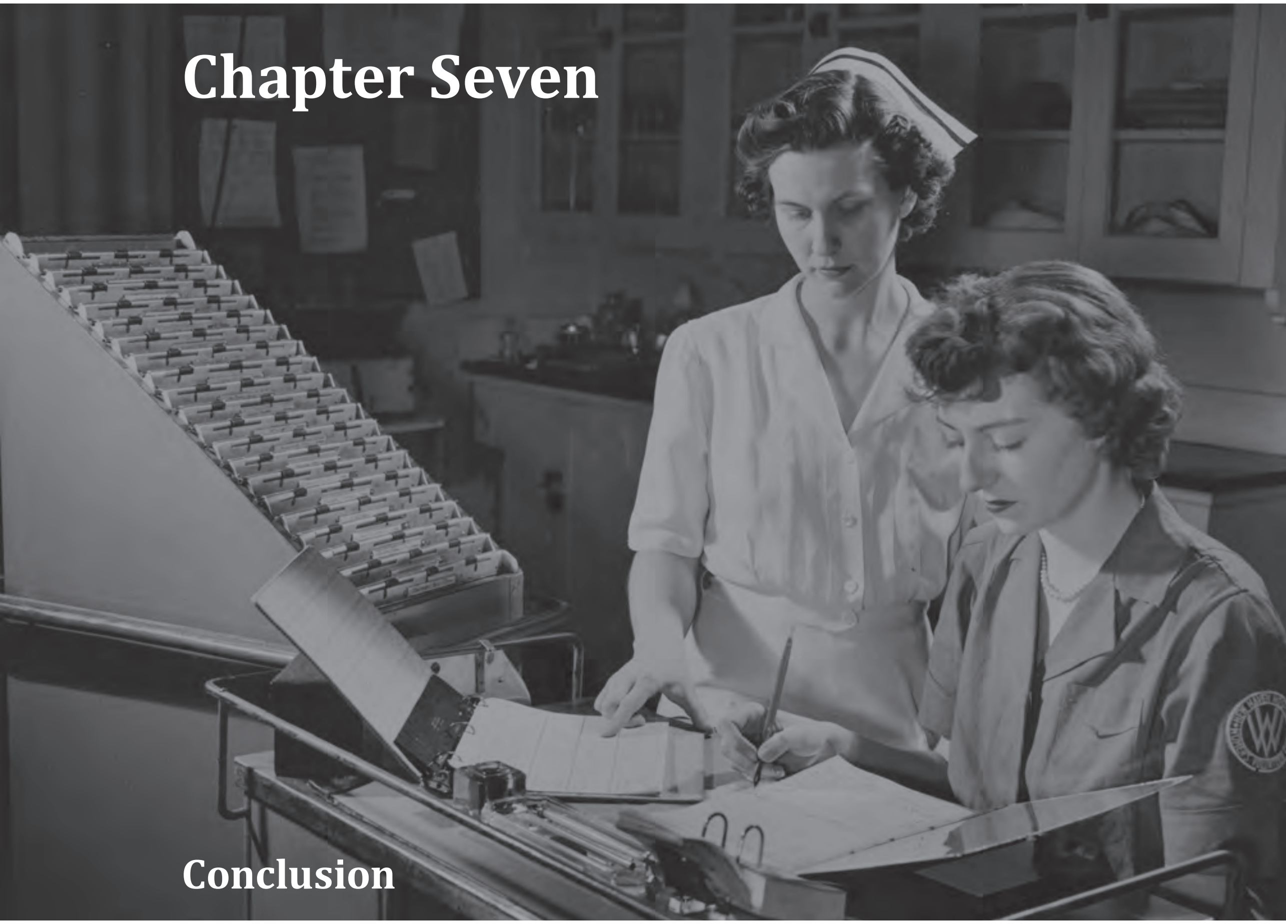
Chapter Seven

Conclusion



As I write this conclusion, my ears hurt. Despite my well-organized care, the oversight from my thoughtful and helpful clinicians (GPs, physical therapists, specialists, dentists, and surgeons), my comprehensive and care-influencing networked electronic medical record, my efforts and the efforts of my clinicians, and my medication, my chronic Eustachian tube dysfunction is no better. It is, however, managed; my clinicians work together for the good of the patient (me), I am consulted about ideas for new care strategies, I am coached in how to self-manage, primarily through medication dosing, and throughout the entire process, my clinicians are working toward being patient-centered and listening to my needs. My pain specialist is open-minded, appreciative of my efforts to learn more about my condition, and, as he says, “happy when patients think along, as it makes them more responsible.” I have his email address to send him my own research and relevant academic articles, as I have better access to medical journals. My concerns are validated. My medical record is updated. As a chronic patient, I now have a new role in the healthcare system, with new responsibilities and duties, such as self-managing, seeing multiple clinicians, and being aware of the care that all of my clinicians have provided. My condition is managed to the best of my abilities, the abilities of my clinicians, and the capacity of my healthcare system.

I know this not only from my personal experience, but from my work as a researcher and project director for disease management programs in the Netherlands and in the US. In this conclusion, I explore what disease management for chronic diseases and conditions means and does in clinical practice. Disease management programs are complex, dynamic, living programs that involve the attention, dedication, and work of many actors, both human and non-human. My questions focus on how project leaders translated the disease management program plans into actual programs, how and why certain programs were more cost-effective than others, how treatment for chronic diseases disciplined and steered the actors involved in the disease management programs and studies, and the work and watching involved in disease management programs. Through my exploration of these questions, I look at the implications beyond the individual patient (though they are very important, as I can personally attest) and think about the implications for clinicians, project leaders, and the healthcare system as a whole. I started my research for this book to better understand disease management programs as a solution for the crisis of chronic disease. I end, of course, having answered but a few of my own questions and having picked up many more along the way.

Chronic disease is a problem that impacts the patient (as my own story shows), the clinicians providing care, and the healthcare system as a whole. But what is this problem and where does it come from? In the years that I have been studying chronic disease and chronic disease programs, I have read hundreds, if not thousands, of articles that start like this: “chronic disease is rising,” “the new health crisis is chronic disease,” or “the chronic disease epidemic”. Even in this book you can see that I (and my co-authors) have written a few like that too:

> *The diagnosis of chronic disease has increased in the developed world in recent years, thought to be due to the aging population and the more successful treatment of acute illness. Many healthcare decision makers have been seeking methods of more efficiently and effectively treating chronic disease; frequently, these methods include the development and implementation of disease management programs.* (Hipple Walters et al., 2012)

> *In recent years, healthcare providers, health policy experts, professionals at ministries of health and health insurers have been struggling to deal with the rise in the number of patients with chronic diseases. In the Netherlands, there has been a 17% growth in diagnoses of chronic disease and a 26% growth of patients with multiple chronic disease diagnoses in the past 8 years.* (Tsiachristas A, Hipple Walters B et al., 2014)

The singular notion of "chronic disease" is often seen as undeniable and a clear problem in society, in people's lives, and in the healthcare system. However, in many ways, this problem has been created at the same time and through the same mechanisms as one of the common solutions to the problem: disease management programs. Disease management programs in this study have been analyzed as technologies of power. As a technology of power, disease management programs (and the study of disease management programs) are disciplinary, productive, and surveillant forces in healthcare settings. These programs, aimed at improving care and efficiency for those with a chronic disease, often serve to sort and discipline patients, clinicians, and project leaders into members of the chronic disease care community. They, in turn, further develop and implement the disease management programs, tailoring the programs to the needs of the community and wider population.

MAIN FINDINGS

This conclusion explores some of the lessons that I have learned and presents some of the questions that I have uncovered[12]. To do this, I use quotes from the chapters of this book, as well as new analyses, to explore the disease management programs at three levels: how the programs worked in and on practice, how and what types of work was conducted in the programs, and how the programs steered and disciplined patients, clinicians, and project leaders. The use of quotes from the chapters was done to highlight the connections between the chapters, which were previously published or submitted as academic journal articles.

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[12] While 'I' is used throughout, there is actually no 'I' in research. This book is dependent on the contributions of others, including but not limited to, my advisors, my department, my research team, my respondents, and my writing partners.

How were the disease management programs enacted in practice?

In the research for this book, one of the first objectives was to understand how disease management programs actually happened in practice from the point of view of the project leaders, clinicians, and patients. I wanted to know how each project leader and clinician developed and implemented the programs, how the disease management programs changed care delivery for those with a chronic disease, and what barriers and facilitators were seen by the project leaders who oversaw the disease management programs. As I was exploring how each project leader and clinician developed and implemented the disease management programs, I tried to answer two distinct questions:

- How do disease management programs get started; specifically, in what ways do project leaders move the programs from plans to realities?
- What are the facilitators of cost-effective disease management programs and development?

This research found, in line with the broader literature on disease management, that the researched disease management programs were complex entities influenced by forces outside of the programs and their study. Sometimes project leaders went on maternity or paternity leave, leaving the project without a project leader for a time. One project leader passed away. Sometimes the project leader or clinician who wrote the program was not the one who implemented the program, or the patients did not attend planned courses, which caused added work for the project leader. The disease management programs were shaped by many factors: time, technology, patient populations, conflicting agendas, limited resources, and recalcitrant workers and patients.

