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POWER TO THE PATIENT?

Analyzing online communities and their potential for changing power processes in Parkinson’s care

Laura Visser
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CHAPTER 1

INTRODUCTION
After working on this dissertation for five years, I have come to realize that there are two possible ways of introducing the central focus of this dissertation. One is by stating that the focus will be on new ways of organizing care through using technology (with an emphasis on power processes), the other that this dissertation focuses on power processes in organizing (in the context of the healthcare sector). Both would paint an accurate picture of the content of my dissertation, but the former presents an empirical approach to what my dissertation is about, whereas the second reflects the theoretical ambitions that are integral to this project. As you will see in the rest of this chapter, my introduction will depart from the empirical orientation and will then subsequently comment on the theoretical questions on power processes that are integrated into this dissertation. In the final chapter of this dissertation (the conclusion), the theoretical ambitions (and contributions) of my dissertation will be given most emphasis as I work through the different power concepts that I have adopted and as I develop an overall perspective on power processes in organizing.

Virtually all societies in the Global North are nowadays faced with financial pressures on their healthcare provision systems. The causes for these pressures are partially located in the aging of populations and longer life expectancies, resulting in more people who need care and less people to provide and pay for it (Schäfer et al., 2010). To cope with these increasing pressures, (private) organizations and governments are trying to innovate current ways of organizing care provision. Hoping to increase the efficiency (while maintaining effectiveness) of care provision, tools are implemented that restrict time spent on individual patients and steer patients to care provision that is least costly. Because of the age that we live in, many of these tools take a technological form. Apps, devices, and websites have been introduced to support changes in care provision (Alpay, Henkemans, Otten, Rovekamp, & Dumay, 2010; Wicks et al., 2010). Online communities, especially, are a popular tool to implement as they allow communication across time and space. Many different types of online communities exist and have been examined, such as peer-to-peer support for patients (Attard & Coulson, 2012; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004), and large communities of patients and healthcare professionals asking and answering general health questions (Househ, Borycki, & Kushniruk, 2014; Oerle, Mahr, & Lievens, 2016; Van der Eijk et al., 2013), and online communities that are tied to specific hospitals (Wicks, Stamford, Grootenhuis, Haverman, & Ahmed, 2014). In this dissertation, I focus on another specific type of online communities, one that enables direct communication between a patient and her or his own healthcare professionals, which I will, from here on, refer to as personal online health communities (POHCs).

I set out to examine the new ways of organizing care involved in using these POHCs. These POHCs, used by chronically ill patients and their healthcare professionals, are presented as a tool for creating integrated and personalized care, as patients and healthcare professionals get easier access to each other (Alpay, van der Boog, & Dumaij, 2011; Pagliari, Detmer, & Singleton, 2007; ParkinsonNet, 2012). By communicating online with their own healthcare professionals, patients are expected to become empowered and to take on an active role in managing their own care. Healthcare professionals, in turn, are expected to become more aware of each other’s treatment plans, which should lead to more collaboration and less hierarchical relations between them. Therefore, the POHCs come with an expectation of changing current power processes in care provision.

However, this expectation is based on a limited conceptualization of power that requires further critical examination. Rather than defining power as a possession that powerful individuals use in order to dominate others (French & Raven, 1959), I complicate the examination of power processes by conceptualizing power as embedded in action using Foucault’s (1978, 1979, 1982) work as a foundation. In this introduction, I will argue that introducing POHCs happens in concert with wider social and organizational processes that have not been thoroughly examined. My dissertation as a whole, will unpack the impact of POHCs on power processes in care provision using different concepts from Critical Management Studies. Critical Management Studies, with its questioning of mainstream management thinking from the perspective of power and inequality, has generated a number of useful concepts to critically examine power, which I will discuss in more depth below. Using these concepts, this dissertation asks (and answers) the following central research question:
how does organizing care through personal online health communities affect power processes in care provision?

ORGANIZING CARE THROUGH TECHNOLOGY

The impact of technology on care provision has received much attention in academic literature, but that literature presents a limited picture. Research in the medical sciences on implementing new technologies has mostly focused on strategies for adoption (Bishop, Press, Mendelsohn, & Casalino, 2013; Schwamm, 2014), rather than examining POHCs’ use, and effects of their use, after introduction. Discussions of how new technologies are used often stick to general statements about their potential, which include: more space for the patient to ask questions, better accessibility of information, more transparency regarding the healthcare provision process, better collaboration between healthcare professionals, and faster service (Alpay et al., 2011; Clemensen & Rasmussen, 2011; Dedding, van Doorn, Winkler, & Reis, 2011; Detmer, Bloomrosen, Raymond, & Tang, 2008; Krist & Woolf, 2011; Mesko, 2015; Pagliari et al., 2007). How this potential plays out in the actual use of the POHCs remains underexplored, especially in relation to POHCs’ expected impact on power processes.

Scholars such as Annemarie Mol (2002, 2008, 2010), Nelly Oudshoorn (2008, 2009, 2011, 2012), Marianna Fotaki (2006, 2010a, 2010b), and Maggie Mort (2009, 2003) have inspired me to critically examine the use of technology in healthcare. With an emphasis on the (invisible) labor that goes into using technology, these scholars show the use of technology in care within its wider societal context, while describing the everyday reality of care for patients and healthcare professionals (Mol, 2008; Mol et al., 2010; Oudshoorn, 2008). I use their work as a critical foundation on which I build an explicit power analysis of new ways of organizing care through using technology. In the next sections, I address in more depth regarding the different conceptualizations of power and the definition of power I adopt in this dissertation.

POWER IN ORGANIZING CARE

Central to discussions on power in organizing care is the concept of patient-centered care. As the word already indicates, patient-centered care presents a new way of organizing care by giving the patient a position in the center and organizing care around her or his individual needs. As a concept and aspiration, patient-centered care might seem like a recent fad (Davies, 2012; Krist & Woolf, 2011; Prainsack, 2014; Walsh et al., 2014), but it was actually introduced into academic literature by women nurses decades ago (e.g., Leino, 1952; Smith, 1950; Wong, 1979). Patient-centered care is often contrasted with paternalistic care, which is characterized by the healthcare professional taking the lead in making decisions. Recent calls for patient-centered care argue that current ways of organizing care, with professionals as the drivers behind treatment plans, are outdated, and that it is time to “hand the wheel to the patient” (Berwick, 2009; Epstein, Fiscella, Lesser, & Stange, 2010; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Van der Eijk, Faber, Al Shamma, Munneke, & Bloem, 2011). Patient-centered care could simultaneously lead to a more multidisciplinary approach, as all healthcare professionals unite around the patient in the center, breaking the dominance of certain medical disciplines (i.e., medical specialists) (Harrison, Clayton, & Wallace, 1996; Nilsen & Moen, 2008).

Arguments given for introducing patient-centered care are often based on moral standards; patients find themselves in a vulnerable position and their just and equal treatment is supposed to be a central pillar in care provision (Berwick, 2009). Therefore, patients should not be dominated but have a right to be able to have their voice heard. At the same time, quality of care or economic arguments are often given. With more possibilities to personalize your care, the quality of care for individual patients is expected to be higher (Epstein et al., 2010). Moreover, if patients receive higher quality of care, their chances of undergoing unnecessary procedures or experiencing unnecessary symptoms, are also expected to go down, lowering healthcare expenses on those patients (Blanson Henkemans, Molema, Franck, & Otten, 2011; Walsh et al., 2014).

Although patient-centered care, as an idea, is gaining more and more traction, the actual (and true) implementation of it, is still lagging behind (Anderson & Funnell, 2005, 2010; Malterud, 2010; Raad voor de Volksgezondheid en Zorg, 2013). I argue that this lack of implementation is partially due to a limited understanding of power processes involved in (implementing) patient-centered care. Discussions of patient-centered care (and the POHCs that try to implement
it) tend to emphasize power as a zero-sum possession, where (certain) healthcare professionals have too much, causing patients to have too little (Berwick, 2009). This unbalanced hierarchical relationship is expected to be rebalanced by the introduction of the POHCs. In contrast, this dissertation, provides an in-depth understanding of power as a process, that goes beyond power as a possession. Building this in-depth understanding of power processes (which I expand on below) presents a necessary step toward improving care and the relationships between patients and healthcare professionals.

THEORIZING POWER

The conceptualization of power as a possession has a long history in the social sciences. Starting with the classic works of Marx (Tucker, Marx, & Engels, 1978) and Weber (2005/1930), individuals were divided into the ‘haves’ and ‘have nots’ to define power as representing domination and oppression. Such thinking was translated to Organization Studies drawing on authors such as French and Raven (1959), who defined ‘bases’ of power to describe how some individuals in organizations possess certain forms of power which they can yield to make decisions. This idea of power was radically transformed through the introduction of Foucault’s (1978, 1979, 1982) work, which locates power in action rather than in the hands of specific individuals, groups or institutions. Power, using Foucault’s often used quote, is “everywhere; not because it embraces everything, but because it comes from everywhere” (Foucault, 1978, p. 93). Because power is embedded in all that we do in everyday life, it is not just an oppressive force; it can also be a productive element in our daily lives. More specifically, because power is embedded in and guides our actions, it allows us to do certain things (and prevents other things). Therefore, Foucault provides a more complex understanding of power, showing that it is not a few powerful individuals that oppress us and force us to do things. Rather, by doing things (‘action’) in general, we (re)produce a status quo that is much more ‘forceful’ in disciplining our behavior than any individual or institutions can be. This Foucauldian conceptualization is where my dissertation departs from.

Critical Management Studies today still relies heavily on a Foucauldian conceptualization of power. Locating power in action, rather than in the hands of a few individuals, means that there are many different places where one can look for power, because there are a great deal of organizational activities that (re)produce or challenge the status quo. This wide range of possibilities for power to exist is also reflected in the wide range of concepts to which the study of power has been linked in Critical Management Studies. Four of these concepts are pertinent to my empirical context and I will further develop theorizations around those specific concepts in this dissertation. These power concepts are consumerization, identities, surveillance, and bodies. Each of these four concepts presents an opportunity for investigating how the POHCs normalize certain actions and abnormalize others.

First, consumerization, as a process, is part of a macro-level discourse informed by a neoliberal zeitgeist. This macro-level discourse increasingly positions organizational activities in market rhetoric (Gabriel, Korczynski, & Rieder, 2015). Therefore, clients (i.e., patients) become consumers who can demand and choose specific forms of services and professionals become service providers who respond to those demands (Fotaki, 2010a; Mol, 2008). Because consumerization provides and normalizes certain ways of providing care, it becomes part of the structures that discipline the behavior of everyone involved.

Second, organizational identities have a long history as a concept of power: demonstrating how organizations regulate the identity work of organizational members, the theoretical concepts of organizational identities and identity work show how individuals become tied to their understanding of themselves in relation to their organization and discipline their own behavior accordingly (Alvesson & Willmott, 2002; Beech, Gilmore, Hibbert, & Ybema, 2016; Zanoni & Janssens, 2007). The concept of organizational identities, within such a Foucauldian framing, shows how these (patients’) identities are not constituted by an oppressive actor but by a process of (re)production and internalization in which everyone is involved through identity work (Brown & Coupland, 2015; Clarke, Brown, & Hailey, 2009).

Third, surveillance is a classic Foucauldian concept as the act of surveillance (and, more importantly experiencing surveillance) is an important
Introduction

Power to the Patient?

part of the disciplining aspects of power; when you are being watched, you are even more aware of your behavior and how it comes across (Foucault, 1979). Surveillance in organizational contexts is widely present as a system of control (Ball, 2010), through different means, such as surveillance in the private sphere (Watkins Allen, Coopman, Hart, & Walker, 2007), video surveillance (Iedema & Rhodes, 2010), and bodily surveillance (Ball, 2005). As such, surveillance is an important tool through which organizations can ensure that their organizational members (in this case, healthcare professionals) keep in line with organizational goals (Sewell & Wilkinson, 1992; Winiecki, 2009).

Fourth and last, bodies are another Foucauldian concept of power. Foucault wrote that “the body maintains, in life as in death, through its strength or weakness, the sanction of every truth and error” (Foucault, 1977, p. 147). Organizational activities play out on bodies, as these activities (re)produce how the body is supposed to look, behave, and move within the organizational context (Hassard, Holliday, & Willmott, 2000; Michael & Rosengarten, 2012). As such, the way organizations discipline (patients’) bodies to behave in line with organizational goals, forms another concept through which we examine power processes in organizations.

With this dissertation, I contribute to conversations around these individual concepts, which are all topics of current debate in Critical Management Studies. With these contributions, I demonstrate how my dissertation extends beyond Foucault to include concepts of power in intersectionality literature (Cho, Crenshaw, & McCall, 2013; Verloo, 2013), dramaturgical literature (Goffman, 1959) and literature on materiality (Barad, 2007; Orlikowski & Scott, 2015). The joining of these different literatures reflects my journey through the literature on power in organizing, that moves from Foucault, ultimately, to Barad as I will show in my concluding chapter. Embedded in this journey are two overarching debates, a historical one on agency and structure, and a recent one on materiality and discursivity. In my conclusion, I will draw on these debates to further complicate my Foucauldian conceptualization to construct my own perspective on power processes in organizing, with a focus on conceptualizing change.

Research Context and Design

The POHCs under examination in this dissertation were set up by an organization in the Netherlands, called ParkinsonNet. This organization has as its larger aim to improve the care for Parkinson’s patients in the Netherlands. One of the projects they conducted to achieve this aim, was a pilot project, that provides patients with support to set up their own personal online health community, designed by MijnZorgnet, another organization in the Netherlands, whose board members partly overlapped with ParkinsonNet’s. The pilot project (called ‘MyP@rkinsonCare’) forms the central (empirical) context of this dissertation. The project assisted patients in setting up a POHC by financially supporting a Parkinson’s nurse practitioner that helped patients with any technological difficulties they might have encountered. This pilot project ran from 2011 until 2013 and was financed by a grant provided by the Dutch scientific organization for medical sciences. Even though the pilot has since ended, the communities are still online to this day, although due to the absence of support from the Parkinson nurse, their use has dropped significantly.

This pilot project was set up specifically for patients with Parkinson’s disease. Parkinson’s is a chronic and degenerative disease with which most patients are diagnosed at a later stage in their lives (Lees, Hardy, & Revesz, 2009). No cure exists as of yet, and because of the chronic nature of this disease, patients develop a long-term relationship with their healthcare professionals,
most of whom they see on a regular basis. Most patients see their neurologist (generally seen as the main healthcare professional, because of her or his role in the initial diagnosis and medication prescriptions) once every six months. Neurologists can also direct patients to other healthcare professionals. Physical therapists, speech therapists, occupational therapists, and dietitians are among the most commonly visited ‘allied’ healthcare professionals. The involved healthcare professionals are, in most cases, only incidentally in contact with each other about a specific patient, and the pilot project, next to stimulating patients’ active role, is also an attempt to stimulate better involvement of these locally dispersed healthcare professionals and the patient (ParkinsonNet, 2012).