One of the tasks of the project leader in the disease management program was to move (or travel) the disease management program from paper to reality. Seeing how plans became reality provided insight into the roles that disease management programs played within complex, dynamic healthcare organizations. By analyzing the disease management programs as a traveling technology, as can be seen in Chapter Two:

> *the project directors serve as 'travel guides' for the programs, as they oversee the expenditures of the programs, help guide the travel of the disease management programs to an individual clinician's office, assist clinicians involved in the projects in the travel of the programs to and with patients, and connect the disease management programs to a global disease management community.* (Hipple Walters et al., 2012)

However, project leaders could only do so much to move the programs from paper to practice. Project leaders had divided attention, as no project leader worked full time on the disease management program. Project leaders also had limited financial and other resources and (for some) limited experience as project leaders. As well, project leaders shared control of the process of implementing disease management programs. The disease management programs involved patients, clinicians, outside consultants, technicians, health insurers, and researchers. As project leaders revealed, managing the actors in the disease management programs was a time consuming and tricky process.

To learn the barriers and facilitating factors that may have influenced the development and implementation of disease management programs, I researched factors that could have contributed to the variability in and between the programs and their costs. Through comparing two disease management programs (one for those with diabetes, one for cardiovascular risk management [CVRM]), I found that the development and implementation costs of disease management programs may be influenced by the patient population and their chronic condition, the type of information and communications technology (ICT) used, the history of the disease management programs, and the skills and experience of the project leader. The case comparison explored in Chapter Three showed that:

> *the specific disease management program populations, too, may have had a significant impact on the development and intervention of the disease management programs. The cardiovascular risk management DMP was working with patients with low socioeconomic status, many of whom were reported to be complex patients with limited access to resources. Accommodating the needs of this population may have required more tinkering, more effort from project leaders, and more time from clinicians.* (Tsiachristas A, Hipple Walters B et al., 2014)

While some of the factors were more technological in nature, such as the focus of the disease management program and the type and history of the ICT program used, others were more dependent on the experience and staff of the disease management program.

This chapter revealed that the role of and the work done by the project leader was also a factor in the variability in development and implementation costs:

> *the role of the project leader was an important one, with more established projects with experienced project leaders and managers spending less time on the early development of the programs. Project leaders were responsible for guiding the programs, working with clinicians, delegating responsibilities, and developing contacts with outside funders and vendors. In the studied sites, we saw that in projects with a longer history (and with a project leader with more experience in leading healthcare projects and in the disease management program in specific), the relationships needed for smooth, efficient project management were likely developed in the early years of the programs, and the costs for these efforts have not been included in the development and implementation costs (as was seen in the diabetes project).* (Tsiachristas A, Hipple Walters B et al., 2014)

Experience as a project leader, in general, and in disease management programs, were likely crucial to the disease management programs. Disease management programs with a long history and a less complex population, project leaders with a longer history with the programs, and ICT programs that were in place longer could build on existing infrastructures. These differences also could have impacted results on evaluation measures, making some programs seem more successful than others.

How (and what types) of work were conducted in the programs?

My research revealed that disease management programs were made possible through the work of many different actors, each working and mediating the different types and timelines of work in the disease management programs and studies. To learn about work in disease management programs, I focused on learning:

- Who worked and how was work conducted in the disease management programs?
- How was watching a form of work?

By understanding work, which was influenced by how Strauss and his co-authors conceptualized work, I would hopefully be able to analyze the processes inherent in disease management programs. The project leaders worked over the course of the programs and studies in a variety of ways to make the disease management programs and studies happen. As shown in Chapter Two:

> *Through the project leaders' interpretation, translation, adaptation, and adoption of the tenets of disease management, as well as through the management of travel expenditures, the disease management programs travel not only from global notions of disease management, but more importantly, the programs travel within the network of the project teams.* (Hipple Walters B et al., 2012)

Disease management programs traveled from plans to actions, from the international literature to the local implementation. This travel, as shown by others (Nielsen A, 2010), is done through the work of patients, clinicians, educational and support staff at supporting agencies, and project leaders. In the programs, the multiple forms of work of traveling included the interpretation, translation, adaptation, and adoption of the disease management programs and participation in the study of the disease management programs.

The research revealed how and why patients worked on their chronic disease through the shifting of responsibility to patients. This work was conducted primarily through self-management. Patients were educated to self-manage. In general, self-management education focuses on training patients to be their own clinician through the medical management, role management, and emotional management of their chronic condition (Lorig & Holman, 2003). As shown in Chapter Four:

> *Responsibility was another 'skill' that patients learned. Responsibility, though, meant a very specific form of responsibility: compliance with clinicians' recommendations, self-managing according to standard means, being and staying knowledgeable, using tools, knowing and reporting health metrics, being available for veillance. Responsibility was seen as the core of self-management.* (Hipple Walters B et al., submitted)

This responsibility came with the work of learning about and watching their disease and symptoms. This work happened inside and outside of the clinical setting, as patients were being trained to become their own clinicians. This was not always work that patients accepted readily; as seen in Chapter Four, accepting their disease and the work associated with the disease:

> *meant the physical and mental work of living with a chronic condition, including dealing with the biological realities of the disease (such as the disorientation from low blood sugar, selecting food suited to the glucose readings, etc.) and the additional responsibilities of self-managing, the work involved in doing diabetes in the ways suggested by clinicians through self-management education.* (Hipple Walters B et al., submitted)

Sharing responsibility with patients and their families was an effort for clinicians and project leaders as well. Clinicians had to educate and re-educate patients, tailor their efforts to the individual patient's needs and abilities, and coordinate their efforts with other clinicians in the programs.

Helping those with a chronic disease manage their condition was coordinated. For clinicians, this coordination of care was a significant feature of the disease management programs. Care was shared between GPs, nurses, chronic disease specialist assistants, nutritionists, physical therapists, and pharmacists, among others. Each had a specialized role which entailed multiple types of work for clinicians in disease management programs.

Project leaders played a unique role in the disease management programs and studies. The project leaders worked in both the disease management programs and studies. The project leaders worked to improve care for those with a chronic disease through articulation work, cooperative work, and information work. These overlapping, intertwining types of work made the disease management programs *and* studies possible, as seen in Chapter Six:

> *chronic disease programs and research studies create a lot of work for all involved, work that alters care during the project (and is intended to alter care in more practices after the project was completed). However, for the project leaders, much of this work was related to studying the disease management programs for the state-funded study, for health insurers, and for the healthcare organizations' own quality improvement desires, such as organizing focus groups or crafting and distributing surveys. Research, while understood to be necessary by project leaders, was a significant amount of work, enough to drive a person crazy.* (Hipple Walters B et al., submitted)

Research, and the work associated with research, played a large role in the disease management programs and studies. The research added multiple layers of work to already complex programs; research, such as surveys, interviews, and billing information, had to be managed, just as the changes in care delivery had to be managed to provide data in the time set forth by the research team. The consequences of the research are (potentially) wide-reaching, as the results of the research are published in international journals and reported back to funding agencies for broader national implementation. However, the consequences also occurred during the study period, such as the work associated with conducting research, which happened as the disease management programs were being implemented. Project leaders conducted layered work (work on the programs, work on the research) simultaneously, with the work of research seen, in some cases, as taking away from the time available to work on the programs.

The work done by those in the disease management programs and studies produced research findings and the disease management programs themselves, of course, but much more was produced through this work. The work done in disease management programs *and* studies was, as this research uncovered, a technology of power over the body, the mind, the delivery of healthcare, local and national health policy, and research within the healthcare setting. This technology of power steered patients, clinicians, and project leaders. Understanding disease management programs as a technology of power (created through and by the work of the actors in the programs) reveals the ways in which power was created and shifted throughout the duration of the programs and their study.

How did the programs steer and discipline patients, clinicians, and project leaders?

In all stages, the disease management programs relied on disciplined patients, clinicians, and project leaders. From a Foucauldian perspective, discipline is best understood to be comprised of multiple modalities of control ("subtle coercion" on the individual, the body as the object of control, and "uninterrupted, constant" pressure and supervision) (Foucault 1995). These modalities of control were visible in multiple aspects of the disease management programs and shaped the work and thoughts of project leaders, patients, and clinicians, disciplining them into new types of project leaders, patients, and clinicians. To understand the role that control and discipline played in the disease management programs, I looked at three questions:

- How were patients, clinicians, and project leaders disciplined by chronic illnesses and chronic disease care?
- How were the self-management aspects of disease management programs watched by researchers, project leaders, health insurers, patients, and clinicians?
- How did watching influence the programs and studies?

By answering these questions, I was able to explore the consequences of the disease management programs.

The data revealed how clinicians, patients, and project leaders were disciplined through the modalities of control. As other research has shown, clinicians were disciplined through the modalities of control into becoming coaches and educators and into partners in the care of one chronic condition or another (or multiple conditions by multiple clinicians at the same time) (Townsend, Wyke, & Hunt, 2008). Training clinicians to train patients to self-manage:

> *relied, as noted by Tattersall, on a "sea change in attitudes among patients, and more importantly, healthcare professionals" (Tattersall, 2002, pg 229). Self-management and the associated veillance required significant changes in knowledge, skills, interpersonal behavior, and attitude for patients, clinicians, and project leaders.* (Hipple Walters B et al., submitted)

Clinicians were steered (both subtly and not so subtly) to manage patients' chronic disease in the manner set out by their disease management program's plans and protocols. For example, by requiring education sessions on motivational interviewing, clinicians were coerced into participating in the disease management program; motivational interviewing, used as a conversation technique, is a way of sharing goal setting associated with lifestyle changes and long-term conditions. Clinicians were disciplined into relinquishing some of that responsibility to patients through education and partnership building. This altered the relationship between patients and clinicians, how clinicians presented care options, documented care, and interacted with other clinicians in the disease management programs, and has consequences for what it means to have and live with a chronic illness.