In general, the POHCs provide easier access to and visibility of communication which are conditions for integrating a care provision process that was previously dispersed in time and space. On the one hand, patients are supposed to benefit because they can be better informed about their own care, as information that was previously invisible for them, becomes available on the POHC. With this information, the patient is hoped to play a more active role in her or his care provision which will lead to more personalized care. On the other hand, healthcare professionals are expected to benefit because they stay up to date about the treatments provided by their colleagues, allowing them to adjust their treatment in relation to the other healthcare professionals (ParkinsonNet, 2012).

The technological system of the POHCs provides patient and healthcare professionals with a menu of options. These options consist of sections called ‘files,’ ‘diary,’ ‘meeting,’ ‘apps,’ ‘problem list,’ and ‘team.’ The ‘files’ section can be used to upload files, such as a list of medications. Healthcare providers can also use this section to upload reports on a patient’s wellbeing. The ‘diary’ section allows patients to provide updates on their wellbeing. In the ‘meeting’ section patients or healthcare providers can start a virtual meeting and invite specific healthcare providers to participate. These virtual meetings can be on any disease-related topic, but often involve conversations about medication changes. Similar to face-to-face consultations, the virtual meeting space allows for back-and-forth interactions between patient and healthcare professional(s).

Only those invited to the meeting receive an email notification of the start of the meeting and any subsequent postings. However, the meetings are still openly accessible to anyone who is part of the patient’s ‘virtual team’. Those who are not actively invited are not notified, but can still see and participate in the discussion. The ‘apps’ section allows patients to install applications into their communities, but no applications were developed during the pilot project. The ‘problem list’ allows patients to provide an overview of their issues. Lastly, the ‘team’ section lists all of the participants in the specific patient’s POHC.

Methods of data collection and analysis
In this section, I will discuss both the methods and the methodology of my dissertation. First of all, to understand power processes on the POHCs in-depth, I adopted a qualitative research methods approach. I am interested in exploring different theoretical power concepts in my empirical data and a qualitative approach is often seen as an important medium for exploring, because of the method’s flexibility in the kinds of questions asked and the rich data it yields (Alvesson, 2010). After all, a fine grained analysis of power processes is difficult to capture in standardized surveys, because power processes are not located in fixed types of behavior or individuals. A priori formulation of questions for identifying those processes is, therefore, impossible. In my dissertation, I used a case study approach to collect my data, meaning that I collected a large quantity of data on a small number of cases (patients and their POHCs). My plan for data collection was approved by a medical ethics committee.

I gained access to the patients through the nurse practitioners and specifically asked them for names of patients who were actively using the communities, since I found out earlier that there were a great number of ‘dormant’ users, who did have a POHC but were not actively using it. A neurologist, who was closely involved in the pilot (in which at that time about a hundred patients were involved) estimated that of these patients, perhaps one-third was actively using their POHC. These active users were most relevant for my research project since I wanted to gain information on how these POHCs are actually used, rather than find reasons for why they are (not) used.

Focusing on those patients who are actively using their POHC, I included
18 cases (18 patients and their POHCs) in my data collection. For most cases I combined interviews with patients (N=18), observations of POHCs (N=14, in which I observed 14 patients and 32 healthcare professionals, who together produced 691 postings), and interviews with healthcare professionals (N=13, but some were involved in multiple POHCs). Below you can find an overview of the different cases and their characteristics. After that, I will comment on the process of interviews and observations.

<table>
<thead>
<tr>
<th>Case</th>
<th>Sex</th>
<th>Age patient (at time of interview)</th>
<th>Number of healthcare professionals involved</th>
<th>Number of postings</th>
<th>Length of observations in months</th>
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<tbody>
<tr>
<td>POHC 1</td>
<td>F</td>
<td>75</td>
<td>3</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>POHC 2</td>
<td>F</td>
<td>70</td>
<td>4</td>
<td>9</td>
<td>19</td>
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<tr>
<td>POHC 3</td>
<td>M</td>
<td>80</td>
<td>5</td>
<td>-</td>
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<tr>
<td>POHC 4</td>
<td>F</td>
<td>61</td>
<td>2</td>
<td>14</td>
<td>18</td>
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<td>POHC 5</td>
<td>M</td>
<td>67</td>
<td>3</td>
<td>13</td>
<td>22</td>
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<tr>
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<td>2</td>
<td>9</td>
<td>25</td>
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<tr>
<td>POHC 7</td>
<td>M</td>
<td>71</td>
<td>6</td>
<td>60</td>
<td>34</td>
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<tr>
<td>POHC 8</td>
<td>M</td>
<td>64</td>
<td>3</td>
<td>-</td>
<td>-</td>
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<tr>
<td>POHC 9</td>
<td>M</td>
<td>63</td>
<td>4</td>
<td>10</td>
<td>12</td>
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<td>F</td>
<td>63</td>
<td>3</td>
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<td>6</td>
<td>167</td>
<td>33</td>
</tr>
<tr>
<td>POHC 13</td>
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<td>60</td>
<td>4</td>
<td>-</td>
<td>-</td>
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<td>POHC 14</td>
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<td>5</td>
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<td>4</td>
<td>69</td>
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<td>F</td>
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<td>7</td>
<td>68</td>
<td>32</td>
</tr>
<tr>
<td>POHC 18</td>
<td>F</td>
<td>68</td>
<td>5</td>
<td>143</td>
<td>31</td>
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</tbody>
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Table 1. Overview of included cases in the dissertation.

**Interviews**

As mentioned above, I started my data collection with interviewing the patients. Afterwards, I went on to interview healthcare professionals. I made a selection of the POHCs of five patients who were most actively using their POHC. I selected the five POHCs (POHC 5, 7, 12, 16 and 17 in Table 1) on the basis of the multiplicity of medical disciplines of the professionals involved, to allow for an analysis of how healthcare professionals interacted with each other and the patient within one community. After all, if only the neurologist is included in a patient’s POHC, their virtual context would not be much different from the regular context of the consultation room. In choosing the POHCs to focus on, I also ensured that there were distinct sets of healthcare professionals involved. For example, POHC 12 and 14 involved almost the same healthcare professionals and selecting them both would not have yielded distinct data. In total, 19 different healthcare professionals were involved in the five POHCs (four of them were involved with two or three POHCs in our sample), and they included neurologists, physical therapists, nurse practitioners, occupational therapists and rehabilitation specialists. I contacted all 19 healthcare professionals involved in the POHCs but six of them declined to be interviewed because of time constraints.

For the interviews with patients as well as healthcare professionals, I used similar topic lists. I asked patients and healthcare professionals about their experiences with the POHCs, what they found were the benefits and drawbacks, and how they experienced their own role in the care provision process and the changes it might be undergoing. With the patient interviews, I focused on their active involvement in decision-making and for the healthcare professionals I focused on the collaboration with other healthcare professionals and the involvement of the patient. The interviews with the patients lasted between 45 and 90 minutes, with an average duration of 60 minutes. The interviews with healthcare professionals lasted between 15 and 66 minutes, with an average of 34 minutes. The interviews with patients were all conducted face-to-face in the patients’ own homes. In a small number of cases a partner (and in one case grandchildren) were present in the room where the interview took place. Healthcare professionals were interviewed in their own surroundings, being their office or a (consultation) room in a hospital, and in one case, their own
Observations

To be able to observe the use of POHCs, patients had to add me to the ‘virtual team’ of their communities. Patients added me after I interviewed them, as during these interviews I created the trust relationship that was necessary for them to feel comfortable with me observing the communication on the POHCs. At that time, I also informed healthcare professionals (by sending them a message through the POHCs system) of my inclusion in the patient’s POHC and gave them an option to object, but none of them did. The patients were in charge of deciding if I could join because they were the ones who would physically add me to the POHC. All interviewees, with the exception of four, gave me permission for access to their POHCs. The reasons for why I did not get their permission varied from being unable to reach the patient after the interview, patients declining because of privacy concerns, and patients insisting that their POHCs were not useful to observe because they felt they had not posted enough. In all cases, I first provided the patients with more information about why observations were an important part of my data collection and the ways in which I would ensure their confidentiality. However, after sensing that they remained reluctant, I felt it was better to stop trying to convince them. With regard to the patient who could not be reached; I tried contacting her in different ways, on different days, and at different times across the course of a couple of months, but was unable to get in touch with her. It later became clear that she was admitted to a temporary care facility. Therefore, I ended up only using her interview data.

By being added to the POHCs of the 14 patients, I was able to read and be notified of new postings. Of the 14 patients who did give access to their POHC, two patients stipulated that they would only give access to the POHC for a limited amount of time. These patients stated that they preferred not to be observed constantly, but allowed me one-time access to save the conversations posted so far. For the other ten patients, observations lasted between 12 and 33 months. Every couple of months I made screenshots of the POHCs and saved those as PDF documents on my computer. I used a redaction tool to erase any reference to patients’ names or images in these documents to ensure anonymity in case an outsider would gain access to my files. The observational data included the 14 patients, the 32 healthcare professionals involved in their care and the total amount of 691 postings.

The entire dataset, consisting of 691 postings (observed across 14 POHCs), 18 interviews with patients, and 13 interviews with healthcare professionals, was anonymized. The anonymized data is stored on my work account’s virtual drive (which is password protected) where I also keep one Excel file linking patients’ and healthcare professionals’ code names to their actual names. This file was encrypted using encryption software. All of the anonymized data was then combined into one file using ATLAS.ti. I used this program to code all of my data, and I will explain in each individual chapter how the process of analysis unfolded for that specific topic. The names used are aliases to protect the privacy of involved patients and healthcare professionals.

In Table 2 below, you will find for each chapter what part of the data I used.

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Source of data</th>
<th>Interviews patients (N=18)</th>
<th>Interviews professionals (N=13)</th>
<th>Observations (N=14 POHCs and 691 postings)</th>
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<tbody>
<tr>
<td>Chapter 2: Unequal consumers</td>
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<td>Chapter 3: Organized emancipation</td>
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<td>Chapter 4: Prying eyes</td>
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<td>Chapter 5: Mat(t)erializing the body</td>
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Table 2. Use of data per chapter.

Reflexivity

As a reflexive, interpretive researcher, I want to take this opportunity to reflect on my own position in collecting data, analyzing it and writing this dissertation. During the interviews, I became aware of my own social position. As a young, healthy woman academic in my mid-twenties, I was first interviewing men and women with a chronic disease in their fifties to seventies, with varying
educational and professional backgrounds. During the interviews with patients, I was able, and sometimes forced, to recognize my own position. My age and gender, in some cases, allowed for my questions to come across as less intrusive and threatening. The fact that I was healthy and the interviewee was diagnosed with Parkinson's disease sometimes made me uncomfortable, especially when symptoms of the disease became apparent during the conversation (e.g., tremor, speech impairments, or cognitive issues). I will briefly comment on some of the ways in which I dealt with these situations. I do so, because I believe that interviewers should more often (or always) reflexively discuss their own position during the interview (for a great example, see: Essers, 2009) especially when identities such as healthy versus sick play an important role, because this reflexivity adds an awareness to the experience of the interviewer as well as the reader.

Even when the symptoms described above did not directly hamper the interview, they did visibly bring to the foreground that these patients were ill. At times, this made me wonder if I should neglect or address these issues. I ended up only commenting on those situations where patients’ symptoms interfered with the actual interviewing (for example, an inability to place a signature on the consent form). This often resulted in touching conversations about the profound effects Parkinson’s disease has on patients’ lives. Such conversations supported the building of a trust relationship and helped me gain a better understanding of Parkinson’s disease and the role it plays in patients’ lives. Soon, it became clear to me that such conversations were a requirement for a meaningful interview and, therefore, I decided to start off every interview with providing space for these patients to share their stories about how they had been diagnosed with Parkinson’s. This established a situation in which it became clear that I was interested in hearing these patients’ personal stories. Ensuring that patients knew I was interested was also important in alleviating some of my feelings of guilt or discomfort regarding asking these patients to share their personal stories with me, feelings that are commonly experienced by reflexive researchers (Essers, 2009; Mol, 2008). Ultimately, the trust was important to put both interviewer and interviewee more at ease, making it easier to deal with the complex issues involved in interviewing patients. Another way I dealt with these feelings of guilt and discomfort was by promising to send a summary of the findings of this dissertation to my interviewees, so they could read what I concluded from our conversations.

Interestingly, when I then moved into the interviews with healthcare professionals, my experienced social position slightly shifted. While interviewing the allied healthcare professionals (e.g., occupational therapists, Parkinson’s nurses, et cetera), I felt that my appearance helped the conversation because I came across in a non-threatening way, although for them it seemed clear that I had some knowledge about the care provision process. I, therefore, felt that I was almost addressed as a peer. However, with some of the medical specialists (e.g., neurologists), my appearance worked the other way; because of my age, gender, and the absence of an educational background in medicine, I, at times, felt less taken seriously by (some) healthcare professionals that were positioned in the higher ranks of the medical hierarchy. This aspect of being taken less seriously came to the foreground when questions I asked were answered in a critical or questioning manner.

**CONTENT AND STRUCTURE OF THE DISSERTATION**

I dive into my data in four separate chapters. Each chapter draws on one of the different power concepts I introduced earlier. Each chapter also asks a different question and analyzes different sections of my data.

Chapter 2 extends the literature on consumerization by critically analyzing the implicit assumption that all individuals have the capacity to act as consumers. I develop and contribute an intersectional approach to studying consumer identities, by conducting a critical analysis of the structural inequality (re)produced with these identities. The chapter asks how positioning patients as consumers creates unequal access to care between patients. In this chapter, I show how positioning patients as consumers excludes large groups of patients, based on the intersecting social categories of class, gender, disabilities, and age.

In Chapter 3, I coin the concept ‘organized emancipation’ to demonstrate what happens when emancipation is no longer restricted to bottom-up activities but also initiated from the top-down, by organizations. The main question of this
chapter is how does organized emancipation affect the identity work of patients. I argue that in emancipatory contexts, where individuals are encouraged, but left to their own devices to become emancipated, the idea of emancipation moves away from a ‘right’ that individuals possess to a ‘duty’ that they themselves are made partly responsible for. The identity work in this context entails a complex web of practices where especially the responsibility for this emancipation becomes a space for contestation.