Patients, too, were subject to the modalities of control. The chronic condition controlled the bodies of patients, limiting what they could and could not do, eat or not eat, how and when they exercised. However, control was heterogeneous, decentered, and ambivalent; there were many opportunities for patients to resist, work around the control, or drop out of treatment. Through the disease management programs, patients and their clinicians worked to harness the modalities of control. Patients with a chronic disease were coached (and sometimes sought this coaching and more support) to improve their lives and bodies by changing their lifestyle. This discipline to manage their own chronic condition was intended to be (and at times was, to various degrees) internalized by patients, as seen in the illness narratives of young women with eating disorders, which was explored in Chapter Five:

> *Treatment and recovery-focused activities were some of the primary technologies of the self, as one of the goals of these activities was an internalization of the lessons learned from therapists, friends, family, clinicians, other users of the site, and others with an eating disorder. … The young women wrote of being disciplined into care of the self by treatment, recovery-focused activities, and by participating on the website.* (Hipple Walters B et al., 2015)

Patients were disciplined into watching themselves through the disease management programs. This discipline came through meetings with clinicians, through education programs, and through websites and patient portals in electronic medical records.

Internalization by patients of the external disease management principles was one of the primary purposes of the self-management aspects of disease management programs. This is explored in Chapter Four:

> *Without the expectation of internalized discipline, self-management would not have been possible. Discipline (through coaching and education, through constant observation by patients and clinicians [by proxy], through controlling the chronic condition) was internalized by patients (to greater and lesser extents). Internalization of discipline made self-management possible and expanded the realm of the clinic outside of the doctor's office or hospital.* (Hipple Walters B et al., submitted)

Training patients to self-manage at home, on their own, was an ambition of the disease management programs. No one wanted patients to have to see a doctor or nurse every time they had a minor concern with their chronic disease. Managing their chronic disease at home, with the help of clinicians, was hoped to be time-saving for patients *and* clinicians, as well as meaning more independence for patients. Patients, for example, had the ability and responsibility for monitoring their own eating and exercise, tailoring to their chronic disease and symptoms as needed. Before patients were seen as ready to self-manage at home on their own, patients had to be trained to watch themselves and their chronic disease. Watching, controlling one's own body, and submitting to coercion were trained skills that were passed on to patients. In this manner, patients were trained and disciplined to become their own clinicians, especially through technology, as recent work by Lupton reveals (2013). By engaging with technological forms of self-management and disease management, patients were disciplined by the online aspects of the disease management programs through different forms of surveillance and different possibilities for self-management.

Project leaders, too, were disciplined by the disease management programs and studies. While clinicians and patients were disciplined by the studies, this came primarily through the implementation of the disease management programs and, to a lesser extent, through the study measures, such as surveys and interviews. Project leaders, as the connection between the research and the clinical setting, were disciplined more intensively. Project leaders were coerced into acceptable behavior by the funding organization and research team through, for example, the writing of reports about the disease management programs to the funding agency, as seen in Chapter Six:

> *The report was also a form of discipline through coercion on project leaders to complete the report and the reporting of data about the disease management programs as a form of supervision of the activities of patients, clinicians, and project leaders (Foucault, 1995). The report was confirmation that work was being done, that the work met expected standards, and that the work was in a reportable form in the timeframe desired by the funders and the research team.* (Hipple Walters et al., submitted)

The coercion was not subtle, but was a clear method of shaping and steering the actions and work of project leaders, clinicians, and patients.

Project leaders were also shaped by oversight, both the oversight that they conducted and the oversight that was conducted on them. These categories, actually, overlap, as can be seen in the writing of the report; to write the report, project leaders had to report on the work of patient and clinician outcomes, as well as reporting on their own activities and making their own activities open to the oversight of others. Knowing that the reports were open to be read by others served to discipline the project leaders, shaping their work as travel guides, information and veillance workers, coordinators, articulators, leaders, managers, and research subjects.

Through their participation in the funded research program, this research revealed that project leaders oversaw the work and activities of others. This oversight came in multiple forms. In the disease management programs, watching was a technology of power used by patients, clinicians, project leaders, researchers, and funders (Foucault, 2009); as a technology of power, watching influenced how, why, when, and through what means care was provided to patients, how patients cared for themselves, how clinicians offered care options, and how project leaders shaped the disease management programs. Through veillance, for example, clinicians and project leaders saw that patients were not attending a specific self-management course; as a result, the course was discontinued, and patients were educated through other means.

THEORETICAL IMPLICATIONS

Watching and work were intertwined and interdependent in the disease management program. It's impossible to tell what, exactly, was work and who or what, exactly, was watching. Work often took the form of watching, whether watching of data, people, or processes. Watching was conducted through various forms of work done by many different actors, both human and non-human. Work and watching shaped the disease management programs from their early conceptualizations to their full implementation; work and watching were also crucial to the data collection done in and on the disease management programs. Watching was a form of data collection – I conducted observations at meetings and clinical visits – and I promise that I was working as I watched.

The separate concepts of watching and of work are both well-researched themes in healthcare, including in the care for those with a chronic disease. However, combining these two separate theoretical concepts into one conceptual framework (work and watching) allows for a deeper understanding of how disease management programs are enacted in practice.

While useful when taken separately, in this book I propose that the concepts of work and watching should be taken together as one framework. Watching is different types of work; work, especially in the care of those with a chronic disease, often involves various forms of watching. Both watching and work are, as my research has shown, layered concepts. Different forms of watching and work interwove to steer, govern, and, in many ways, control patients, clinicians, and project leaders. Combining the concepts of work and watching into one framework is a representation of what was enacted in practice, in that work is watching and watching is work. To develop this one framework of *work and watching*, I needed to review (some of) the existing theories on work and on watching, especially work and watching in healthcare.

To better understand the theoretical concept of work, I was inspired by Nielsen and her thesis on traveling technologies in care delivery programs (2010) and by Strauss and his literature on the work of chronic disease. My efforts on watching were inspired by the surveillance theory literature (Mann, 2013; Foucault, 1995, 2003; Rose, 1987; Rabinow & Rose, 2003). These theoretical frameworks were incorporated into the framework of *work and watching*; this singular framework allows me to concentrate on what, how, and why work was done in disease management programs, what types of watching were done in the programs, and what the large implications of the watching and work were (and continue to be).

In the disease management programs, clinicians, patients, and project leaders worked by watching and watched for work. Project leaders and clinicians watched and worked to provide care for patients with a chronic disease. First, however, these patients had to be created, found, and categorized based on national and international guidelines for chronic disease. Patients were categorized as chronic patients with a specific disease through the watching of clinicians and project leaders, who compared patients' symptoms and biometric data with national and international guidelines for the condition. This was, in some cases, done without even seeing the patient in person again; clinicians and project leaders conducted veillance on the electronic medical record and categorized patients according to the data that was added to the record before the disease management programs were begun. Looking at the data in the record was looking at a digital double of the patient. Conducting this watching was work – the work of traveling the program from reviewing the proposal to clinical practice, as the clinicians and project leaders defined and interacted with the patients who would be impacted by the program; information work as the clinicians and project leaders extracted information about patients from (networked) electronic medical record; and cooperative work as patients, clinicians, and project leaders worked together to create and find patients with a chronic disease through biometric testing. Patients with chronic diseases were created through the work of watching.

Work and watching steered the programs before, during, and (likely) after the study period. Patients were trained (through the work of clinicians and project leaders) to watch themselves and their chronic condition. Clinicians watched patients and other clinicians, tailoring care (their efforts) according to what they saw. Project leaders worked and watched throughout the programs, watching patients' data and responses to internal research (conducted through the work of many) and gathering information from clinicians about the programs through meetings, emails, phone calls, and research. Research was a major source of work and watching for project leaders, who coordinated the research efforts of many, worked with patients and clinicians to collect data, and worked with research teams to provide the desired research.

Work and watching combined in the *research* to create the biopolitical paradigm of research-healthcare-state (Epstein, 2008). The work and watching had implications far beyond the project period and the project sites, with the potential to shape national care standards, funding decisions, and the work of other clinicians, patients, and researchers. However, the potential to influence the delivery of care for chronic conditions at the national level was not of the utmost importance to clinicians and project leaders, who were much more interested in how they could improve the care that they currently provided to their own patients over the potential political ramifications of the project as a whole. In many ways, participating in the research study was just one more thing that project leaders and clinicians had to do, more (and more types) of work. The work of coordinating and participating in all of this research drove some project leaders and clinicians 'crazy,' to use their own words.

The combination of analyzing the disease management programs and studies from a work and watching theoretical perspective highlighted the broader implications of the disease management programs and study. The different types of watching and work influenced the care infrastructure, care delivery, and patient, clinician, and project leader roles throughout and beyond the researched program period.

PRACTICAL IMPLICATIONS

Throughout the course of my interviews, many of the project leaders asked for tips on how to improve the development and implementation of their disease management programs. I didn't always have an answer for them, but I hope that these bullet points can help for the next program or study.

- Preparation was a key component of developing and implementing the disease management programs. The more work that project leaders had done in advance (before the programs were funded by the study), the smoother the programs were developed and implemented once the funding was awarded.
- Many of the disease management programs focused on developing and implementing various new ICT systems. While technology is often touted as a cure for problems in healthcare, this research found, in line with findings from others (Himmelstein & Woolhandler, 2005; Miller & Sim, 2004; Wears & Berg, 2005), that the development and implementation of the ICT systems was much more complicated and time-consuming than planned, often for reasons outside of the project leaders' control. The experiences of the project leaders show that allowing for more time for the development and implementation ICT systems would be helpful, as would having more realistic expectations of what ICT can do and are likely to do in practice.
- Disease management programs can be a significant source of work for project leaders, clinicians, and patients. Knowing the types of work involved and why the work is necessary may provide more guidance to those working in and on the disease management programs, as well as developing a clear yet flexible workflow. Communicating frequently

with clinicians and patients can improve the workflow of disease management programs in clinical practice and in the lives of patients.
- Disease management programs are a technology of power. This technology of power should be used judiciously in and around healthcare practices, with the understanding that disease management programs impact lives and work. While it is tempting to implement a disease management program as a solution for the problem of chronic disease, disease management programs may not always be the best solution for the patient population or the clinical setting. As other research has shown, disease management programs transformed patient roles (self-managed patients, chronic patients, networked patients, active patients) but not all patients could or would cope with such roles (Fox & Ward, 2005; Langstrup & Winthereik, 2008; Taylor & Bury, 2007). Knowing the patient population and the capacity and interests of the clinical staff can help determine whether or not a disease management program is appropriate.
- Understanding disease management programs as a technology of power will be an even more important conceptualization in the future, as the Ministry of Health has pledged research, funding, and support for the treatment of patients with chronic conditions, and as health insurance companies can require a significant amount of work for project leaders, clinicians, and patients and significant oversight of the care practices of patients and clinicians. This funding allows, too, for more research on care delivery for those with a chronic illness; this research in and of itself is a technology of power on and over the disease management programs.

REFLECTIONS

While there are many ways to research (and analyze) disease management programs, I focused the data analysis on the work and watching conducted through and in the disease management programs and their study. This method of analysis was chosen for a variety of reasons: it allowed for continual analysis of the program and the projects as they were being developed and implemented; this method of analysis could be done in all of the disease management programs, regardless of the chronic disease that the disease management program focused on; and, looking at the data from a work and watching perspective could also include looking at the research study around the disease management programs.

Though outcomes research is a very popular method of analyzing disease management programs, I was more interested in the process of developing and implementing a disease management program in practice. In part, this interest stems from a desire to understand the nuances and changes involved in altering care practice over time – learning what happens first, what work is needed, and who is involved at what points in time. Using a work and watching analytical frame allowed me to see what work was conducted when, how watching was a form of work that was often used early in the programs, and how the program plans changed over time with the needs of the population, with technological developments, and as a result of the desires of other actors, such as clinicians, funders, and researchers.

The disease management programs included in the study focused on a range of chronic diseases. Some focused on mental illnesses, some on the risk for disease, some on multiple chronic diseases, and some on more typical chronic diseases, such as COPD and diabetes. The programs, too, differed greatly; while all the programs could be described as 'disease management' programs, the approaches that the project leaders and programs took were different.

Knowing that the qualitative, quantitative, and economic study of the disease management programs played a large role in how the programs were developed and implemented, I also analyzed the research on the programs throughout the duration of the study. The work and watching perspective used to analyze the data meant that we could look in-depth at the different types of research conducted in and on the disease management programs, including the internal research conducted, the work of research, and the broader consequences of the research conducted in and on the programs.

While I analyzed the data from a work and watching analytical perspective, other analytical perspectives would have also been useful to understand the processes of developing and implementing disease management programs. My perspective provided benefits, but also limitations: as I focused on the processes of disease management programs, I have less data on the outcomes; I have less information on the nuances of the facets of disease management programs; and my perspective is more sociological than medical and misses details about care delivery. I decided to use a descriptive rather than an explanatory analytical framework. This choice was deliberate, as there is of yet very little research done that describes in a qualitative way the work of and in disease management programs leading to a sometimes meager understanding of the mechanisms that lead to success. As my study was part of a mixed methods project, such a focus was moreover instrumental to the other studies (Cramm, J et al., 2014; Cramm J et al., 2013). My research was also limited by data collection; while I focused on 5 disease management programs, not all of the programs were as open to research or as developed in their implementation of the programs. I was also limited in patients' willingness and ability to participate in research; I worked around this limitation by looking for patient perspective on the disease management programs from different sources, such as patient support websites and reports from the clinicians about the patients. As well, I collected longitudinal data on all programs through interviews with project leaders and analyses of progress reports.

CONCLUDING REMARKS

Disease management programs and studies are likely to continue growing and spreading in healthcare practices, just as the diagnosis of chronic diseases are likely to continue to increase. While disease management programs are seen as an approach to the problem of chronic disease, they are a solution with broad implications. Disease management programs require much from those involved in the programs – much more than the project leaders, clinicians, or patients are often expecting. And as many disease management programs are conducted as part of research programs, the work required includes research, the work and watching of bodies, processes, and procedures. This work and watching impacts the health, lives, and employment of many during and beyond the arenas of the studies and programs. These implications, both ‘good’ (improved health, more cost-effective care, more patient-centered clinicians) and ‘bad’ (more work for patients and clinicians, unclear and new roles, more and new forms of management) are often not and cannot be made fully explicit to those involved. As such, disease management programs and studies should be handled with care.

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Summary

BACKGROUND

The diagnosis of chronic diseases and conditions has been increasing in the past fifty years. There are multiple causes for this increase, such as more sedentary lifestyles, improved treatment for many infectious diseases, and the reduction in mortality rates for diseases such as cancer and heart disease. The increase in chronic diseases is also related to earlier diagnosis and intervention and a broader understanding and criteria for what is considered a chronic disease. Ministries of Health, health insurance providers, and healthcare collectives have been promoting the use of disease management programs as method of treating and managing chronic disease.

In general, disease management programs entail coordinating care for those with one or more chronic conditions. Disease management programs often focus on shifting care and management of chronic diseases to non-physician clinicians (nurses, nutritionists, physical therapists) and to the patients and/or their social networks (Bodenheimer et al., 2002; Solberg et al., 2006; Wagner et al., 2001). Disease management programs also promote creating care teams to share care for the chronic disease between different kinds of clinicians in order to provide patients with a network of experts on different aspects of managing their chronic disease. Information is shared between clinicians (and, at times, the patient) through computer-support systems, such as forums, websites, and (networked) electronic medical records (Bodenheimer et al., 2002; Wagner et al., 2001). Treatment protocols for chronic diseases rely heavily on patient involvement in the treatment and management of their condition, through educating patients to self-manage (Bodenheimer, et al., 2002). Treatment strategies also include sharing and coordinating care between multiple medical professionals and using information systems to support chronic disease treatment (Wagner et al., 2001; Green et al., 2006).

This thesis is based on research conducted on twenty-two disease management programs in the Netherlands. These programs were predominantly based in primary care facilities and focused on chronic diseases including diabetes, COPD, risk of cardiovascular disease, mental health issues, or co-morbidity for patients with multiple chronic diseases. The disease management programs were carried out by teams of clinicians and were supported by internal and external communication and chronic disease experts. As part of the programs, patients were invited to participate in extra educational sessions, offered additional appointments to discuss their concerns with their chronic disease, and/or given access to their medical record via an online patient portal; through the disease management programs, much emphasis was put on partnering with patients to manage their chronic disease. To understand how these disease management programs worked in practice, I conducted interviews with clinicians, patients, and external supporters; I also conducted online data collection of a patients' support website to get further observations and deeper insight into the lives of those with a chronic disease. This research uncovers how the programs changed the lives of those who participated in them, and how disease management programs changed care in the programs. It also reveals how the research program that ran alongside the disease management program impacted healthcare delivery.

Each disease management program had a project leader who coordinated the research in the practices and oversaw the changes in care delivery related to the disease management programs. Based on document analysis of project plans and interviews with project leaders and managers, this thesis explores how disease management programs moved from plans to action, as well as what barriers project leaders faced, and how, in the implementation and development of disease management programs.

THEORETICAL FRAMEWORK

The changes in care delivery associated with disease management programs hinged on monitoring healthcare delivery and observing the changes associated with the disease management programs; in a broad sense, watching was a crucial component of the disease management programs. For the disease management programs, project leaders observed the care that clinicians provided before the implementation of the disease management programs in clinical practice, and suggested changes in care delivery in line with disease management principles. Project leaders watched clinicians and patients by looking at the electronic medical records to understand the patient population; through focus groups, interviews, and surveys of clinicians and patients; and through meetings and conversations. This watching was done before the disease management programs were put into place as well as during the implementation of programs in order to improve care for those with a chronic disease. Clinicians observed patients' health metrics and lifestyle changes and the care provided by the other clinicians in the care team by reviewing the information in the electronic health records. Patients, too, watched their own activities and chronic disease symptoms, especially in relation to the changes in how they managed their chronic disease. Watching changed how care was provided, how clinicians and patients acted, and how the project leaders developed the programs, interacted with clinicians, and worked with patients; thus, watching governed and steered patients, clinicians, and project leaders. Watching was powerful.

This thesis analyzes 'watching' as a form of power that impacts the actions of those in the disease management programs (Armstrong, 1997; Foucault, 1995; Foucault, 2003; Lupton, 1997; Mann & Ferenbok, 2013; Mann et al., 2003; Mann, 2013). Project leaders, clinicians, and patients are shaped by the watching inherent in the disease management programs and studies. Surveillance has been increasing in medical care, and has been tied to the rise of non-acute illnesses and changes in the care structure, such as changes related to chronic disease care (Armstrong, 1995). All of this watching was needed for disease management programs to run smoothly; watching was work.