In Chapter 4, I link up with a (current) conversation in the literature on surveillance that has complicated the dichotomy between compliance and resistance as reactions to surveillance. With this chapter, I answer the question as to how healthcare professionals enact surveillance in their daily work. I contribute to this conversation a reconceptualization of professional surveillance at the micro-level of interaction by demonstrating that at this level, professionals enact, rather than react to surveillance. I build this enactive view of professional surveillance by developing a dramaturgical approach. The chapter reconceptualizes surveillance as an integral part of displaying one’s professionalism, through which professionals can play with medical hierarchies. As such, when professionals enact surveillance, they also enact power.

Chapter 5 focuses on bodies and their discursive-materiality. The chapter contributes to the conversations around materiality in Critical Management Studies, arguing that the increased focus on materiality has underexplored potential for understanding power in organizing. Drawing on agential realism’s idea of agential cuts (temporary separations between subject and object), I coin the concept of matterializing (with two Ts) to reposition agential cuts in explicit power terms. In this chapter, I ask how agential cuts enact the matterializing of patients’ bodies. This concept demonstrates how agential cuts enact how (certain) matter comes to matter. The different power concepts, and the order in which they are presented, allow me to tell a story about my data. I move from a larger, macro discussion of the increasing positioning of patients as consumers and how this creates hierarchies of patients (Chapter 2), to a micro-oriented examination of how the patients, privileged enough to use the POHCs, are regulated by organized emancipation and how it affects their daily identity work (Chapter 3). Thereafter, I discuss professionals’ daily work, focusing on how surveillance becomes enacted as part of their sense of professionalism (Chapter 4). I then dive deeper into this idea of enactment as a way to understand the (re)production of power processes (Chapter 5), where I take the body as a locus of the enactment of power. In the discussion chapter of my dissertation, I bring the different chapters together to contribute my perspective on power processes in organizing. I make this contribution specifically with regard to conceptualizing change.
CHAPTER 2
UNEQUAL CONSUMERS

Understanding how consumerization (re)produces inequalities in healthcare*

* This chapter is based on an article, co-authored with Inge Bleijenbergh, Yvonne Benschop, and Allard van Riel. The article is currently being prepared for a second round of review at Organization Studies. A previous version of this article was presented at the Critical Management Studies Conference of 2015 in Leicester, UK.
With this chapter, I link up with a currently emerging critical literature on consumers. This critical literature, so far, has focused on the exploitation and control of consumers being asked and assumed to co-create value without being compensated for this labor. This chapter extends this literature by critically analyzing the implicit assumption that all individuals have the capacity to act as consumers. To conduct this analysis, I develop and contribute an intersectional approach to studying constructed consumer identities, which demonstrates the structural inequality (re)produced with these identities. I conduct this examination in the specific context of healthcare and show how positioning patients as consumers excludes large groups of patients, based on their class, gender, disabilities, and age. Moreover, these social categories often intersect, creating specific social positions of exclusion. As such, the dominance of consumerization is a dangerous strategy for increasing the quality of care, as the patient-consumer identity becomes part of the “systemic dynamics of power” through which existing inequalities and privileges become further institutionalized.

INTRODUCTION

Our understanding of consumers and especially their role in organizing has transitioned from that of passive recipients of goods and services to active participants in organizing processes (Holbrook, 1999; Holbrook & Hirschman, 1982; Neghina, Caniëls, Bloemer, & van Birgelen, 2015; Vargo & Lusch, 2004, 2008). Two topics characterize this transition, ‘co-creating value’ and ‘individualization’, together resulting in a new consumer identity where the consumer actively co-creates value that is individualized to personal preferences. The new identity has not only taken hold in private corporations but also in the public domain (Fontenelle, 2015). One example in the latter domain is the healthcare sector, where patients are (re)constructed as patient-consumers who co-create their personalized care (Potaki, 2006; Oerle et al., 2016; Reay & Hinings, 2009; Tonkens, 2008).

An important aspect of the patient-consumer identity is the ‘logic of choice’ (Mol, 2008), where empowerment of patients, and their involvement in personalized decision-making, has become the polar opposite of old, paternalistic ways of dealing with patients (Doolin, 2002; Tuck, 2013). Therefore, treating the patient as a consumer is generally seen as a positive development (Berwick, 2009; Coulter, 1999; Davies, 2012). However, the hybrid of market and citizenship rhetoric instilled in this new consumer identity also brings along other issues as patients are asked to take responsibility for their choices and the effects they might have on larger society (Dent, 1995; Gabriel & Lang, 2008; Mol, 2008). At the same time, “not all consumers have the time, the financial resources, the skills or the energy to protect their interests” (Gabriel et al., 2015, p. 639). In this chapter, I aim to answer the question of how positioning patients as consumers creates unequal access to care between patients.

Although focused on patients and the healthcare sector, this chapter speaks to consumerization processes across different sectors. Therefore, I look to Critical Management Studies literature for a critical analysis of consumers and consumerization (Gabriel, 2015; Gabriel et al., 2015; Schwarzkopf, 2012; Ureta, 2013). This critical analysis, which has only recently been developed, is often aimed at the co-creation topic within the consumerization process; the existence of so-called ‘prosumers’ who take (unpaid) part in the production practices of the products and services they consume (Cova & Dalli, 2009; Fontenelle, 2015; Rieder & Voß, 2010). Critique of the co-creation topic has provided valuable insights into the power processes embedded in the positioning of individuals as consumers. To further extend our understanding of the power processes involved in consumerization, I add, with this chapter, a critical examination of the hitherto underexposed second topic of consumerization: the individualization of consumer identities. Using healthcare as a pertinent example of a sector in which consumerization is becoming widely spread and possibly problematic, I unpack the assumption that all individuals are able to be (positioned as) a consumer.

My critical analysis demonstrates that the use of words such as ‘personalization’ and ‘individualization’ suggest that there is room for difference but that there is actually a very narrow mold in which only some patients fit. Although differences between patients in their specific needs and desires for care provision are accounted for, differences in the capacity to voice those needs
and desires are only scarcely acknowledged and require further examination, especially with regard to how it influences patients’ access to care (Fotaki, 2010a). To understand these different (in)capacities, I draw on intersectionality literature (Crenshaw, 1989; Verloo, 2013) which will help me theorize the multiple intersecting and structural processes that (re)produce differences between patients, exacerbated by consumerization processes. An intersectional lens sees people as defined by multiple, intersecting social categories at the same time. This lens stands in contrast to a ‘single-axis’ categorization that highlights one social category at a time, while ignoring others (Cho et al., 2013; Crenshaw, 1989; Verloo, 2013). An intersectional approach is becoming somewhat more common in Critical Management Studies (Essers, Doorewaard, & Benschop, 2013; Riach, Rumens, & Tyler, 2014; Natasha Slutskaya, Simpson, Hughes, Simpson, & Uygur, 2016; Wasserman & Frenkel, 2015), but has not been linked to the examination of consumers to date. This chapter develops and contributes, to the emerging critical literature on consumers, an intersectional approach to studying consumer identities, as I conduct a critical analysis of the structural inequality (re)produced with these identities.

I make this contribution in the empirical context of personal online health communities (POHCs). POHCs are often used as an instrument to encourage patient involvement in care provision (Schwamm, 2014). Through these communities, patients are expected to gain easier access to their healthcare professionals and are provided with tools to take charge of their own care provision (Bishop et al., 2013; Pagliari et al., 2007). The POHCs under examination here are set up for and by patients who are chronically ill (Parkinson’s disease), so they can interact online with their own healthcare professionals. I have collected data on these POHCs through conducting interviews with 18 patients and with 13 of their healthcare professionals. In these interviews, I asked both groups to talk about the patient’s role in healthcare provision in relation to the POHCs.

In the next sections, I will lay out my theoretical framework for studying the patient-consumer identity, which draws on Critical Management Studies literature on consumer identities (partly specifically related to the healthcare sector), and intersectionality. After this theoretical discussion, I will describe my methods of data collection and analysis. Thereafter, I will display the results of my analysis which I discuss in broader theoretical and practical contexts in my discussion section.
consumers into organizational identification processes, organizations gain access to new forms of controlling them, and the position of the prosumer has been criticized for it (Arnould & Cayla, 2015; Fontenelle, 2015; Gabriel et al., 2015). For example, profits that are derived from the labor that consumers put in voluntarily often times do not flow back to these individual consumers but to the organizations. Moreover, with closer links between consumers and organizations, organizations create a sense of belonging and responsibility for the success of the organization, but make consumers responsible for improving the experiences of other consumers by actively providing feedback (Peddibhotla & Subramani, 2007; Wiertz & de Ruyter, 2007).

To contribute to the developing stream of literature on consumers and organizing, I study an aspect of consumerization that has received less critical attention, by asking if everyone is able to act as a consumer in the same way. The patient-consumer identity is marked by a ‘logic of choice’ (Mol, 2008). In this logic, choice is positioned as highly individualized (Collyer, Willis, Franklin, Harley, & Short, 2015; Fotaki, 2006; Gabe et al., 2015). The individual, and her or his preferences, are central to making choices as a consumer (Gabriel, 2015). However, wanting or having choices itself is not deemed an individual trait: within consumerization processes, one cannot choose not to be involved in making choices. Rather, making choices is assumed to be a universal desire and capacity. I posit that the capacity to actively choose and to be involved in producing one’s care is neither an individual trait nor a universal desire, but a position that is only accessible to those from certain social categories. Patients’ social positions should, therefore, be considered to understand how the patient-consumer identity is structured by social categories and how they might play a role in the access these patients have to care.

**Access to health services**

Research on different capacities to act as a (patient-)consumer is still limited. Some authors refer to different capacities, but such statements often conclude an article rather than start it (Fotaki, 2006; Gabriel et al., 2015), or they portray these differences as an individualized disability (Karpen, Bove, & Lukas, 2012). Outside of the management journals, in the wider social sciences, Fotaki (2010a) probably provides the most comprehensive overview of inequality in patients’ access to care. Her argument is located in debates around choice in healthcare, as she argues that a focus on choice might actually increase inequality, particularly when it comes to choosing specific healthcare professionals. In other words, patients who are not able to express their own interests, but who are confused, scared or too sick, are in danger of being left behind (Tonkens, 2008, p. 8). Fotaki (2006, 2010a) draws together different theoretical lenses, such as psychoanalysis, Bourdieu’s work on capital, and economics, to make the point that more choice does not necessarily contribute to more equality. She calls for more research into the linkages between choice and inequality. I contribute to this debate by zooming out to the patient-consumer identity (going beyond just the aspect of choice) and taking an intersectional approach to develop an analysis of the multiple and intersecting social categories that create inequality in access to care provided to patient-consumers.

**An intersectional approach to patient-consumers**

In this section, I introduce the concept of intersectionality to my analysis of the patient-consumer identity. Work on intersectionality originated in feminist (legal) research, in response to a tendency of feminist scholarship to focus on white middle and upper class women (Collins, 1998; Crenshaw, 1989). The concept of intersectionality has become a powerful tool to understand people’s different experiences based on multiple social categories such as gender, ethnicity, class, and sexuality (Atewologun & Singh, 2010; Cho et al., 2013; Crenshaw, 1989; Essers et al., 2013; McCall, 2001; Rodriguez, Holvino, Fletcher, & Nkomo, 2016; Verloo, 2013). Intersectionality scholars argue that social categories are not distinct but “always permeated by other categories, fluid and changing, always in the process of creating and being created by dynamics of power” (Cho et al., 2013, p. 797). A woman, therefore, is not just defined by her gender, but simultaneously also by her age, ethnicity, sexual orientation, class et cetera. In different contexts, different constellations of these categories become prominent, making it possible to adopt a fluid take on how individuals define themselves and are defined in a particular situation. More importantly, an intersectional approach to examining individuals allows for understanding
how the multiple, intersecting social categories produce structural inequalities (Cho et al., 2013; Verloo, 2013; Yuval-Davis, 2006).

By bringing in this literature, I can build a better framework to understand the identity of the patient-consumer and unequal access to care that may result from it. Therefore, I contend that an intersectional approach lends itself well for an analysis of power processes in the positioning of patients as consumers. Patients who are using a new technology to communicate, such as the POHC, are not just defined by their health status but by multiple intersecting categories (e.g., their gender, ethnicity, and class) that inform their position in care provision. I bring out the relevant, multiple social categories that remain hidden within the current ‘single-axis approach’ to understanding the patient-consumer. I develop an intersectional approach to the analysis of the patient-consumer that paints a more complex picture, especially with regard to the unequal access to this care provision.

METHODS

Data collection
My data collection revolved around personal online health communities (POHCs) set up by ParkinsonNet, an organization in the Netherlands that offers a range of programs to improve the quality of life for patients with Parkinson’s disease. I conducted interviews with patients (N=18) and healthcare professionals (N=13). The patients were part of a pilot project (called ‘MyP@rkinsonCare’) which assisted patients in setting up a POHC by financially supporting a Parkinson’s nurse practitioner that helped patients with any technological difficulties they might have encountered. When data collection started, about 100 patients were officially enrolled in the project, of which I interviewed 18 patients. I gained access to the interviewees through the nurse practitioners and specifically asked them for names of patients who were actively using the communities. These active users were most relevant for my research project since I wanted to gain information on how these POHCs are actually used, rather than reasons for why they are (not) used. From these 18 patients, I then selected five patients with a large number of healthcare professionals involved in their POHC. This led me to approach 19 healthcare professionals of which I ended up interviewing 13. The six remaining healthcare professionals declined an interview because of time restrictions.

The interviews with patients were all conducted face-to-face in the patients’ own homes. In a small number of cases a partner (and in one case even grandchildren) were present in the room where the interview took place. The interviews with patients lasted between 45 and 90 minutes, with an average of about 60 minutes. Healthcare professionals were interviewed in their own surroundings, being their office or a (consultation) room in a hospital. Five interviews were conducted over the phone at the request of these healthcare professionals. Interviews with healthcare professionals lasted between 15 and 66 minutes, with an average of about 34 minutes. This broad range in interview times is caused by the different communication methods used (i.e., telephone versus face-to-face). All interviews were transcribed verbatim and analyzed using the ATLAS.ti software package.

During the interviews specific questions about the patients’ roles on the communities were asked, but the word ‘consumer’ was never used. The data used and analyzed in this chapter, therefore, were not part of a pre-existing interest in patient-consumers, but the topic arose out of a first analysis of the data, conducted with a team of researchers.

Data analysis
After this idea to focus on patient-consumers was established, I went back to the data and used guiding questions such as: can every patient act as a consumer; who might have (or be ascribed) the technological, intellectual, and social skills to take on the active role regarding their care required by consumerization, and how are inequalities (re)produced in the way my interviewees talk about these skills?

I identified quotes that answered these questions and then analyzed them using the literature on intersectionality. This intersectional perspective helped to sensitize me to how certain quotes contained subtle references to social categories, but it is by no means an easy task to use intersectionality for
the analysis of interview data. As McCall (2005) has stated, there are different approaches to using intersectionality as an ‘analytical sensibility’ guiding your research. These different approaches use and deconstruct social categories in different ways. I follow her suggestion of taking a strategic approach to using these social categories: I understand social categories to be fluid and changing, but believe it is necessary to ‘provisionally adopt’ (McCall, 2005) them to understand the material effects these categories have in a society that tends to treat these categories as a stable given. In McCall’s words, such a ‘provisional adoption’ of these categories is necessary to ultimately speak to the inequalities they cause among social groups. Therefore, in my intersectional approach I focused on “what intersectionality does, rather than what intersectionality is” (Cho et al., 2013, p. 795).

An intersectional analysis of the quotes that answered my guiding questions allowed me to see the social categories behind the description of who can take on an active role. Using a focus on what was said and what was not said (Fairclough, 1992; Hardy & Clegg, 2006), I analyzed the deeper (inequality producing) layers underneath the superficial text produced in the interview. I will build my analysis in a number of steps. First, I will show that interviewees identify differences between groups of patients who use POHCs. Then, I will analyze how these differences are constructed, on what symbolic representations the interviewees draw, and what social structures are present in their discussions of the POHCs. Through this analysis, I reconstruct the identity of a patient-consumer on the POHCs. Moreover, I emphasize how this identity represents a specific mold of a patient, one that not all patients fit or feel comfortable with. I will focus on how this, in turn, limits patients’ access to care provided under the guise of patient-consumers.

Moreover, I saw the interview text as created in interaction with the interviewer. Therefore, the text produced is an effect of the similarities and differences in social categories between interviewee and interviewer. The interviewer (the first author) identified as a young woman in the early stages of her academic career. Her middle class and Dutch background also played a role in her interviews with healthcare professionals and patients who were from different class backgrounds (although most healthcare professionals were middle and upper middle class), but who all grew up in the Netherlands. Most of the patients fell into the middle class category, although two of them could be identified as working class. In general, though, all patients interviewed could be regarded as relatively privileged; since they already had demonstrated the skills to be able to use the POHCs and were able to reflect on their own position. These privileged positions (and the fact that the interviewer also held a privileged position) made it easier to conduct the interview, because of a shared knowledge and language, especially around the use of technology.

RESULTS

Making the difference
Innovations in the healthcare sector often carry some aspect of patient-consumer thinking as they are generally aimed at increased involvement of the patient. Finn (an occupational therapist) talks about how the POHCs position patients:

What I like is that, through the community, you can put more responsibility on the patient. She [a specific patient] asked me something, but it was for the neurologist. [so I said] “Why don’t you ask that through the POHC to your own neurologist?” In the past, I felt the urge to go directly to him; “ok, I’ll make a call to discuss the problem”. So, I just think that for the people, you actually put more responsibility with the patient.

Finn, occupational therapist (m)

As Finn describes how the patient can take over some of the care responsibilities from him as a healthcare professional, he implicitly suggests that the POHCs help to position the patient as consumers who are actively involved in their own care. On the POHCs, patients can take the initiative to contact their healthcare professionals, bring them together in one conversation, and request answers to questions they identify themselves as important. The healthcare professional no longer has to act as a messenger between patient and neurologist, and instead,
Power to the Patient?

patients are expected to know which questions are meant for which healthcare professionals and to ask those questions directly to them.

With the illustration of the construction of the patient-consumer on the POHCs, I continue with answering my main analytical question which is if every patient can act as a consumer in the same way. Although the POHCs are positioned as a neutral technology, Will (a neurologist) provides a first indication that the technology is used differently by different patients:

[in the current version of the POHCs] the patient is free to decide on the content of their community and to manage their treatment plan, to put it that way. They just can’t do that. That’s already difficult for us, to really decide what the important aspects are of the treatment for this or that patient. And they just can’t really oversee that [...] It would already be nice if you have a bit of a separation, I am just coming up with this right now, a separation in this. Because for one part of the people, you should just make it easy. They won’t coordinate their whole treatment plan, but they should be helped with addressing those things that they think are important and then having an easy way of communicating. Like, bam! Log in like that and then just a couple of taps on the keys. And other people can easily, like that woman who has a lot of her own ideas about how it should be, she wants to be able to communicate about this, she wants to lay out her ideas. And there I should give her the means, so that she can do that even better. And then a third of Parkinson patients, I think the group is about that big, can in such a way easily manage his own treatment.

Will, neurologist (m)

Will describes the distinction that can and, in his opinion, should be made between different types of patients. This distinction is positioned as fact: some patients “just” cannot take an active role in care provision. In his description of the patients who might be less able to work with the unstructured version of the POHC, he constantly links their use of the POHC to things that they “cannot” or “will not” do, whereas when he talks about the more active patients, he emphasizes what they “want” to do. These active patients are, therefore, linked to their needs and desires, whereas the other patients become associated with their inabilities. Here, I see the first traces of unequal access to care as those patients who are active appear to be better heared when they express their desires, whereas those who are less active or disabled seem to be hindered in the expression of needs and desires to the point that their needs and desires disappear from the neurologist’s view, and what are left are their inabilities. This quote also shows the first signs of differentiations made according to gender. Although Will provides an example of a woman who is active and able in terms of using the POHC, he ends his quote with masculinizing the group of active and able group of patients by using the male pronoun ‘his’. To further tease out these constructed differences in abilities, I delve deeper into the ascribed characteristics of the patient-consumer on the POHC.

Communication

As my interviewees show, an important characteristic of the patient-consumer is to be able to communicate well with one’s healthcare professionals:

Some are also a lot more articulate on paper than others. And, well, I don’t really have issues with that. I can write down my thoughts, my opinions quite easily. Because you’re used to that, from your work. But not everyone has that.

Howard, patient (m, 75)

Yes, she [a patient] is also able to do it [work with POHC]. I think that’s also because of her strength in communicating. She is also not too scared to write about things while others have to really think about it.

Diane, rehabilitation specialist (w)

But, it comes down to the initiative patients take. I also know people that don’t even dare to say anything. Just take everything without questioning.

Peter, patient (m, 71)

Howard (a patient) describes the importance of his capacity to write down his thoughts. Being able to express what is on your mind in a way that is comprehensible for others is something that he has learned through his work
(he is a retired municipality official). But Howard also acknowledges that not everyone has this same background. Diane (a rehabilitation specialist) in turn, describes strength in communicating in terms of (an absence of) fear; patient-consumers are not afraid to speak (or write) their mind. Similarly, Peter (another patient) talks about daring to talk, but describes this in terms of taking initiative. He argues that some people are afraid to say or question some things. The way these interviewees speak about these different abilities suggests that these abilities are determined by personality or past life experiences. This reflects a highly individualized explanation.

In contrast, my intersectional approach allows me to know (and show) that communication skills are not just a characteristic of one’s personality, but also strongly structurally assigned to certain groups of people. As Howard already mentions, he learned his communication skills at work. Working, and the job rank you end up in, is regulated by social categories of which class, gender, and race are important ones. Therefore, the fact that one knows how to write down one’s thoughts is learned and structured by one’s social position.

In the next paragraphs, I will further develop how a certain social background helps patients and healthcare professionals to better understand and hear each other.

An important aspect of speaking the right language is ‘knowing the vocabulary’. As Robyn (a physical therapist) describes below:

[It: you just said that some patients have an easier time articulating. What are…] […] I may not be able to say this, but those are often also the higher educated. [It: how does education play a role?] Well, understanding foreign concepts. That you know how your body functions. Yes, that… lower educated just don’t possess those communication techniques.

Robyn, physical therapist (w)

Robyn describes how being articulate when conversing with your healthcare professionals entails understanding the concepts that are part of medical language. In her discussion, she explicitly refers to the importance of education in knowing such concepts. However, she also shows hesitance in being this explicit about the role of education as she states that this is something she “may not be able to say […], but…”. Her choice of words shows that she is aware of the sensitive nature of linking patients’ abilities to be a patient-consumer to something like educational background.

Robyn’s hesitance to discuss the educational background is more easily understood when you link it to the term of class. Class is a concept that is associated with structural factors and lays bare the structural inequalities that the concept of educational background hides (Lareau, 2003). In the concept of class, the idea of transferring and teaching of skills from generation to generation is much more present. These skills, masked by ‘education’, are not individually achieved, but structurally assigned to certain groups and not to others (Gill, 2014). Bringing in this concept of class, therefore, reveals the structural inequalities embedded in, and reproduced by, the constructed patient-consumer identity; only those patients who have the ‘right’ class background, and therefore, the communications skills, fit the identity of the patient-consumer and benefit from its advantages.

But even when patients do speak, they might not be heard in the same way as others, as Louis (a Parkinson’s nurse) evidences:

[It: do you feel that there any topics that are appropriate or inappropriate to discuss on the POHCs?] she [talking about a particular woman patient] also has a lot, from her diary, like “today I feel like this and today I feel like that”; […] Some psycho-social problems are also discussed, in the diaries, at least by the ladies. The ladies make use of those […] and if you then also transport it to the meeting space… that is mostly the case with Jackie, and sometimes also with Marissa. And also with Elsabeth. But not so much with the others, in the diary, with psycho-social problems. Those [psycho-social issues] are mostly with the ladies, not so much with the gentlemen. I believe, I’m not actually sure […] If you look at Bishop [last name man patient], with his diary, he has all sorts of “I feel”. Is also more practical: “I have biked and had a good week”. Also all practically oriented.

Louis, Parkinson’s nurse (m)

In terms of communication, Louis identifies a difference between men and women. He links women’s use of the diary to discussions of psychosocial issues
(i.e., emotions), describing their statements as "today I feel like this". When he links that to "transporting it to the meeting space", he suggests that mentioning psychosocial issues becomes more appropriate when it is linked to a discussion in the meeting space. In other words, just a simple description of those issues is less useful compared to linking it to a specific (practical) question. He argues that this mentioning of psychosocial issues is mostly done by 'the ladies'. 'The gentlemen' also sometimes talk about how they feel but the nurse immediately follows this up by stating that their postings are also more practically oriented.

His description of the use of the POHCs by men and women draws heavily on gendered stereotypes around expression of emotions. Women's postings are linked to emotions, whereas men's postings are discussed in terms of practical orientation. However, when the nurse continues, he gives an example of one of the men's postings including a reference to 'having had a good week', arguably another example of the discussion of emotions or psychosocial issues. The nurse himself does not frame this as emotional content, and instead casts it as more practical (Bishop's diary is "also all practical") and more relevant for healthcare professionals to read about. Women's use of the POHCs is, therefore, cast in a different light and might be regarded differently by healthcare professionals. These constructed differences can have an impact on the access to care that women and men gain, as their questions and comments are interpreted in gendered ways, affecting how they are responded to and, ultimately, treated.

The way Louis distinguishes between men and women is fraught with hesitations, again indicating that healthcare professionals feel discomfort when differentiating between patients on the basis of social categories such as gender. By bringing in both gender and class, I show that communication is structured by social categories that ultimately impact access to care that patients from different social positions get, as a result of this emphasis on patients as consumers. Below, I bring in additional patients and healthcare professionals who help to further complicate the patient-consumer identity.

Cognitive functions
A known symptom of Parkinson's disease is diminishing cognitive functions. Grace (a Parkinson's nurse) discusses how this affects patients’ judgment regarding their health:

*Very many patients become a bit cognitively impaired. Because of that, the insight into themselves [deteriorates], which is why the moment they ask for help, is maybe sometimes not really judged right.*

Grace, Parkinson’s nurse (w)

This Parkinson’s nurse argues that cognitive impairments affect patients’ insight into themselves and their ability to ask for help at the right time. From the patients’ view, the effect of changing cognitive abilities is, in some cases, also acknowledged:

*Because of that Parkinson’s you are pretty heavily impacted. Also in thinking. Finding of words. In the past I spoke to people, now they speak to me [laughs].*  

Peter, patient (m, 71)

The way Peter (an aforementioned patient) describes his cognitive functions, shows how the fact that his thinking and speaking process has changed, has had far-reaching consequences: he no longer speaks to people, people speak to him. In Parkinson’s disease, changing cognitive functions are a rather common symptom and one that increasingly impacts patients while their disease progresses as they grow older. For being a patient-consumer, such cognitive functions are highly necessary because one of the core concepts of this identity is that you speak to people. Peter’s self-identified difficulties with finding words (something that did not seem to bother him while speaking during the interview), have the effect of others no longer approaching him in the same way as before.

Here, I see that these diminishing cognitive functions become a form of disability. Disability, seen as a social category and intersecting with that of aging in general, is tied to a cultural meaning of lack and decline (Thomas, Hardy, Cutcher, & Ainsworth, 2014). For example, being increasingly disabled comes with expectations that others might have about your functioning (Jammaers, Zanoni, & Hardonk, 2016). Having difficulties with finding your words can cause
others to expect you to have less demands and, therefore, be less able to use the POHC as a patient-consumer. Since the technology does not acknowledge, let alone provide any support for, diminishing cognitive functions, inequalities are (re)produced between differently able patients. These inequalities present themselves in terms of the access that patients get to care provided through the POHC: lower expectations around those patients with diminishing cognitive functions will affect how they are approached by their healthcare professionals and will affect their care provision.

**Technological skills**

Next to the communication skills and cognitive functions patients need to possess to be a patient-consumer, the POHCs also require specific technological skills. As the POHCs are accessed through a website, patients need to have a computer and some ability to work with it. As Alicia (a Parkinson’s nurse) describes below, this is not possible for everyone:

> This is too complicated, especially for patients with Parkinson’s, too many actions to get somewhere. And I think that 10 years from now, we’ll have a very different population. So people who already know a lot more about computers. I think that the 60 year-olds, the 70 year-olds, a lot can work a bit with the computer, but a lot also can’t. And that is currently an issue.

*Alicia, Parkinson's nurse (w)*

Alicia explains that these patients with Parkinson’s disease might have a difficult time using the technology, both because of their cognitive disabilities and their age. This quote shows how age (which, as Alicia constructs, is mostly generational) intersects with cognitive (dis)ability to affect how Parkinson's patients' use the POHC. She argues that the fact that they are from a generation that is not used to using computers adds to the disabilities that Parkinson's patients experience.

Similar to the earlier quotes under the heading of cognitive functions, here, I again witness a construction of those who are older and disabled that is based on stereotypical ideas surrounding these social categories (Thomas et al., 2014). Because of the expected lack of skills and decline of functions, only those patients who do not experience the advanced cognitive impairments associated with Parkinson’s disease, and who are good with computers despite of their age, are expected to successfully use the POHC and, therefore, fit the constructed identity of a patient-consumer.