The changes in care associated with disease management programs were done though the work of clinicians, patients, and project leaders; changing care to match disease management principles was a process that involved many different types of work. By analyzing the disease management programs from a work theoretical perspective, this thesis looks at the different forms of work involved in disease management programs, as well as how these forms of work interact. Theoretically, Strauss conceptualized work in healthcare projects as being "made up of many tasks done over time, and divided up according to various criteria among the actors (persons, classes of persons, departments, or other organizational units)" (Strauss, 1985b, pg 2). Strauss further categorized the work done by medical professionals in treating chronic illness as machine work, safety work, comfort work, sentimental work, and work in The Social Organization of Medical Work (Strauss, 1985). Articulation work, defined as work "done to assure that the staff's collective efforts add up to more than discrete and conflicting bits of accomplished work" (ibid, pg 151), is often work done behind the scenes, but is necessary for the success of a given program or endeavor. In healthcare, including the researched disease management programs, this work was often done by nurses and by those leading projects (Bowker & Star, 2000; Strauss, 1988). This work was done to ensure that standard operating procedures and care protocols run smoothly in the face of changes, that interruptions are dealt with quickly, and that routines are established or continued (Strauss, 1985; Star & Strauss, 1999). Cooperative work was also a large component of the work done in disease management programs; cooperative work "interleaves distributed tasks" and people (Star & Strauss, 1999, pg 10). The creation, coordination, and observation of information was important in the disease management programs. Also called information work, this work was done most often by project leaders and focused on creating and gathering numerical data, staff information, collecting, cleaning, and sharing budgets, reviewing and documenting processes, and gathering literature with which to make informed decisions.

FINDINGS

The research on the development and early implementation of the disease management programs (as seen in Chapter Two - Disease management projects and the Chronic Care Model in action: baseline qualitative research) looked into how disease management programs moved from paper plans to local programs through the work and guidance of project leaders and managers. However, this was not a straightforward implementation of a program, but was a series of interpretations, manipulations, and movements of a traveling technology. Traveling technologies are programs or healthcare principles that travel between a global (often academic) stage and the local practices and actions of healthcare leaders and providers. In the disease management programs, the project leaders served as ‘travel guides’ for the programs, as they oversaw the expenditures of the programs, helped guide the travel of the disease management programs to an individual clinician’s office, assisted clinicians involved in the projects in the travel of the programs to and with patients, and connected the disease management programs to a global disease management community. As ‘travel guides,’ project leaders were constantly watching the programs and working to meet the needs of clinicians and patients. However, despite their dedication and efforts, project leaders and managers could only do so much to move the programs from paper to practice, from the global plans to the local actions. They were limited by their own time and ability, as well as by the actions of others, technical systems involved in the programs, the structure of the research in the programs, and funding available.

Further research (Chapter Three - Identifying and explaining the variability in development and implementation costs of disease management programs in the Netherlands) analyzed the barriers and facilitators of developing and implementing cost-effective disease management programs. The qualitative aspects of this research uncovered three common characteristics of the studied disease management programs that may explain the variability in costs between similar programs. These characteristics included attributes of the interventions, information and communications technology (ICT) systems, and the experience of the project leaders. The history of the programs, including personnel time invested and ICT systems already in place, may have also played an important role in the variability in costs and was an underlying characteristic. These characteristics represented the work done by project leaders, clinicians, patients, and outside associates. The role of the project leader was an important one, with more established projects with experienced project leaders and managers spending less time on the early development of the programs. Project leaders were responsible for guiding the programs, working with clinicians, delegating responsibilities, and developing contacts with outside funders and vendors. This research found that in projects with a longer history (and with a project leader with more experience in leading healthcare projects and in the disease management program in specific), the relationships needed for smooth, efficient project management were likely developed in the early years of the programs, and the costs for these efforts have not been included in the development and intervention costs.

Project leaders had fluid roles and flexible work within the project; project leaders watched the programs to see where changes were needed, based on the needs of the population. Whether by offering new tools online or printing for patients who have limited computer access at home, this constant adaptation by project leaders and clinicians was “persistent tinkering in a world full of complex ambivalence and shifting tensions” (Mol, 2010). Tinkering is work done through large and small efforts, done to make the disease management programs fit into existing systems. Tinkering is impossible without both work and watching; watching is needed to understand what should be tinkered with, while work is needed to do the actual tinkering. Through tinkering, project leaders worked to meet the changing needs of patients, the healthcare system, and themselves. Yet tinkering was a slow and often invisible process, as was much of the work of project leaders when tailoring interventions, applying for funding, or working with researchers. This tinkering was constant during the study and programs but, as the data shows, appeared to be more prevalent in the development and intervention stages as the project leaders were working with new vendors, systems, and care plans.

Chronic diseases, such as eating disorders, require much work and watching of the patients themselves – watching to ensure that the disease is well managed, and work to manage the disease on their own and to navigate the care system set up to help them. Chapter Five (Proud2Bme: exploratory research on care and control in young women's online eating disorder narratives) looked at stories posted on an online eating disorder support community hosted by a treatment center to understand the patient's point of view on his/her treatment, recovery, self-management, and life with a chronic disease, especially in regard to control. Control and discipline play large roles in many chronic diseases; the treatment and management of chronic disease often shape (or discipline) patient's lives. To explore the role of control and discipline in the lives of those with an eating disorder, the stories were analyzed using Foucault's definition of discipline, which is comprised of multiple modalities of control: "subtle coercion" on the individual, the body as the object of control, and "uninterrupted, constant" pressure and supervision (Foucault, 1995).

The narratives revealed that a complex network of relationships between work, writing, agents, actions, and control was formed to help manage and treat eating disorders. Much of this control came through the work of the young women, clinicians, project leaders, and webmasters. This research revealed the different manifestations of control apparent in the stories, such as control manifested in and over the body, control and steering from outsiders like parents and treatment providers, control over the stories on the website by various actors, and control through oversight and supervision of the patients' bodies and stories. Through their eating disorders, the patients strove to control lives and emotions that felt chaotic; many of the women noted that after a time, it felt like the eating disorder had taken control of their lives. Treatment was one way that young women regained control of their lives, though many patients felt that treatment controlled their lives to an unacceptable degree. One of the goals of treatment was to discipline the young women into better ways of dealing with the stresses that may lead to an eating disorder, as well as better self-management of their disorder. The young women noted that treatment, set up by project leaders and conducted by clinicians, trained them to watch their own bodies and minds while the clinicians were watching the behavior, responses, and bodies of the patients.

Watching, when conducted in healthcare as the medical gaze, is one of the primary means of understanding a patient's symptoms and illness, overseeing and tailoring treatments to patients, and comparing symptoms and signs between patients to create standardized notions of disease (Foucault, 2003). The medical gaze consists of multiple forms of observation and watching. In Chapter Four (Dynamics of on-line and off-line watching in self-management programs), this thesis explored the implications of watching in the self-management of chronic conditions. Self-management is a useful lens for understanding watching and the expansion of the clinic, online and off.

In the self-management aspects of the disease management programs, managing chronic diseases was shared between clinicians, patients, and sometimes patients' families, with some researchers claiming that sharing responsibilities embodies effective chronic illness management (Thille & Russell, 2010). Patients were given responsibility for self-managing through watching and managing their chronic condition outside of the doctor's office, with the additional responsibility of reporting data back to the clinic for veillance. This reported data changed the ways that care was provided during the visit, during future visits, and, potentially, outside of the exam room by the patient conducting self-management activities by changing, for example, medication doses or exercise regimes. Through self-management, patients learned to care for themselves, for example, by watching and documenting their own blood sugar, watching what they eat, or observing any problems with breathing and responding to what they have observed according to their needs and the guidelines agreed upon with their healthcare providers. However, not all patients were willing or able to self-manage. Project leaders and clinicians found that older patients were less interested in self-management and often were less able to self-manage, as they were used to their care being more directly guided by their clinicians; other patients were resistant, such as those early in eating disorder treatment. Self-management was an ideal that was not always realized.

In general, disease management programs are often funded as experiments, whether by ministries of health, as research studies, or by health insurance providers, as innovative and potentially cost-saving mechanisms for chronic care delivery. These forms of funding, and the strings attached to the funding, brought new forms of work for clinicians, patients, and project leaders. Knowing that the qualitative, quantitative, and economic study of the disease management programs played a large role in how the programs were developed and implemented, this thesis analyzed the research on the programs throughout the duration of the study, as seen in Chapter Six.

Project leaders simultaneously managed the research and the programs in the practices. Research, in simple terms, is an organized, routinized form of watching, often done by external experts; project leaders managed the internal and external watching done in the practices by managing the research in the practices. The research (and the funding attached to the research) impacted the types of chronic disease programs that were implemented, the timeline of changing care, and those with chronic diseases. Project leaders and researchers found that some populations, while impacted by the programs in potentially positive ways, were difficult to collect data due to age, vulnerability, or language; the project leaders had to manage this intersection between research and care.

Multiple forms of research were conducted in the sites. The project leaders conducted their own research on the disease management programs for quality improvement reasons; research was needed for reports to health insurance providers; project leaders oversaw other research projects; and students conducted research in some of the practices, with help from project leaders. Studies, including the one that funded this research program, involve some sort of systematized watching in the form of data collection, whether through surveys, interviews, data extraction from medical records, and/or billing information. Through this work of collecting data, as others have shown, clinicians and researchers were creating 'evidence' to be used in the future delivery of evidence-based medicine (Nielsen & Jensen, 2013). Project leaders however reported feeling driven 'crazy' by research, even when they valued the outcomes.

Coordinating research in the sites happened in addition to the work of managing and changing care to meet the needs of patients with a chronic disease, in line with disease management principles. The funding for the programs and the study shaped the care in the programs; project leaders were encouraged by the Call for Proposals to focus on new ICT systems to coordinate care between multiple clinicians and patients, to include patient and clinician education on patient self-management, and to support multidisciplinary teams to treat and manage chronic disease. The changes in care often required much negotiation and communication between project leaders and clinicians; to support and promote the disease management programs, project leaders watched the changes in care through meetings, phone calls, and emails with clinicians, through their own data collection (such as focus groups and surveys), and through the data collection by Erasmus University. This data fed back into the intervention and helped project leaders to work to improve the disease management program by addressing gaps in knowledge, responding to clinicians' needs, and moving towards broader disease management goals.