However, it is not just age and disability that play a role in having or not having the right technological skills, as Will, the neurologist, discusses:

> I haven’t made a stratification of this, but my feeling is that it’s a relatively high educated group. And for younger people it’s less of an issue, because they are all used to doing things with computer. But then, when you look at beyond 60, then it’s I think almost all higher educated [patients]. [...] I fear that with this older group, men are also better with computers than women. Because women have never done that, never learned it, so that will probably be connected. Men have often worked a bit with computer in their job. And that way, they learned it [...]. That’s how they know what a computer is, and they have continued working with them. And the women, some of them have, because sometimes you also have relatively well educated women, who email and chat with people around the world.

*Will, neurologist (m)*

According to Will, having enjoyed higher education is important for using the POHCs, because this impacts one’s technological skills, especially older patients. The group of younger people (as Alicia also mentioned) are more used to working with computers and, for them, Will believes that the effect of educational background will be smaller. Technological skills are based on class, since (as I argued before), work experience itself is classed. In Will’s quotes, we can see that technological skills are also constructed in intersection with gender and age, as well as disability as Alicia mentioned. The neurologist reasons that because of the lack of work experience, older women have not gained the necessary technological skills. According to Will, only those women who are “relatively” well-educated might be able to use a computer, and, therefore, a
POHC. Interestingly, he says he “fears” older men are better at working with computers than older women. This falls in line with the pattern of displayed discomfort with articulating differences between groups of patients that I have identified with earlier interviewees as well. I will further deconstruct this discomfort in my discussion section.

Together, the interviewees position the patients with the right communication skills, with lasting cognitive functions and technological skills as best able to work with the POHCs. Therefore, the patient-consumer identity constructed through the POHCs by the interviewees, seems to revolve around these three characteristics. However, the intersectional analysis I conducted on these interviews coupled these categories with social categories, which shows that the patient-consumer identity is regulated through structural factors to create a limited mold for who fits the patient-consumer identity. As the interviewees show, intersections of social categories create specific positions for patients working with POHCs. At the intersection of the social categories of disability, class, age, and gender; older women, cognitively disabled and of a lower class background seem to be the farthest removed from the identity of the patient-consumer, compared to other groups defined by different constellations of these social categories. Comparing the quotes of the interviewees, I find that discussions of why some patients are more able to work with the POHCs, are based on stereotypical perceptions of certain social groups (e.g., women being more emotional or people who are lower-educated not knowing the right language), whereas other discussions focus on ‘factual’ barriers (e.g., deteriorating cognitive functions and not knowing how to work with a computer). Both of these mechanisms create inequality in access to care among patients, but the way stereotypes and factual barriers should be addressed differs. In the next section, I will go into further detail about the created inequality and the dangers it presents for the healthcare sector.

DISCUSSION

With this chapter, I set out to develop a more in-depth understanding of a current trend toward positioning individuals as consumers. Although the idea of consumerization has been critically examined within the wider Critical Management Studies (Gabriel, 2015; Gabriel et al., 2015; Nyberg, Spicer, & Wright, 2013; Osborne & Strokosch, 2013; Tuck, 2013; Ureta, 2013), this criticism has tended to focus on the access organizations gain to consumers and the increasing ways of exploitation and control they receive through promoting co-creation of value (Arnould & Cayla, 2015; Fontenelle, 2015; Gabriel et al., 2015). Such critical examinations have not yet drawn attention to the different capacities of individuals with regard to being positioned as a consumer. In other words, although these constructed consumer identities superficially seem in reach for all individuals, I add an understanding of the inequalities, based on social categories, embedded in these constructed identities. To bring out these inequalities, I have contributed an intersectional study of the patient-consumer identity.

The empirical basis for this contribution was the analysis of patients being positioned as consumers as they use a new communication technology, referred to as POHCs. The patient-consumer identity constructed through the POHC is one where patients play an active role, ask questions, and give updates. However, the demands that come with these activities, such as communicating the right kind of content (i.e., not just emotions) are not within reach for all patients. As I have seen, interviewees often refer to these differences in benign terms (e.g., communication skills), silencing the structural inequalities behind the divisions they make. These tendencies to individualize reflect larger societal conversations where patients are judged on their so-called ‘health literacy’ (Commission on Social Determinants of Health, 2007; Rademakers, 2014). This term presents the abilities one needs to be actively involved as something that can be taught in a lesson, much like you have programs to teach people to read. Using the term ‘health literacy’, instead of the social categories it silences, hides the political and structural nature of the inequality produced through positioning patients as consumers (Calás, Ou, & Smircich, 2013; Garland & Darcy, 2009). With this chapter, I go beyond a critical analysis of patient-consumers through the aforementioned lens of exploitation and control, by unpacking the assumed universal capacity to access care provided to patient-consumers. Rather, I use an
intersectional lens to extend my understanding of the power processes involved in consumerization, showing how inequalities to access are (re)produced.

Although I have focused on the healthcare sector and patients in particular, the intersectional approach that I contribute can be applied to understand inequalities in other sectors as well (e.g., public transportation or a Department of Labor and its unemployment benefits service). POHCs, and other innovations that try to position individuals as consumers, only reach the 'low-hanging fruit', being the relatively privileged people. As a result, this strategy of targeting the 'within-reach' individuals, works to exclude certain groups of social categories, and, therefore, is a potentially dangerous strategy for increasing the quality of care or service provision. Because there often is an absence of recognition of the political nature of these exclusionary practices (Calás et al., 2013; Garland & Darcy, 2009), the dominance of consumerization processes becomes part of the 'systemic dynamics of power' through which already existing inequalities and privileges become further institutionalized (Rodriguez et al., 2016, p. 202).

Silences
Theorizing further from my analysis, I want to bring in a discussion of what was not said. Throughout my results section, there were a number of moments where interviewees showed hesitation about being explicit with regard to certain differences between patients. For example, Will used the words "I fear" and Robyn mentioned "I may not be able to say this". These hesitations speak to the discomfort of discussing these differences. The awkwardness the interviewees display surrounding the explicit mention of these differences highlights that normally these aspects are silenced. Silence, as a theoretical concept, has been linked to intersectionality before (Tuori, 2014), and is helpful to understand why interviewees talk about a certain subject without mentioning other aspects that are associated with this topic. These silences draw our attention to the fact that inequalities are hardly ever discussed, especially when they are produced through social backgrounds over which people have very little control.

Moreover, focusing on silences illuminates which social categories and inequalities are openly talked about, where others are (consciously) hidden (Simpson & Lewis, 2005; Tuori, 2014). One of these categories that is completely silenced is ethnicity and/or race: the fact that all patients and healthcare professionals in my sample are native Dutch speakers, sharing a cultural background within the Netherlands. A shared (majority) background affords cultural privileges, as internalized norms around care provision (e.g., who makes decisions, who takes the lead, or what expertise is valued) are easier to navigate when both healthcare professional and patient share the same cultural background. However, these privileges were not acknowledged and were simply taken for granted. As an effect of the silencing of the importance of ethnicity and race (and their intersections with class), the experiences of the users who were all white native Dutch speakers seem to stand for all experiences, silencing the different experiences Dutch people of color might have with being positioned as patient-consumers.

The patient-consumer identity in a wider context
I started this chapter with describing the wider societal processes that led to positioning patients as consumers. I close this chapter with discussing what my findings mean in relation to these larger societal processes. More specifically, the case of POHCs connects to an increasing emphasis on self-management in healthcare provision, aiming at making patients more ‘literate’ regarding their health (Rademakers, 2014). This self-management ideal is partly a response to rising healthcare costs without a sufficient number of younger, working people to financially contribute for adequate welfare provision. Putting patients in charge of part of their own care is one important way of lowering healthcare costs. After all, if a patient can take on some of the care, the healthcare professional does not need to be paid for doing it.

This chapter presents a criticism of the exclusionary practices of care provided under the heading of the patient-consumer, but I also want to briefly reflect on the consequences for those patients that fit the mold relatively well. The small group of patients who fit the patient-consumer identity might have easier access to their healthcare professionals, but also bear a stronger responsibility for managing their own care. This responsibility can be perceived as burdensome by some patients, when they do not feel equipped to take
ownership over decisions regarding their health. This added responsibility is, therefore, another reason to remain critical of consumerization in healthcare and more generally.

Moreover, these exclusionary practices of the patient-consumer identity will become even more significant when financial consequences are linked to this new care provision, which is a likely future scenario. Imagine that insurance companies attach financial compensation or penalties based on a patient’s capacity to take on some of the care. Such financial consequences would affect the affordability of care for these groups identified by disability, class, age, gender, and ethnicity. Such developments would only further ensure the exclusion of more vulnerable people within our societies.

*Future research topics*

Whereas I have talked about capacities here, one might wonder if different patients also have different desires to be positioned as consumers. Previous research has already argued that patients, and clients more generally, differ in their desire for receiving information about their health or other services and their willingness to be involved in decision-making (Joosten, Bloemer, & Hillebrand, 2016; Nordgren, 2010). Bringing this aspect of varying willingness might shed interesting new light on the questions of inequality and power I have asked with this chapter. The incapacity to behave in certain ways might, by some, be seen as a more legitimate reason to resist a patient-consumer position than unwillingness. An interesting analysis might involve the comparison between capacities and desires in terms of how they might both be driven by social categories, but they might not both be understood and accepted in the same way by wider society.

Moreover, continuing along the line of one of my findings, I would be interested in further exploring the aspect of emotions and their expression on the POHCs. As I have seen in my analysis, emotions are more easily linked to women’s experiences; when women discuss how they are doing their experiences are more easily recognized as emotional issues by others. At the same time, emotions, and body language in general, are less easily transferred to the technology of the POHC, because they are no longer physically and visually observable. Absence of extra cues to support the communication of emotional issues might result in further inequalities related to gender in the expression and recognition of emotions. Conducting such a study would deepen our understanding of gender as a social category and its impact on positioning patients (or other individuals) as consumers.
Organized emancipation
Challenging the assumption of emancipation as an exclusively bottom-up affair*

* A previous version of this chapter was presented at the European Group of Organization Studies of 2013 in Montréal, Canada.
In this chapter, I make a contribution to the literature on organizational identities through coining the concept of 'organized emancipation'. Organized emancipation refers to the ways in which identities are regulated at the organizational level with an explicit aspiration of emancipation in mind. Organized emancipation, therefore, challenges the common conceptualization of emancipation as an exclusively bottom-up affair, achieved through individual identity work. I make this contribution in the context of healthcare and the emancipation of patients by answering the question of how organized emancipation affects the identity work of patients. Through analyzing interviews and observations of online communities, I contend that in emancipatory contexts, where individuals are encouraged, but left to their own devices to become emancipated, the idea of emancipation moves away from a 'right' that individuals possess to a 'duty' that they themselves are made partly responsible for. The identity work in this context entails a complex web of practices where especially the responsibility for this emancipation becomes a space for contestation.

INTRODUCTION

Research on organizational identities is flourishing and multiple organizational journals have devoted special issues to this topic in the last decade (Alvesson et al., 2008; Ybema et al., 2009). Based on a Foucauldian framework of subjectivity, many scholars see identities as a site for power processes in organizations (Brown & Coupland, 2015; Clarke et al., 2009; Jammaers et al., 2016; Zanoni & Janssens, 2007). In this scholarship on organizational identities, a framework examining identity regulation on the one hand, and individual identity work on the other hand is often present (Alvesson & Willmott, 2002; Brown & Coupland, 2015; Essers et al., 2013; Laine & Vaara, 2007). Identity regulation is portrayed as a way in which organizations can control their organizational members. These organizations members, in turn conduct individual identity work that either complies with or resists organizational control. Whereas compliance is conceptualized as disciplining, resisting identity work is seen as (micro-) emancipatory (Alvesson & Willmott, 2002; Zanoni & Janssens, 2007).

Therefore, emancipation is commonly conceptualized as the ways in which individuals resist existing control mechanisms through bottom-up identity work (Ainsworth & Hardy, 2009; Essers et al., 2013; Rumens & Kerfoot, 2009).

This division between control in the organizational realm and emancipation in the individual realm can be conceptually restricting, especially if we want to understand emancipation as a possible goal of an organization, and, thus take it out of its sole existence in bottom-up activities. Recently, increasing recognition has come for the role organizations can play in emancipatory practices (Huault, Perret, & Spicer, 2014; Ogden, Glaister, & Marginson, 2006). This trend moves emancipation from being a concept overwhelmingly studied as it occurs from the bottom-up, through individualized identity work (Ainsworth & Hardy, 2009; Laine & Vaara, 2007; Zanoni & Janssens, 2007), to something that might be organized top-down to liberate individuals from restricting power processes. These emancipatory contexts are becoming more common as some organizations explicitly work toward ‘humanistic ideals’ (Ezzamel & Willmott, 1998; Gotsi, Andriopoulos, Lewis, & Ingram, 2010; Huault et al., 2014; Ogden et al., 2006). For example, organizing in the creative industry often emphasizes values of self-exploration and the assertion of “an own sense of self”, which is how Huault et al. (2014) define emancipation. To examine such a top-down version of emancipation, I coin the concept of ‘organized emancipation’, to refer to the ways of organizing that regulate identities with an explicit aspiration of emancipation in mind. However, a critical examination of what organized emancipation does, in turn, to the (emancipatory) identity work of individuals engaging with this organized emancipation forms an underexplored avenue for research.

With this chapter, I coin the concept of ‘organized emancipation’ to contribute to the literature on identity constructions in organizing. In coining this concept, I specifically focus on identity work in changing or conflicting environments (Beech et al., 2016; Clarke et al., 2009; Rosenthal, 2004). Part of this literature shows that identity work can be inherently unstable and that some organizational members embrace this instability rather than try to solve it (Beech et al., 2016). I contribute a better understanding of identity work and emancipation in contexts where emancipation is not just an individual
I make this contribution in the context of healthcare. The subject of emancipation is a large part of current conversations around how to better organize healthcare (Fotaki, 2006). A stronger role for patients, through emancipating them, is advocated by academics and practitioners alike (Berwick, 2009; Davies, 2012). Oftentimes, these emancipatory efforts are coupled with a technological innovation, stemming from the idea that implementing new technologies will improve the way care is provided (Schwamm, 2014). I examine one of those innovations, namely a communication technology in the form of so-called personal online health communities (POHCs). Chronically ill patients can interact online with their own healthcare professionals on these communities. The POHCs are designed to give patients easier access to their healthcare professionals, no longer bound by the time, space, and gatekeeper restrictions that existed before. Previously, a patient would have gone through the process of contacting a secretary, setting up an appointment, and ultimately talking to a healthcare professional over the phone or face-to-face, at a time that was convenient for both. POHCs are a way to organize emancipation through taking these restrictions away and by increasing patients’ information about and say in their treatment (Pagliari et al., 2007; ParkinsonNet, 2012).