CONCLUSION

The research presented in this thesis found, in line with the broader literature on disease management, that the studied disease management programs were complex entities, influenced by a variety of factors outside of the programs and studies. Sometimes other issues were a bigger priority. Sometimes project leaders went on maternity or paternity leave, leaving the project without a project leader for a time. Sometimes the hired project manager wasn't a good fit for the program and had to be replaced. One project leader passed away. Sometimes the project leader or clinician who wrote the program was not the one who implemented the program, the electronic medical record provider went bankrupt, or the patients did not attend planned courses, which caused added work for the project leader.

The combination of analyzing the disease management programs and studies from a work theoretical perspective and a Foucauldian perspective allowed for a deeper understanding of the implications of the disease management programs and study. These implications, as this research shows, impacted patients' lives, clinicians' practices, project leaders' management, funding decisions, and the research on disease management in the greater academic community. They showed the work involved in designing and implementing disease management programs and how this affects clinician's, patients' and project leaders' roles, and how on the other hand disease management is contingent on the possibilities and cooperation of these and a multitude of other actors, including technologies. The combined lens of watching and work is a useful method of researching and analyzing disease management programs and studies, as it provides insight into how disease management programs happen in the real world and in the ever popular disease management research studies.

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Samenvatting

INTRODUCTIE

De diagnose van chronische ziekten en condities is toegenomen in de afgelopen vijftig jaar. Er zijn meerdere verklaringen voor deze toename, zoals minder beweging, en verbeterde behandeling voor veel infectieziekten. De toename in chronische ziekten is eveneens gerelateerd aan eerdere diagnose en behandeling en bredere criteria voor wat als een chronische ziekte wordt gezien. Ministeries van gezondheid, ziektekostenverzekeraars en gezondheidsaanbieders moedigen het gebruik van ziektemanagementprogramma's aan als methode voor het behandelen en managen van chronische ziekten.

Ziektemanagementprogramma's zijn programma's gericht op het coördineren van de zorg voor mensen met chronische condities. Deze programma's richten zich vaak op het verschuiven van de zorg en het management van chronische ziekten naar andere medische professionals dan artsen (zoals verpleegkundigen, diëtisten en fysiotherapeuten) en naar de patiënten en/of hun sociale netwerken (Bodenheimer et al., 2013; Solberg et al., 2006; Wagner et al., 2001) . Ziektemanagementprogramma's zijn tevens vaak gericht op het creëren van zorgteams die de zorg voor chronische ziektes samen op zich nemen en de taken verdelen over verschillende medische professionals. Zodoende worden patiënten geholpen door een netwerk van verschillende experts voor de diverse elementen in het managen van hun chronische ziekte. Informatie over de patiënt wordt tussen professionals (en, soms, de patiënt) gedeeld door middel van electronische systemen, zoals forums, websites, en electronische medische dossiers (Bodenheimer et al., 2013; Wagner et al., 2001). Behandelprotocollen voor chronische ziekten zijn met name gericht op de betrokkenheid van de patiënten in de behandeling en het management van hun ziekte door patiënten zelfmanagement te leren (Bodenheimer, et al., 2002). Behandelstrategieën zijn eveneens gericht op het delen en coordineren van de zorg tussen verschillende medische professionals, alsmede op het gebruik van informatiesystemen, om de behandeling van de chronische ziekte te ondersteunen (Wagner et al., 2001; Green et al., 2006).

In de afgelopen jaren zijn ziektemanagementprogramma's in Nederland geïntroduceerd en onderzocht. Dit proefschrift is gebaseerd op onderzoek naar 22 ziektemanagementprogramma's in Nederland. Deze programma's werden voornamelijk uitgevoerd in de eerstelijnszorg en waren gefocused op ziekten zoals diabetes, COPD, risico op hart-en vaatziekten, problemen in de geestelijke gezondheid, of co-morbiditeit voor patiënten die meerdere chronische ziekten hebben. De ziektemanagementprogramma's werden uitgevoerd door een team van medische professionals en werden ondersteund door interne en externe communicatie en experts op het gebied van chronische ziekten. Patiënten werden uitgenodigd om deel te nemen aan cursussen, kregen extra afspraken aangeboden om hun vragen over hun chronische ziekte te bespreken, en/of kregen toegang tot hun medisch dossier via een online systeem. Kortom, tijdens en door de ziektemanagementprogramma's lag er veel nadruk op het samenwerken met patiënten om hun chronische ziekte te managen.

Om te onderzoeken hoe deze ziektemanagementprogramma's in de praktijk werkten, heb ik interviews uitgevoerd met professionals, patiënten en externe betrokkenen. Ook heb ik data verzameld via een website die ondersteuning biedt aan patiënten om zo een beter inzicht te krijgen in het leven van mensen met een chronische ziekte. Daarnaast heb ik observaties gedaan bij cursusdagen, vergaderingen en andere activiteiten binnen de projecten. Dit onderzoek analyseert hoe de programma's het leven veranderden van diegenen die erbij betrokken waren, alsmede hoe de zorg veranderde door de programma's. Ook analyseert het hoe het onderzoek zelf van invloed was op de uitvoering van de programma's.

Elk ziektemanagementprogramma had een projectleider die het onderzoek in de praktijken coördineerde en de veranderingen in de zorg als gevolg van de programma's overzag. Gebaseerd op documentenanalyse van projectplannen en interviews met projectleiders en managers onderzoekt dit proefschrift hoe ziektemanagementprogramma's uitgevoerd worden en welke barrières projectleiders tegenkwamen in de implementatie en ontwikkeling van ziektemanagementprogramma's.

THEORETISCH KADER

Kijken was een cruciaal aspect van de ziektemanagementprogramma's, en de veranderingen in de zorg die met de programma's gepaard gingen, waren dan ook met name het gevolg van zorgvuldige observaties. Voor de implementatie van de ziektemanagementprogramma's observeerden projectleiders de zorg die professionals leverden en stelden op basis hiervan veranderingen voor in de uitvoering van de zorg, gebaseerd op principes van ziektemanagement. Projectleiders bekeken professionals en patiënten via het elektronisch patiënten dossier (EPD) om zo de patiëntenpopulatie in kaart te brengen, via het organiseren van focusgroepen en interviews en het afnemen van vragenlijsten met professionals en patienten, en door afspraken en gesprekken. Dit kijken vond zowel plaats voordat de ziektemanagementprogramma's werden geïmplementeerd als tijdens de implementatie van de programma's, om zo de zorg te verbeteren voor mensen met een chronische aandoening. Professionals gebruikten de elektronische patiëntendossiers om gezondheidsdata van patiënten en de veranderingen die patiënten aanbrachten in hun leefstijl te observeren, alsmede de zorg die andere professionals aan patiënten leverden. Ook patiënten hielden hun eigen activiteiten en symptomen in de gaten, met name gerelateerd aan veranderingen in hoe ze hun ziekte onder controle hielden. Kijken veranderde dus hoe de zorg werd geleverd, hoe professionals en patiënten zich gedroegen, en hoe de projectleiders de programma's ontwikkelden, omgingen met professionals en werkten met patiënten. In die zin stuurde kijken patiënten, professionals en projectleiders. Kijken betekende macht.

Dit proefschrift analyseert ‘kijken’ als een vorm van macht die invloed uitoefent op het gedrag van diegenen die betrokken zijn bij ziektemanagementprogramma’s (Armstrong, 1997; Foucault, 1995; Foucault, 2003; Lupton, 1997; Mann & Ferenbok, 2013; Mann et al., 2003; Mann, 2013). Projectleiders, professionals en patiënten worden gevormd door het kijken inherent aan ziektemanagementprogramma’s en studies. Toezicht is toegenomen in de gezondheidszorg en is gerelateerd aan de toename van niet-acute ziekten en veranderingen in het zorgsysteem (Armstrong, 1995). Alle genoemde vormen van kijken waren nodig om de ziektemanagementprogramma’s goed te laten lopen; kijken was werk.

Het werk van professionals, patiënten en projectleiders zorgde voor de veranderingen in de zorg die met de ziektemanagementprogramma’s gepaard gingen. Het veranderen van de zorg aan de hand van ziektemanagementprogramma’s was een proces dat verschillende vormen van werk vereiste. Door het analyseren van ziektemanagementprogramma’s door middel van een theoretisch perspectief dat ‘werk’ in acht neemt, bestudeert dit proefschrift de verschillende vormen van werk waaruit ziektemanagementprogramma’s bestaan en hoe deze vormen van werk met elkaar samenhangen. Strauss definieerde werk in zorgprojecten als “bestaande uit veel taken die worden uitgevoerd over een periode, en verdeeld over de verschillende betrokken actoren (personen, groepen personen, afdelingen of andere organisationele eenheden)” (Strauss, 1985b, pg 2). Verder categoriseerde Strauss (1985), in *The Social Organization of Medical Work*, werk uitgevoerd door medische professionals in het behandelen van chronische ziekten als: machinewerk, veiligheidswerk, ‘comfort’ werk, affectief werk, en articulatiewerk. Articulatiewerk, gedefineerd als werk “gedaan om te verzekeren dat de collectieve inspanningen van de staf meer zijn dan de individuele en conflicterende resultaten”, is vaak werk dat gedaan wordt achter de coulissen, maar dat noodzakelijk is voor het succes van elk programma of activiteit (Strauss, 1985b, pg 2). In de gezondheidszorg, waaronder de onderzochte ziektemanagementprogramma’s, wordt dit werk vaak gedaan door verpleegkundigen en door projectleiders (Bowker & Star, 2000; Strauss 1988). Dit werk helpt om de standaard operatieprocedures en zorgprotocollen goed te laten verlopen (ook als er veranderingen zijn), om verstoringen snel uit de weg te helpen en om routines to ontwikkelen of te continueren (Strauss, 1985; Star & Strauss, 1999). Samenwerken was tevens een belangrijk onderdeel van het werk zoals gedaan in ziektemanagementprogramma’s; samenwerken gaat om het distribueren van taken (Star & Strauss, 1999, pg 10). Het ontwikkelen, coördineren en observeren van informatie was erg belangrijk in de ziektemanagementprogramma’s. Dit wordt ook wel informatiewerk genoemd en werd meestal uitgevoerd door projectleiders. Informatiewerk bestond uit het creëren en verzamelen van numerieke data, informatie over en van professionals, het beheren van het budget, het in de gaten houden en registreren van processen en het verzamelen van literatuur die kan helpen bij het nemen van belissingen.