To examine this context, I ask the following research question: how does organized emancipation affect the identity work of patients? On the basis of my empirical data, I demonstrate that the idea of emancipation moves away from a ‘right’ that individuals possess to a ‘duty’ that they themselves are made partly responsible for: Whereas before this right was solely in the hands of the individual, this duty to emancipate is shared with the organization, constituting an ambiguous environment for emancipated identities to be constructed. I contend that identity regulation through organized emancipation in its (reciprocal) relation to identity work entails a complex web of practices where especially the responsibility for this emancipation becomes a space for contestation.

In the following sections, I discuss the theoretical background that I draw on and contribute to. Thereafter, I present detailed information about the POHCs. I explain my methods of data collection (in-depth interviews with patients and observations of POHCs) and analysis (critical discourse analysis). In the final sections I display my analyses and discuss their broader theoretical and practical implications.

THEORETICAL BACKGROUND

Identity regulation and identity work
Organizational identities have been looked at in relation to a wide variety of actors, ranging from a more standard type of organizational members such as managers (Golant, Sillince, Harvey, & Maclean, 2015; Thomas & Davies, 2005) to individuals that find themselves further removed from the core of organizational processes such as unemployed workers (Ainsworth & Hardy, 2009) and consumers (Nayak & Beckett, 2008). Organizational identities have also been examined in a wide variety of contexts such as engineering, banking or law firms (Clarke et al., 2009; Laine & Vaara, 2007; Mangen & Brivot, 2015) but also more atypical contexts such as the creative industries (Beech et al., 2016; Gotsi et al., 2010). Many studies on organizational identities draw upon Alvesson and Willmott’s (2002) model that relates identity regulation, identity work, and self-identity (e.g., Ainsworth & Hardy, 2009; Brown & Coupland, 2015; Essers et al., 2013; Gotsi et al., 2010; Watson, 2008; Zanoni & Janssens, 2007). In this model, a distinction is made between identity regulation at the organizational level and identity work at the individual level (Ybema et al., 2009). Identity regulation involves all organizational and social practices through which organizations control individuals by setting standards for appropriate behavior. Conducted both through discursive and material ways, identity regulation, therefore, plays a large role in organizational power processes (Alvesson & Willmott, 2002; Zanoni & Janssens, 2007). Identity work, on the other hand, is defined by the active participation of individuals in “forming, repairing, maintaining, strengthening or revising [identities]” (Alvesson et al., 2008, p. 626). Certain events, like changes in the regulatory environment that make individuals aware of their self-identity, can trigger identity work (Alvesson et al., 2008).
Identity work in changing environments

Identity work is considered an ongoing process to maintain one’s identity (Golant et al., 2015; Ybema et al., 2009). However, in changing environments identity work might lose some of its coherence and stability and this topic has recently become a popular area of investigation (Beech, 2011; Golant et al., 2015; Mangen & Brivot, 2015). Golant et al. (2015) discuss how organizational identities change but remain stable at the same time. Focusing specifically on leaders’ identity work, they examine how organizational changes force leaders to adapt their identities to the new situation while simultaneously remaining coherent in relation to the past in a satisfying way. Such (forced) ‘identity maintenance’ can also be an opportunity: when the organizational identity is threatened, new possibilities for identity work arise in terms of constructing a more desirable identity (Brown & Coupland, 2015). Identity work, conceived of as such, presents a way to repair and adjust one’s self-identity in a changing context, in order to restore a sense of coherence.

At the same time, identity work can also provide an impetus for change, reversing the relationship between identity work and changing environments. This reversal challenges the assumption that identity work is mostly geared toward constructing a coherent sense of self (Beech et al., 2016; Clarke et al., 2009). Conflicting discourses might be drawn upon as managers continually attempt to construct themselves as ‘moral beings’ (Clarke et al., 2009). Individuals might even embrace this conflict and incoherence in their identity work; Beech et al. (2016) recently expanded on this subject, arguing that identity work does not always start from a desire to feel coherent. These authors examined musicians’ identity work, showing how it consists of continuous practices where ambiguity is central to their understanding of themselves. They conclude that “self-questioning was ongoing and unresolved; it was not a means to an end; it was an end in itself” (Beech et al., 2016, p. 519). Using this conceptualization of ambiguity as central to individuals’ identity work, we can ask how such an understanding of identity work relates to the context of organized emancipation. I will start building this conceptualization in the next section.

Introducing organized emancipation

Huault et al. (2014) define the concept of emancipation as “how employees seek to assert their own sense of self, worth and dignity” (p. 43). As such, this concept of emancipation is strongly tied to individuals’ resisting identity work. For example, Rosenthal (2004) shows how individuals, at times, can manipulate organizational regulation through their individualized emancipatory identity work. Alvesson and Willmott’s (1992) definition of emancipation as “the process through which individuals and groups become freed from repressive social and ideological conditions” (p. 432) leaves more space for actors who create this emancipatory potential. However, empirically, we know little of organizations’ potential for creating emancipation beyond this emancipatory resistance of individuals against organizational control.

The limited research that exists on emancipation at the organizational level has focused on how, when organizations try to create less hierarchical contexts, privileged organizational members resist their expected loss of hierarchical status through their professional identity constructions (Mangen & Brivot, 2015). This research, therefore, focuses more on the resistance to organized emancipation than what it does to the identity work of those individuals the organization tries to emancipate. Other scholars have argued that organizations saying they promote ‘emancipation’ need to be examined in light of neoliberalist ideals (Fleming & Sturdy, 2009). Emancipatory discourses might merely mask new forms of organizational control, ultimately aimed at further tying individuals to organizations to increase profit (Ezzamel & Willmott, 1998; Fleming & Sturdy, 2009; Fotaki, 2006). Such critical reflection on emancipation is warranted, but might simultaneously too easily dismiss an in-depth examination of the potentially disruptive effects that organized emancipation can have.

In an examination outside of a strict organizational setting, Case and Hunter (2014) show that an organized intervention aimed at at-risk youth created a counterspace in which these individuals could construct an emerging, more positive identity. Looking at such spaces specifically from the concept of ‘organized emancipation’, we can further explore what happens to identity work when emancipation is actively encouraged by organizations. In other words, based on a definition of identity regulation as “strategies aimed at influencing
identity work in directions that support organization goals” (Gotsi et al., 2010, p. 784), we can ask what if those organizational goals consist of emancipating their organizational members? If organizations become part of emancipatory movements, does this upset the dynamic between organizational regulation and individual identity work? The current literature does not provide satisfying answers to those questions, yet.

Turning specifically to the case of patients, recent conversations in the healthcare literature have emphasized the need for patient-centered care, where patients are emancipated to gain a larger role in the care provision process (Berwick, 2009; Davies, 2012). In implementing technology to aid such emancipation, patients’ emancipation is organized top-down. Patients are therefore regulated by an explicitly emancipatory agenda, and have to conduct their own identity work in this changing environment. As emancipation is no longer solely up to the individual patient, we suggest that the idea of emancipation becomes more ambiguous, potentially leading to the exacerbation of conflicts and tensions in individuals’ (ambiguous) identity work.

**METHODS**

In this chapter, I draw on data from 18 patients with Parkinson’s disease using a POHC. The criterion for selection was the frequency with which they used their community. By focusing on frequent users, I ensure that I have enough data to analyze patients’ identity work regulated through POHCs. The 18 patients were selected from a larger sample of over one hundred patients who joined a pilot project set up by ParkinsonNet in the Netherlands from 2011 to 2013. The data collection consisted of conducting in-depth interviews with patients and observing their POHCs. The combination of the two types of data allows me to gain a multisided understanding of patients’ use of their communities. Before the data collection started, my project was screened and approved by the local hospital’s medical ethics committee.

¹ I display excerpts from seven of these patients. See Table 3 for an overview of the characteristics of these seven patients.

Parkinson’s disease and the POHC system

The POHCs used by my sample of patients were set up by the ParkinsonNet foundation. ParkinsonNet aims to improve care for patients with Parkinson’s disease by finding innovative ways to improve the current complex and multidisciplinary care provision process (ParkinsonNet, 2012). Parkinson’s is a neurodegenerative disease and patients are generally treated by a number of healthcare professionals. The neurologist is generally the principal healthcare professional and makes the diagnosis. She or he is in charge of the medication regime, and most patients are on some kind of medication to alleviate the symptoms of Parkinson’s. Other healthcare professionals such as nurses, physical therapists, dietitians, general practitioners, and speech therapists are sometimes involved in care provision. Therapies offered by these healthcare professionals focus on the cognitive and physical exercises and food intake that can help patients deal better with symptoms they experience, such as falling, lack of concentration, and difficulties swallowing.

The technological system of the communities provides patients and healthcare professionals with a menu of options (ParkinsonNet, 2012). These options consist of sections called ‘files’, ‘diary’, ‘meeting’, ‘apps’, ‘problem list’ and ‘team’. The ‘files’ section can be used to upload files, such as a list of medications. Healthcare professionals can also use this section to upload reports on a patient’s wellbeing. The ‘diary’ section allows patients to provide updates on their wellbeing. In the ‘meeting’ section patients or healthcare professionals can start a virtual meeting and invite specific healthcare professionals to participate. Only these invitees will receive an email notification of the start of the meeting. However, the meetings are still openly accessible to anyone who is part of the patient’s team. Those who are not invited are not notified, but can still see and participate in the discussion. The apps section allows patients to install applications into their communities, but no applications have been developed so far. The ‘problem list’ allows patients to provide an overview of their issues. Lastly, the ‘team’ section lists all of the participants in the specific patient’s POHC.

Collecting the data

In this chapter, I combined interviews with seven patients with observations
of their POHCs (see Table 3). I selected these seven patients from the larger sample of 18 patients, because they used their communities intensively and their cases presented the richest data for analyzing identity constructions. For the interviews, I used a topic list, which focuses on how patients experience the use of their POHC, how they experience their relationship with their healthcare professionals, and how they experience their role in the care provision process. Interviews lasted between 45 and 90 minutes, with an average duration of 60 minutes. After each interview, I described my future process of data collection, including observations of the POHC. At this point, I asked all interviewees if they would be willing to participate in those future data collection efforts. All interviewees, with the exception of four, gave me permission to access their POHCs. Some patients stipulated that they would only give access to the POHC for a limited amount of time. These patients stated that they preferred not to be watched constantly, but allowed me access to save the necessary data. The access to the POHCs allowed me to read and be notified of new postings. The names used are aliases to protect the privacy of involved patients.

<table>
<thead>
<tr>
<th>Name</th>
<th>Number of months on the POHCs</th>
<th>Number of healthcare professionals</th>
<th>Number of diary entries</th>
<th>Number of virtual meeting entries</th>
<th>Number of documents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>34</td>
<td>6</td>
<td>6</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Kristina</td>
<td>28</td>
<td>4</td>
<td>22</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Camille</td>
<td>18</td>
<td>4</td>
<td>11</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sarah</td>
<td>31</td>
<td>5</td>
<td>108</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Julia</td>
<td>32</td>
<td>6</td>
<td>33</td>
<td>8</td>
<td>26</td>
</tr>
<tr>
<td>Victor</td>
<td>27</td>
<td>5</td>
<td>4</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Nora</td>
<td>33</td>
<td>5</td>
<td>8</td>
<td>26</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3. Overview of included patients in Chapter 3.

Analyzing the data

I analyzed what patients wrote on their POHC and said during the interviews using a critical discourse analysis approach. Going beyond the superficial content of quotes, I analyzed how patients phrase their accounts in the interviews and on the POHCs. Critical discourse analysis allows for the examination of power processes embedded in use of language by paying close attention to not only what was said (or not said), but also to how what is said is embedded in a certain place and time (Alvesson, 2010). Such an analysis enables me to reflect on how language constitutes patients’ identities and relations with others (Fairclough, 1993). Therefore, I treat the text produced by my interviewees not as a reflection of a stable reality, but as language created in that specific context in relation to the interviewer (Alvesson, 2010).

In coding my data, I looked for normative statements such as phrases that included ‘I should (not)’ or ‘I do (not) want’, implying some sort of (societal) norm in their statement. I also marked sections that included words such as ‘complain’, ‘nagging’, ‘burden’, or ‘responsibility’ which showed how patients were reflecting on their own behavior. Lastly, I coded sections that included words such as ‘already’ and ‘it’s been a while’, as they referenced (the appropriateness of) the frequency of postings. Such phrasing enabled me to understand patients’ identities, both during the interview and on the POHC, and how these responses were embedded in a larger societal context. Furthermore, I analyzed patients’ responses in relation to the materiality of the system of the POHC. This meant studying where patients were posting their comments and questions. Moreover, I studied the design of the different parts of the system, as the placement of the postings was also important in understanding patients’ use of their POHCs, as I will examine in the results section.

Bringing out nuances within the written and spoken text is crucial when conducting critical discourse analysis (Clegg, Courpasson, & Phillips, 2006; Fairclough, 1993; Hardy & Clegg, 2006). The interviews were conducted in Dutch and to preserve these nuances, I analyzed the data in Dutch. Only in the last stages did I translate my text and the analysis to English, to secure an interpretation that is as close to the original text as possible. When translating my excerpts, I focused more on preservation of nuances and underlying meanings than on literal word-for-word translation of the text. I have attempted to convey these meanings as adequately as possible. Any grammatical errors or punctuation are left intact, in an attempt to stay as close to the original text as possible.
RESULTS

In this section I will show patients’ identity work in relation to regulation through the organized emancipation of the POHCs. I have divided my analysis in three themes that link theory and my data, each representing a subject which links to patients’ identity work.

Number of postings

In the sections below I illustrate how the number of postings is a topic that patients explicitly reflect on. Patients show variations in the number of postings in the different locations of their POHCs. Some use their diary to give an update multiple times a week; others only use the virtual meeting space to ask questions. Let me first introduce Adam, who is a 72-year-old married man who used to be in sales, and was diagnosed with Parkinson’s thirteen years ago. He started using his POHC two years ago, and has posted twelve times in the virtual meeting. He uses his diary much less often, only having posted six diary entries.

When asked about the frequency of his postings, he states:

“To me it’s also about not too much... Because if you ask too many questions to... but then they [healthcare professionals] will also think “here’s that nuisance again”

Adam, interview

Adam talks about what the result would be if he makes 'too much' use of his POHC: his healthcare professionals thinking “here’s that nuisance again”. Interestingly, Adam uses the Dutch word ‘lastpost’, which, next to being translated to ‘nuisance’ can be literally translated as ‘source of burden’. This indicates that as a patient you can become a source of burden, and Adam performs identity work to avoid this identification through not posting ‘too much’.

Kristina also discusses the number of postings. She is a 63-year-old married woman with a professional background in homecare, and was diagnosed four and a half years ago. She has been using the POHC for about a year and a half and mainly uses the diary option to keep track of how she is doing. She has posted 13 entries in the virtual meeting space. However, half of these postings were about learning how to use the technology. During the interview she states:

“It has also happened that I had a little question and that I thought “well no, it can also wait”. I shouldn’t always have to have everything... like share my whole story every week... Then Dr. (name neurologist) will also start to think like “oh, that’s her again. Well let’s just put her aside for a while”

Kristina, interview

Kristina describes the question she had as a “little question”. Using this phrasing to categorize her question diminishes the importance and the urgency of her question. The way she approaches the asking of her (‘little’) question, comes with a strong norm, as the word ‘should’ indicates when she states that she “should not always...”. Just like Adam, Kristina describes what a possible consequence would be if she would post every ‘little question’ she has. For her, this consequence exists not only in terms of how she is being judged (“that’s her again”), but also in terms of a more material consequence where she is put “aside for a while”, meaning that she will not receive an answer to her question. This last consequence, which would be the absence of a response from her neurologist, urges her to come up with seemingly paradoxical identity work: to prevent this possible outcome she does not ask the question at all.

When patients discuss the number of postings, they mostly relate this to the activity of asking questions. The POHC system is set up in such a way that when patients ask questions (in the virtual meeting section), they actively approach their healthcare professionals for a response. When patients write in the diary section, healthcare professionals do not receive a notification and generally a response to these messages is not required and/or provided. While writing in their diary, patients are regulated by a different norm than what I have seen so far: informing your healthcare professionals as frequently as possible. I illustrate this with the excerpts below:
“It’s been a while since I last wrote something in my diary”  
Camille, diary

“From today on, going back again to writing a short diary entry regularly”

“Had no energy to write for a couple of days. Wasn’t feeling well at all”  
Sarah, diary

“Already sixteen days since I last wrote”  
Kristina, diary

“Already been a while since I last wrote in my diary, but was in Portugal for 4 weeks, next time I’ll write there as well, if there’s ever going to be a next time”  
Julia, diary

In these excerpts I notice the importance of the materiality of the design of the POHC. The diary section, if I translate it from Dutch, is actually labeled as a ‘day journal’, implying one is expected to write in it on a daily basis. Indeed, patients start some of their diary entries referring to the regularity with which they write in this section of their POHCs. These postings often contain justifications and apologies. Julia even apologizes for not posting while she was on vacation, promising that next time she will also update her diary from over there. These excerpts expose an interesting development: the meticulous recording of one’s symptoms is not something that patients are normally asked to do, let alone asked to share with their healthcare professionals. In the past, this kind of information was discussed in a much more limited way, if at all, during the biyearly consultation with the neurologist. With the availability of the diary section in the POHC, and the suggestion that it should be used on a daily basis, I witness how this imposes extra duties on patients.

In the excerpts displayed so far, I see patients phrasing their identity work in terms of cause and effect. If they write many postings, then their healthcare professionals will respond in a certain way. Their choice of words positions this result as inevitable; they present it as a fact that their healthcare professionals will respond negatively. By not questioning these norms, patients demonstrate the strong identity regulation through discourses and materiality around the frequency of contact with your healthcare professionals. This frequency of contact can potentially be increased within the frame of organized emancipation promoted with the POHCs, because the POHCs, in principle, take away the regulations around frequency of contact. However, I see patients, as it were, resisting this organized emancipation by disciplining themselves to not post ‘too much’.

Content of postings

Patients do not only carefully reflect on the number of postings, but also on the content of their postings. The materiality of the POHC does not allow for non-verbal communication, meaning that what patients say cannot be nuanced by other methods of communication. Therefore, they consciously reflect on how the content of their postings comes across to their healthcare professionals. Different patients reflect differently on what they believe ‘appropriate content’ is, as I will examine in what follows next.

One concept that came up frequently during the interviews and the observations of the POHCs, is that of ‘complaining’. Victor brings this issue up during an interview. He is a 63-year-old man and lives with his wife. He was diagnosed with Parkinson’s nine years ago and used to work in a managing position in an IT department at a multinational company. Victor started using his POHC a year and a half ago, and makes the following statement:

“You are... very consciously thinking... should I bother him with this, yes or no? [I: Do you hesitate when posting?] Yes. [silence] Yes... I am not someone who complains quickly”.

Victor, interview

Victor positions himself as not being someone “who complains quickly”. He uses an opposition to show how he relates to this norm of complaining. Rather than
stating what kind of person he is or wants to be (i.e., someone who does not complain quickly) he states what he is not. In using this sentence construction, he engages in identity work that further distances him from the undesirable identity of a complainer. When I analyze his postings, I indeed see a picture of a business-like person emerging. See, for example the following excerpt from his diary:

Participated in a research trial Sleeping disorders at [Hospital A], by [Healthcare professional Z]  
Was assigned to the control group  
On MARCH 8TH 2010 AND MAY 1ST, 2012 meetings and discussed questionnaires.  
On own request kept ‘sleeping journal’ from May 6-12, 2012.  
On May 25th, 2012 in a final conversation with [healthcare professional Z] went through sleeping journal and discussed several issues, such as  
- taking [medication A] right before going to bed  
- frequency of waking up and need to pee/defecate during the night  
In the end left with sleeping advice and methods for relaxation  
Victor, diary

Victor focuses his posting on the dates he went to consultations and gives very short summaries of the content of those consultations. His sentences are written in a staccato form and they do not form complete, grammatically correct, sentences. Most noticeably, he does not use a subject (I) or auxiliary verbs (was or have), leaving him as an individual invisible. His body, and he as a person, remains hidden behind the text. He mentions that he was placed in the control group, meaning he did not receive actual treatment for his sleeping disorder, but he does not show any emotion regarding the impact of that decision. As a result, his identity work constructs him as a seemingly bodiless and emotionless patient. At the same time, this excerpt shows how Victor is actually a patient who consciously thinks about how he can improve his life, because he took the initiative to enter a trial.

I compare his identity work as a patient with another patient, named Nora. She is a 67-year-old woman, who lives by herself in an apartment. She used to work as a physical therapist and was diagnosed with Parkinson’s disease 13 years ago. She has been using her POHC for over a year now. Nora states:

“[Certain things are part of the] acceptance of Parkinson’s disease and the deterioration of it, the progression in it. That, yes, that’s just part of it and I have to handle that on my own. Only when it is something that I think can be solved… I will take the time to complain and describe what is going on. […] There’s a hurdle, I don’t want to nag… I think. I would rather be a bit tough than… than that I complain.”

Nora, interview

Juxtaposing being tough to complaining, Nora draws on a discourse that values toughness over communicating what is on your mind. According to Nora’s standards, complaining is only appropriate when she thinks an issue “can be solved”. This means that she puts the responsibility on herself to know which issues are solvable and which are not, as she “has to handle it on her own”. Although this phrasing mirrors the autonomous image of an empowered patient, the autonomy is described more as a duty than a liberating right. Exploring Nora’s ambivalence toward posting too much further, she describes below, that when there are issues that she feels are important to discuss, she uses different techniques to ‘lighten’ the tone of her message:

[In face-to-face interactions] I am there as my whole person interacting with someone and that person will see some sort of… I also often use self-mockery. […] And you include that in your story […] and on the electronic [system], you have to put that into words… if you want to include that aspect. […] With that surgery on my foot… then I make a little bit of a dramatic… how should I put it… story out of it. [Laughing:] because it needs to be a taken a bit serious of course. So I use my negative mood to really emphasize my worries, like gosh, I am really worried about that.”

Nora, interview
Nora states that she finds it easier to avoid coming across as a complainer by interacting face-to-face with her healthcare professionals and harder to avoid this on the POHCs. The face-to-face contact allows her to display her ‘self-mockery’ through which she can nuance her stories. She frequently laughs and jokes when she explains to the interviewer how she uses her community. She states that she “should be taken a bit serious of course” while she starts laughing. Through her joking and storytelling, she is able to display her “whole person”, and the emotions she experiences in dealing with her disease. During the excerpt she consistently talks about ‘stories’. Her use of that word is telling. Story has the connotation of something that is made up and therefore not real. If she had talked about ‘an overview of events’, it would have sounded more like an objective record of her symptoms. However, she chooses the word story which matches her use of ‘dramatic’ to show how she dramatizes how she is doing. She frames her storytelling not as an overreaction to her symptoms but as a way to emphasize her worries and convince her healthcare professionals of the severity of her symptoms. As Nora describes, she expects that such emphasizing makes sure that her healthcare professionals (and the interviewer) are able to take her seriously. In fact, with her use of the word ‘should’, Nora voices an expectation that she has of her healthcare professionals; they should take her seriously. Continuing on with this patient, I show how she incorporates self-mockery by analyzing one of her postings.

I am increasingly confronted with my annoying feet. I used to be able to trot across the fish market whenever there was a market, now I stumble from stand to stand and it has become too much to keep walking with my bike at my side. So, I just limit myself to the bare minimum; the rest is luxury.

What’s going on with those feet: big-toe-lump is looking for space in the wrong direction and therefore pushes other toes away and this hurts, there’s extra callus forming, before, when it was still standing straight. This is true for both toes. Next to that there’s Parkinson’s weakening of the foot muscles; the foot is sagging all the way to the ground when moving. And becomes extra wide because of that. (Try buying shoes for that!) I have frequent and strong muscle aches in my feet. Sometimes there’s this burning sensation and I only have one desire: shoes off. And try doing that in the middle of a concert.

From [name physical therapist], the physical therapist I got the response: have surgery. No matter how much your fear this.

And so I return to a year and a half ago, where I was hesitating about having surgery on both feet: stopped halfway during the process with orthopedics. Was a picture taken? I don’t remember; repressed. Was fearing the long rehabilitation period for both feet. How do I manage on my own? Now that I live in city, home care might be easier to arrange...

The first thing to notice here is that the content and tone of Nora’s diary posting is very different from Victor’s (see his earlier excerpt). Her body and emotions are front and center in describing her daily activities, as she illustrates how she is urgently confronted with her troubling feet. She offers a detailed analysis of what is wrong with her feet and describes how this impacts her daily life. In her description she uses little jokes, such as the playful “try doing that at a concert”. Her joking seems to work in two ways: it helps her to relieve some of the seriousness of her message. At the same time, it draws attention to how seriously her symptoms are impacting her life. The underlying message of her words would have been entirely different if she had written “when I am at a concert, I cannot take my shoes off”. This alternative sentence would have made her message sound less dramatic and would not have portrayed the same feelings of frustration and helplessness, although they would have made her experiences sound less like jokes and more like serious symptoms that require attention. However, the alternative sentence might also have, according to Nora’s standards expressed during the interview, transgressed the norm of ‘not complaining’.
Next to the tone of Nora’s diary entry being different, I can also see that her posting is much longer than Victor’s. Nora goes into detail about her daily struggles. The extensive account she gives would have been less feasible in the space of the offline consultation room, because of material regulations that prescribe the limited time she gets with her neurologist. By using the POHC she is able to get her story out, in a rather emancipatory way, allowing her healthcare professionals to know how she is doing. By writing them down on the community, her experiences are less easy to brush off. To a large extent she is in control of the content and tone of the conversation, more than she might have been in an offline consultation. The POHCs, therefore, provide a unique setting for Nora to perform her identity work, broadening the different ways in which she can construct her own identity.

Although all of these patients express that they do not want to complain, they take different approaches; Victor works to construct his identity as a patient without an apparent body or emotions, where Nora is sometimes able to complain, but only does so by consciously displaying self-mockery and when she thinks the issues can be solved. With this combination she ensures that she is taken seriously as a patient. In this online space, patients reflectively navigate that line between reaching out to their healthcare professionals and disturbing them with too much (irrelevant) information.

Intersection of online and offline spaces

As we have seen in Nora’s case, the online space does not exist separately from the offline space. To understand how the offline and online spaces intersect, I need to provide more background information about the normal pattern of interaction between Parkinson patients and their healthcare professionals. Almost all patients have biyearly appointments with their neurologist for which they tend to save up questions. Most patients also see other healthcare professionals, but the intensity of contact with them varies, and the POHCs provide the opportunity for patients to reach out to their healthcare professionals at any time.

In this section, I return to Kristina, who earlier talked about the number of postings. One of her diary entries was written in preparation for the first time she was meeting her new neurologist (after she switched from an academic to a local hospital). The title of this diary entry is “Is everything actually fine?” and in it she writes:

Tomorrow first time to Dr [name neurologist]. Knowing myself, I will say that everything’s going fine. It is going fine, but I haven’t been sleeping well lately because the tremor is becoming more apparent.
Kristina, diary

Kristina indicates that she is aware that she will probably find it difficult to articulate that she is not doing fine when she is meeting with the neurologist. She suggests that she is not inclined to truthfully discuss her health status, and counteracts this tendency by making this comment in her diary. Through this statement she (deliberately) dismissed the opportunity to pretend she is fine in the offline consultation room. In a rather complex way, Kristina uses the online space to change her behavior offline. However, this communication is indirect in two respects. First, she writes this in her diary, less than a day before she is meeting with her neurologist for the first time. It is possible that he is not able to read her posting in time before the consult, especially since the diary section does not notify members of new postings. Secondly, she is not actually saying that she is not feeling well. After commenting about the fact that she always pretends to be fine, she says “I am also doing fine“, and then uses the contrasting ‘but’ to imply otherwise. Using the word ‘but’ indicates her own ambivalence about how she is actually doing and how she should communicate this. She avoids transgressing the norm of coming across as a complainer, but is still able to transfer that she is not feeling “fine”. During the interview, Kristina shows another example of how she could impact her communication in the consultation room through using her POHC:

“I have read all about Parkinson’s and you can also get bladder issues. Then you might not bring that up so easily if you’re there [consultation room neurologist]. And then it would be much easier if you can just type
Kristina repeats three times that she thinks posting sensitive information online is "much easier", the last time even emphasizing the word 'much'. She finds it hard to discuss sensitive issues with her neurologist and welcomes this opportunity to make those situations less uncomfortable, stressing the fact that it would be easier to continue the conversation offline afterward. Her offline identity work will then become regulated through her neurologist reading her online postings and him bringing these up during consultations. She describes the neurologist’s response in a factual manner, expressing confidence in the fact that her neurologist will bring up her issues for her. Therefore, she shows a certain reliance on the neurologist to do what she does not: vocalize her problems and questions during consultations.