RESULTATEN

In het tweede hoofdstuk (Disease management projects and the Chronic Care Model in action: baseline qualitative research) onderzoek ik de ontwikkeling en eerste fasen van de implementatie van ziektemanagementprogramma’s, waarbij ik vooral onderzocht hoe deze programma’s van papier tot werkelijkheid werden door het werk en de begeleiding van projectleiders en managers. Dit was geen eenduidige implementatie van een programma, maar was een reeks van interpretaties, wijzigingen en bewegingen van een ‘reizende technologie’. Reizende of bewegende technologieën zijn programma’s of gezondheidszorgprincipes die zich bewegen tussen een hoger (vaak academisch) niveau en de lokale praktijken en acties van zorgmanagers en uitvoerders. In de ziektemanagementprogramma’s konden de projectleiders worden gezien als ‘reisgidsen’ voor de programma’s, want zij overzagen het budget van de programma’s, begeleiden de ziektemanagementprogramma’s naar het werk van individuele professionals, hielpen professionals die betrokken waren bij het project om de programma’s te vervoeren naar en met patiënten, en verbonden de programma’s, zodat een nationale gemeenschap van ziektemanagement ontstond. Als ‘reisgidsen’ hielden de projectleiders de programma’s continu in de gaten en probeerden ze om tegemoet te komen aan de behoeften van professionals en patiënten. Maar ondanks hun toewijding en inspanningen waren projectleiders en managers beperkt in wat ze zelf konden doen om de programma’s van papier tot praktijk, van globale plannen tot lokale acties, te bewegen. Ze waren beperkt door hun eigen tijd en capaciteit, alsmede door de acties van anderen, door de technische systemen behorende bij de programma’s, de manier waarop het onderzoek naar de programma’s was georganiseerd en door het beschikbare budget.

In hoofdstuk drie (Identifying and explaining the variability in development and implementation costs of disease management programs in the Netherlands) analyseerde ik (met een collega-onderzoeker) de belemmerende en bevorderende factoren voor het ontwikkelen en implementeren van kosteneffectieve ziektemanagementprogramma’s. Het kwalitatieve onderdeel van dit onderzoek liet zien hoe drie kenmerken van de onderzochte ziektemanagementprogramma’s een verklaring konden bieden voor de verschillen in kosten tussen gelijkwaardige programma’s. Deze kenmerken waren gerelateerd aan de interventies zelf, de computersystemen en de ervaring van projectleiders. De ontwikkeling van het programma, waaronder de hoeveelheid tijd geïnvesteerd en de al aanwezige ICT systemen, kwamen in dit onderzoek tevens naar voren als een belangrijke verklaring voor de verschillen in kosten. Het werk dat projectleiders, clinici, patiënten en andere betrokkenen deden, bepaalde veel van de kenmerken die variatie in kosten verklaarden. Met name de rol van de projectleider was belangrijk, aangezien ervaren projectleiders in al meer ontwikkelde projecten minder tijd nodig hadden voor de eerste fasen van de ontwikkeling van de programma’s. Projectleiders waren verantwoordelijk voor het begeleiden van de programma’s, het werken met professionals, het delegeren van verantwoordelijkheden en het ontwikkelen en onderhouden van contacten met financiers. Dit onderzoek liet zien hoe in projecten met een langere geschiedenis (en met een projectleider met meer ervaring in het leiden van projecten in de gezondheidszorg en projecten in het specifieke ziektemanagementprogramma) de relaties die nodig waren voor goed en efficiënt projectmanagement al ontwikkeld waren. De kosten hiervoor hoefden dus niet te worden opgenomen in de ontwikkelings- en interventiekosten. Evaluaties van projecten dienen meer rekening te houden met de voorgeschiedenis van die projecten.

Projectleiders vervulden flexibele en telkens andere rollen in het project; ze observeerden het programma om te zien waar veranderingen nodig waren, gebaseerd op de behoeften van de populatie. Zo installeerden ze bijvoorbeeld nieuwe functies voor online programma's of printen ze informatie voor patiënten die thuis weinig tot geen toegang hadden tot een computer. Deze constante adaptatie van projectleiders en clinici was "persistent tinkering in a world full of complex ambivalence and shifting tensions" (Mol, 2010). Tinkering is werk dat wordt gedaan door grote en kleinere inspanningen om zo de ziektemanagementprogramma's aan te laten sluiten op bestaande systemen; het gaat om voortdurende kleinere en grotere aanpassingen. Tinkering is onmogelijk zonder zowel werk als observeren; observeren is nodig om te begrijpen wat er aangepast moet worden, terwijl werk nodig is om het tinkeren zelf te doen. Projectleiders waren continu bezig om aan te sluiten op de steeds veranderende behoeften van patiënten, van het gezondheidszorgsysteem en van zichzelf. Desalniettemin was dit tinkeren vaak een traag en onzichtbaar proces, zoals ook veel van het werk dat projectleiders verrichten om interventies aan te passen, financiering aan te vragen of samen te werken met onderzoekers dat was. Dit 'dokteren' vond voortdurend plaats gedurende het onderzoek en de programma's, maar, zoals mijn data laat zien, leek meer aanwezig in de ontwikkelings- en interventiefasen van de programma's. De reden hiervoor is dat projectleiders in die fasen moesten samenwerken met nieuwe financiers, systemen en zorgplannen.

Chronische ziekten zoals eetstoornissen vereisen veel werk en observeren van patiënten zelf – observeren om te zien of de ziekte goed gemanaged is, werken om de ziekte zelf te managen en om het zorgsysteem te begrijpen en te navigeren. In hoofdstuk 4 (Proud2Bme: exploratory research on care and control in young women's online eating disorder narratives) heb ik verhalen onderzocht die geplaatst waren op een website die ondersteuning biedt voor mensen met eetstoornissen, opgezet door een behandelingscentrum. Ik bestudeerde deze verhalen om te begrijpen hoe patiënten hun behandeling, herstel, zelfmanagement en leven met een chronische ziekte ervaren. Met name keek ik naar de notie van 'controle' in deze verhalen. Controle en discipline spelen belangrijke rollen in veel chronische ziekten; de behandeling en management van chronische ziekten vormen (of disciplineren) vaak het leven van patiënten. Om te onderzoeken hoe controle en discipline een rol spelen in het leven van mensen met een eetstoornis heb ik de verhalen op de website geanalyseerd, waarbij ik gebruik maakte van Foucault's definitie van discipline. Volgens Foucault bevat discipline verschillende vormen van controle: subtiele dwang gericht op het individu, het lichaam als object van controle, en het continu uitoefenen van druk en toezicht (Foucault, 1995).

De verhalen lieten een complex netwerk bestaande uit werk, schrijven, acties, controle en verschillende actoren zien die tezamen en in wisselwerking het management en de behandeling van eetstoornissen ondersteunden. Veel van de controle in deze netwerken was gerelateerd aan het werk van mensen met een eetstoornis (met name jongere vrouwen), professionals, projectleiders en webbeheerders. In mijn onderzoek beschreef ik verschillende vormen van controle die in de verhalen naar voren kwamen, zoals controle over het lichaam, controle en sturing van anderen zoals ouders en zorgverleners, controle over de verhalen op de website, en controle door toezicht op het lichaam en de verhalen van patiënten. Via hun eetstoornissen probeerden patiënten hun leven en emoties, die ze als chaotisch beleefden, onder controle te houden. Veel van de vrouwen observeerden echter ook hoe het leek of de eetstoornis na verloop van tijd de controle over hun leven had overgenomen. Behandeling was een van de manieren waarop jonge vrouwen weer controle kregen over hun leven, hoewel veel patiënten ook ervaarden hoe de behandeling teveel controle uitoefende over hun leven. Een van de doelen van de behandeling was om jonge vrouwen te disciplineren tot betere manieren om om te gaan met stress-factoren die kunnen leiden tot een eetstoornis, alsmede tot betere zelfmanagement van hun stoornis. De jonge vrouwen observeerden dat de behandeling, zoals opgezet door projectleiders en utigevoerd door (medische) professionals, hen trainde om hun eigen lichaam en geest te observeren terwijl, tegelijkertijd, de professionals hun gedrag, reacties en lichamen in de gaten hielden.

De klinische blik is een van de belangrijkste middelen om de symptomen en ziekte van een patiënt te begrijpen, hun behandeling te overzien en aan te passen, en symptomen en signalen van verschillende patiënten te vergelijken om zo gestandaardiseerde noties van ziekte te ontwikkelen (Foucault, 2003). De klinische blik bestaat uit meerdere vormen van observatie en kijken. In hoofdstuk 5 (Dynamics of on-line and off-line watching in self-management programs), exploreer ik de implicaties van kijken in het zelfmanagement van chronische ziekten. Zelfmanagement biedt een goede plaats voor het onderzoeken en begrijpen van de werking van kijken en de uitbreiding van de kliniek, online en offline.

Zelfmanagement van chronische ziekten, zoals uitgevoerd in de onderzochte ziektemanagementprogramma’s, was een activiteit die gedeeld werd door professionals, patiënten, en soms de familie van patiënten. Sommige onderzoekers claimen dan ook dat gedeelde verantwoordelijkheden een belangrijke voorwaarde is voor effectief management van chronische ziekten (Thille & Russell, 2010). Door middel van het observeren en het managen van hun chronische ziekte buiten de kliniek kregen patiënten verantwoordelijkheid voor zelfmanagement, waarbij ook van hen werd verwacht dat ze de vergaarde data terugkoppelden aan de medische professionals, zodat deze toezicht konden houden over patiënten en hun ziekte. Deze vergaarde data veranderde de manier waarop zorg werd verleend gedurende een consult en ook gedurende toekomstige consulten. Tevens kon het consequenties hebben buiten de consultatiekamer gedurende zelfmanagementactiviteiten van de patiënt, zoals het veranderen van de medicatiedosis of de mate van en manier waarop patienten bewogen. Door zelfmanagement leerden patiënten om voor zichzelf te zorgen, bijvoorbeeld door het observeren en documenteren van hun suikerwaardes, in de gaten te houden wat ze aten, of het observeren van problemen met ademen. Hierbij geldt overigens dat niet alle (groepen) patiënten evenveel in staat of bereid zijn tot het uitvoeren van dit werk.

In het algemeen worden ziektemanagementprogramma's gefinanceerd als experimenten, hetzij door ministeries van gezondheid als onderzoek, hetzij door zorgverzekeraars als innovatieve en mogelijk kostenbesparende programma's voor de uitvoering van chronische ziektenzorg. Deze vormen van financiering en de eisen die gepaard gaan met de financiering brengen tevens nieuwe vormen van werk met zich mee voor clinici, patiënten en projectleiders. Aangezien de kwalitatieve, kwantatieve en economische studies van de ziektemanagementprogramma's een belangrijke rol speelden in de manier waarop de programma's werden ontwikkeld en uitgevoerd, analyseer ik hoofdstuk 6 van dit proefschrift het onderzoek naar de programma's.

Projectleiders begeleidden tegelijkertijd het onderzoek en de programma's in de praktijk. Onderzoek, in simpele termen, is een georganiseerde, geroutiniseerde vorm van observeren, vaak uitgevoerd door externe experts. Projectleiders manageden zowel de interne als externe observaties die werden uitgevoerd in de praktijken. Het onderzoek (en de financiering verbonden aan het onderzoek) oefende invloed uit op het type programma dat werd geïmplementeerd en het tijdsschema voor het veranderen van de zorg. Projectleiders en onderzoekers ondervonden dat het lastig was data te verzamelen voor sommige groepen patiënten vanwege hun leeftijd, kwetsbaarheid, of taal, ook al hadden de programma's mogelijk positive gevolgen voor deze patiëntengroepen. De projectleiders moesten deze discrepantie tussen onderzoek en zorg managen.

In de praktijken werden verschillende vormen van onderzoek uitgevoerd. De projectleiders voerden hun eigen onderzoek uit naar de ziektemanagementprogramma's met het oog op het verbeteren van de kwaliteit van zorg, onderzoek was nodig voor rapporten voor zorgverzekeraars, projectleiders overzagen andere onderzoeksprojecten, en studenten voerden onderzoek uit in sommige praktijken, waarbij ze ondersteund werden door projectleiders. Onderzoek, waaronder het onderzoek waarop dit proefschrift is gebaseerd, kan gezien worden als een vorm van systematisch observeren, bijvoorbeeld door het afnemen van vragenlijsten of interviews, het gebruik van data uit medische dossiers, en/of het gebruik van informatie over kosten. Door dataverzamelingswerk creëerden clinici en onderzoekers bewijs dat gebruikt kan worden voor toekomstige uitvoering van evidence-based zorg, zoals andere onderzoekers ook hebben beargumenteerd (Nielsen & Jensen, 2013). Projectleiders vertelden dat ze 'gek' werden van het onderzoek, zelfs als ze de uitkomsten ervan op prijs stelden.

Het coördineren van onderzoek in de praktijken kwam bovenop het werk dat gepaard ging met het managen en veranderen van de zorg. De financiering voor de programma's en het onderzoek gaf de zorg in de programma's vorm. Zo werden projectleiders bijvoorbeeld in de Call for Proposals gestimuleerd om zich te focussen op nieuwe ICT systemen om de zorg tussen verschillende professionals en patiënten te coördineren, om zelfmanagementcursussen voor patiënten en professionals aan te bieden en om multidisciplinaire teams in te zetten voor de behandeling en management van chronische ziekten. Deze veranderingen in de zorg vereisten vaak veel onderhandeling en communicatie tussen projectleiders en clinici. Om de ziektemanagementprogramma's te ondersteunen en te verankeren, observeerden projectleiders veranderingen in de zorg door vergaderingen bij te wonen, door telefoongesprekken en emails met professionals, en door hun eigen dataverzameling (zoals focusgroepen en vragenlijsten), en door de dataverzameling die de Erasmus Universiteit uitvoerde. Deze data werd gebruikt voor de interventie en hielp projectleiders in hun werk om de ziektemanagementprogramma's te verbeteren door het blootleggen van, bijvoorbeeld, een gebrek aan kennis, door beter tegemoet te kunnen komen aan behoeften van clinici, en om zo dichterbij de lange termijn doelen van ziektemanagement te komen.

CONCLUSIE

Het onderzoek zoals beschreven in dit proefschrift laat, vergelijkbaar met andere literatuur over ziektemanagement, ziektemanagementprogramma's zien als complexe entiteiten, die beïnvloed worden door een reeks factoren buiten de programma's en onderzoeken zelf. Soms waren andere zaken een grotere prioriteit. Soms gingen projectleiders met ouderschapsverlof, waardoor het project een tijd zonder projectleider zat. Soms was de ingehuurde projectmanager niet geschikt voor het specifieke programma en moest dus vervangen worden. Een projectleider overleed gedurende het project. Soms was de projectleider of medische professional die het programma had geschreven niet degene die het programma implementeerde, of ging het bedrijf dat het electronische medische dossier leverde failliet, of waren patienten niet aanwezig bij de cursussen die voor hen werden verzorgd, wat allemaal extra werk opleverde voor de projectleider.

De analyse van ziektemanagementprogramma's en onderzoek door middel van een combinatie van een theoretisch perspectief op 'werk' en 'kijken' bood een breder en dieper inzicht in de implicaties van ziektemanagementprogramma's en –onderzoeken. Deze implicaties, zoals dit onderzoek laat zien, beïnvloeden het leven van patiënten, de praktijken van professionals, het management van projectleiders, beslissingen betreffende financiering, en het academisch onderzoek naar ziektemanagement meer in het algemeen. Ze laten het werk zien dat gedaan moet worden om ziektemanagement programma's te ontwikkelen en te implementeren en hoe dit de rollen van zorgprofessionals, patiënten en projectmanagers beïnvloed; en hoe anderzijds ziektemanagement afhankelijk is van de mogelijkheden en medewerking van deze en vele andere actoren, inclusief technieken. De combinatie van werk en observatie is een bruikbare methode voor het onderzoeken en analyseren van ziektemanagementprogramma's en –onderzoeken, omdat het inzicht biedt in hoe ziektemanagementprogramma's plaatsvinden in de praktijk en in onderzoek naar ziektemanagement.

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WTMC Workshop ‘Seeing through Numbers’ (5 days)	2012
WTMC Workshop ‘Normativity as Object and as Practice’ (3 days)	2012
WTMC Workshop ‘STS goes mental’ (3 days)	2011
WTMC Workshop ‘Models and Simulations’ (3 days)	2011

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Society for the Social Studies of Science Annual Meeting (Cleveland, U.S.)	2011
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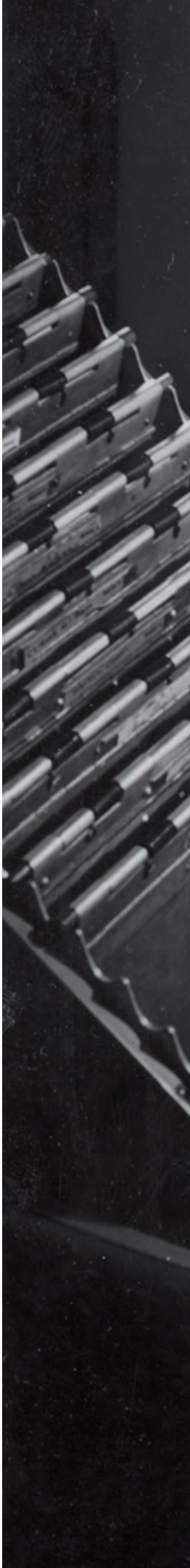
ABOUT THE AUTHOR

Bethany Hipple Walters was born in Peoria Illinois on November 14, 1976. She studied anthropology at the University of Massachusetts Amherst (1995-1999). She then studied public health at Columbia University; she obtained an MPH in 2002. Bethany has long been fascinated by healthcare processes, especially small-scale processes and interventions. She worked as the Yale-New Haven Hospital as the hospital archivist from 2002-2004 and as a project coordinator for a maternal morbidity and mortality endeavor from 2002-2003. From 2004 onwards, she has worked as a project director with the Clinical Effort Against Second-hand Smoke Exposure study at Massachusetts General Hospital. In 2009, she moved to the Netherlands and began her PhD research at the Institute of Health Policy and Management (iBMG) on the implementation of disease management programs in primary care settings in the Netherlands. She currently lives in Delft with her husband Carey and her two house rabbits Knetter and Baby Gigantor (Tor).



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