Later in the interview, Kristina also explains how she prepares for a consultation with the neurologist. She, as many other patients, likes to bring a piece of paper listing all of the questions she has, when she goes into the neurologist’s office. However, Kristina describes how she never actually takes the piece of paper out of her bag once she is there, because she feels this makes her look “self-important”. Since she started using the POHC, she and the neurologist have found a new way to bring up Kristina’s questions, during the offline consultations:

“Before I go there, I write down some things [on the POHC], that I want to discuss for a bit. So he has... he prints it out and has it there with him. And that’s what I also think is very convenient. Because, I think, if I come in myself with a piece of paper, then I always think “that’s so [self-important]”. But then he has that piece of paper with him [...] and just the other time as well, I had forgotten something and then he said as well “I haven’t talked about that yet."

Kristina, interview

Kristina describes how she uses her POHC to post an overview of issues she would otherwise bring in print. While describing what she wants to discuss, Kristina uses expressions like "some things" and "for a bit", making her issues seem unworthy of much attention. She further signals that her questions are not that worthy of attention when she states that she feels "so self-important" when she comes to the consultation and brings out a piece of paper. However, through Kristina’s words, it becomes clear that the neurologist is deserving of portraying this importance. By appreciating that he uses a printout of her questions, she ascribes him the importance necessary to possess such physical evidence of her problems.

In these excerpts, we witness Kristina engage in identity work that is specifically geared to impacting her offline identity. The POHC changes her previous ways of communicating with the neurologist and offers a new space to reflect on herself as a patient, where she engages in identity work that both downplays her issues, but also makes sure that her issues are discussed. Although she leaves much of the ability to actually discuss her issues in the hands of her neurologist, Kristina is able to navigate the identity regulation embedded in the POHC, in a way she feels comfortable with. Where she, in the past, left it completely up to the neurologist to initiate the conversation, she now gives stronger (but ambivalent) suggestions online for what she wants to discuss offline.

Based on this analysis, we can conclude that patients’ identity work is based on reflecting on the number and content of posting and the way the different spaces intersect. However, the regulation of their self-identities has become ambiguous because this regulation is specifically aimed at patients’ emancipation. Although the POHCS are supposed to organize emancipation, patients’ identity work does not automatically follow this identity regulation. Focusing on the
regulation through norms, my analysis shows that the technology comes with an ambiguous norm dictating that patients should provide more information, without asking more questions. Equally ambiguous is the norm that emotional elements should not appear in postings unless one explicitly includes humor into accounts of daily life. Lastly, the offline integration of online communication shows that by posting sensitive topics online, patients create space for these topics to be discussed during the offline consultations. Although the online space seems to take away some barriers to address certain issues, there is a layer of ambiguity as the initiative to discuss those issues still remains with the healthcare professional.

The identity regulation on the POHCs is, therefore, affected by the material constraints and abilities embedded in the technological system of the POHCs. The materiality of the POHC allows easier access to healthcare professionals, because formal barriers such as a secretary regulating the making of appointments do not exist on the POHCs. However, the material structure of the POHC also restricts patients’ identity work. For example, because the website sends email alerts for certain postings (virtual meetings) and not for others (diary entries), a distinction is made between postings that are more and less intrusive for healthcare professionals to receive and read. Moreover, the materiality of the POHCs is focused on the provision of information by the patients (through posting diary entries) and much less so on healthcare professionals feeding back information to the patient. Therefore, the exchange of information, or knowledge, occurs rather unidirectional as the design of the POHC is much less inviting for (or forceful toward) healthcare professionals with respect to sharing their expert knowledge.

**DISCUSSION**

In this chapter, I coined the concept of ‘organized emancipation’. Organized emancipation refers to the ways in which ways of organization regulate identities with an explicit aspiration of emancipation in mind. Organized emancipation, therefore, challenges a commonly held assumption that emancipation is an exclusively bottom-up affair; achieved through identity work. In coining the concept of organized emancipation and examining its effects on identity work, I have contributed to the wider organizational identities literature, and, more specifically the literature that examines identity work in changing environments (Beech et al., 2016; Clarke et al., 2009; Rosenthal, 2004).

The POHCs that are the vessels through which this emancipation is organized, present a new regulatory context. Regulation on POHCs regarding when and how to access healthcare professionals is not done by an external actor (such as a secretary), as is the case in offline communications. The absence of such formal regulation makes POHCs seem highly emancipatory at first sight (individuals are free to post when and what they want to), but the (emancipatory) organizational regulation also creates a responsibility and pressure for the patient to become emancipated, which stand in opposition to the emancipatory ideals of freedom and agency. Phrased in theoretical terms, although some argue that such ‘blurred lines’ provide space for actively resisting restricting norms (Fleming, 2007), I argue that in emancipatory contexts, where individuals are encouraged but left to their own devices to become emancipated, the idea of emancipation moves away from a ‘right’ that individuals possess to a ‘duty’ that they themselves are becoming partly responsible for. Whereas before this right was in the hands of the individual, this duty to emancipate is now shared with the organization, constituting an ambiguous environment for emancipated identities to be constructed. Therefore, on the basis of my empirical analysis, I have contributed a theoretical exploration of how identity regulation through organized emancipation leads to identity work that entails a complex web of practices where especially the responsibility for this emancipation becomes a space for contestation.

This contestation over responsibility becomes clear through examining the increased ambiguity of patients’ identity work. When dealing with organized emancipation, patients displayed identity work that often showed tensions, further substantiating the idea that identity work is not always aimed at developing a coherent self (Beech et al., 2016). The ambiguity is central to their self-identity of a ‘good patient’; while patients work to become more active, by using the increased options that the POHCs present to contact their healthcare professionals, patients also remained wary of bothering their healthcare
professionals ‘too much’. As the regulation of what ‘good patients’ do (i.e., how much and what they should post) is less clear as a result of the organized emancipation of the POHCs, incoherence, ambiguity, and self-questioning was an integral part of their identity work. Part of patients’ identity work involved creative ways of embracing this ambiguity, for example by writing on the POHCs about experiences that the neurologist could later bring up for discussion in the offline consultation room.

Another contribution of this chapter is the recognition of the importance of materiality in the organizing of emancipation. Drawing on recent work on materiality (Orlikowski, 2010; Zanoni & Janssens, 2007), I argue that materiality forms a vital component of the identity regulation through the POHCs. The materiality, or material conditions, of technological systems constitute the space that exists for certain practices and discourses to arise (Barad, 2003; Eriksson-Zetterquist, Lindberg, & Styhre, 2009; Orlikowski, 2010). With my emphasis on materiality, I link up with, for example, Korica and Molloy (2010) who have shown how surgeons’ professional identity needed to be (re)negotiated when new technology was introduced. These surgeons became active agents in the process of using and embedding this new technology in their daily practices, and their professional identities changed because of it.

In the case of the POHCs, I see a shift in material regulations. Previously, a secretary’s office would represent this material regulation by managing access to a healthcare professional in terms of time and space, or a pre-consult questionnaire that structured the topics that would or would not be addressed during consultations. In the context of the POHCs, the design of the technology changes the material regulation of patients’ identities and their identity work. Allowing patients to post when and where it suits them, ensures that POHCs stimulate (and regulate) a different, (pro-)active position for the patient. Simultaneously, the materiality of the POHCs also regulated patients’ identity work as certain behaviors were designed to be less intrusive (writing diary posts) than others (asking questions in the ‘virtual meeting’ space). Emphasizing the materiality of the POHCs, shows how it is linked to the discursive (normative) regulation of care provision, and makes it clear that technology and identity stand together in a mutually constitutive relationship (Korica & Molloy, 2010; Leclercq-Vandelannoitte, 2011).

Although I have no simple recipe for how patients could gain an emancipated role, I recommend that users of this technology (both healthcare professionals and patients) engage in open dialogue, to voice their expectations and wishes with regard to using the system. As opposed to setting up user guidelines (which could be seen as another, but strongly regulatory, alternative) such conversations could create a space where both parties can express their ideal use of the communication technology. Although I have no illusions that such conversations can be devoid of power; they might make each party more aware of the assumptions they hold about the abilities the other parties have in terms of using the technology. With regard to the materiality, or design, of the technology, I suggest changing the system to encourage two-way knowledge exchange. In the current state, the POHCs most actively promote the information provision by patients, without there being a clear way for them to gather information from their healthcare professionals, other than the occasional knowledge exchange within a virtual meeting, that is almost always initiated by the patient. Two-way knowledge exchange could give patients additional resources (such as updated information on medication or trials) with which they can get more say in their own treatment.

I also want to emphasize that the emancipation that is organized by the POHCs is not merely driven by ‘humanistic’ ideals of liberation from organizational power processes. The other side of introducing the POHCs is one of increased efficiency and cutting costs. Emancipating patients through encouraging them to play an active, self-managing role in their care, is also expected to come with financial benefits. With patients partly taking the lead in their care, professionals will save time (and thus, money) and the care itself is also expected to be of higher quality because it is explicitly adjusted to the patients’ individual needs and desires. This economic discourse, and its ties to neoliberal celebrations of the individual and the market, has received less attention in this chapter. In the data, there were some suggestions of patients’ awareness of the financial aspects of their care in relation to the POHCs and I would want to further explore this in relation to identity work in future research.

This study also presents some limitations. One topic for consideration
is the socio-economic status of the patients who use these communities. In the sample and the pilot project as a whole, the majority of patients had a relatively high job status, possibly because this correlates with their (perceived) technical skills required for using a computer. When these POHCs will be launched for a greater audience, issues of class and abilities might become more apparent. As I discussed in the previous chapter, patients’ identities were ‘classed’: patients’ educational and job background allowed access to discourses and practices that those with lower socio-economic status might not have access to (e.g., understanding of medical terms or the Dutch medical insurance system). In future research projects, this topic should be investigated in more depth in relation to the concept of organized emancipation.

Furthermore, I focused on those patients who use their communities relatively intensively. Limiting my sample to this group allowed me to conduct an in-depth analysis of patients’ identity work and regulation embedded in POHCs. After all, if patients post very little, there is very little data about identity constructions on POHCs to analyze. However, because of my narrow sample, I cannot draw any conclusions on those patients who are not able or willing to use their community frequently. This group of patients would be a relevant population for future research, since they allow me to ask other interesting questions, such as what differences exist between patients who are and who are not using their POHC and what this means for the identification processes involved in their care provision.
PRYING EYES

A dramaturgical approach to professional surveillance

* This chapter is based on an article, co-authored with Inge Bleijenbergh, Yvonne Benschop, and Allard van Riel. The article is currently in the fourth round of review at Journal of Management Studies. A previous version of this article was presented at the European Group of Organization Studies of 2014 in Rotterdam, the Netherlands.
Surveillance has intensified in the last decades, especially for formerly relatively autonomous individuals such as professionals. With this chapter, I contribute an examination of professional surveillance at the micro-level of interaction. Moving beyond the common distinction between complying and resisting reactions to surveillance, I demonstrate how professionals enact rather than react to surveillance. I build this enactive view of professional surveillance by developing a dramaturgical approach and asking how professionals enact surveillance in their daily work. By interviewing and observing healthcare professionals, who use a new technology to communicate simultaneously with each other and individual patients, I demonstrate that professionals use different elements of the theater to enact surveillance. The significance of my contribution to professional surveillance lies especially in the reconceptualization of surveillance as an integral part of displaying one's professionalism and the power enacted through it.

INTRODUCTION

Surveillance, defined as the activity of watching or being watched, has increasingly become a reality in the daily practice of contemporary organizations. In parallel, surveillance studies developed into a specialized field of study, spanning a number of disciplines such as Organization Studies, Sociology, Political Sciences, and Law (Ball, 2010; Bogard, 2006; Lyon, 2007; Marx, 2003; Sewell & Wilkinson, 1992; Townley, 1993), and drawing on a myriad of classic theories, such as Marx' capitalist labor process, Weber’s bureaucracy, and Foucault’s Panopticon (Foucault, 1979; Tucker et al., 1978; Weber, 2005/1930). A common thread in the Organization Studies literature is to understand surveillance as a form of power, examining how those in higher hierarchical positions (i.e., the few) watch those in lower positions (i.e., the many) and the opportunities to resist or comply with this surveillance (Knights & McCabe, 2000b; Rosenthal, 2004; Sewell & Barker, 2006; Sewell, Barker, & Nyberg, 2012).

However, other forms of surveillance have started to develop, due to technological innovations (Ball, 2005) and organizational audit systems (McGivern & Ferlie, 2007), giving way to mutual surveillance (e.g., peers watching each other) (Adler & Kwon, 2013), and to surveillance in networks, where those in lower positions can watch those in higher positions (Mann, Nolan, & Wellman, 2003). Coinciding with this trend, surveillance has intensified, especially for formerly relatively autonomous individuals such as professionals (Adler & Kwon, 2013; Muzio, Brock, & Suddaby, 2013). The emergence of increased professional surveillance is driven by macro regulations stemming from the ‘audit society’, in which professionals are required to account for their actions (Power, 1997). As a consequence, professionalism is no longer self-evidently established and has become something that professionals should constantly and repeatedly prove (Mulgan, 2000).

This opens up a new area of inquiry on how professionals engage with this increased surveillance at the micro-level of interaction. Earlier studies on this micro-level describe professionals’ responses to intrusion into their professional autonomy, often echoing the dominant dichotomy between compliance and resistance (Adler & Kwon, 2013; Rosenthal, 2004). A few articles in surveillance studies have acknowledged (in some cases implicitly) the need to go beyond resistance and compliance (Brivot & Gendron, 2011; Gleeson & Knights, 2006; Iedema, Rhodes, & Scheeres, 2006; Levay & Waks, 2009; Noordegraaf, 2011), and I link up with this developing line of research. To the literature on professional surveillance, I contribute a reconceptualization of how professionals engage with surveillance by demonstrating that at the micro-level of interaction, professionals enact, rather than react to surveillance.

To demonstrate this enactment of surveillance at the micro-level of interaction, I draw on dramaturgical literature. Dramaturgical approaches are largely based in Erving Goffman’s (1959) work, in which he uses the theatrical metaphor to show how people’s daily interactions can be seen as performances. In performances, people strive for making a good impression and avoiding a negative one in front of an audience, and try to maintain order (Kivisto & Pittman, 2013; Manning, 2008). Using elements of this theatrical metaphor (e.g., front- and backstage), I develop a dramaturgical approach to professional surveillance to illuminate how professionals interact with the watching eyes of a heterogeneous audience.
I establish the idea of ‘enacting surveillance’ in a context in which possibilities for surveillance of professionals’ work increased after the introduction of a new communication technology. More specifically, I examine so-called personal online health communities (POHCs) that facilitate communication between healthcare professionals and their patients with Parkinson’s disease. The initiators set up this secure online space, in which a patient can communicate with her or his locally dispersed healthcare professionals from different disciplinary backgrounds, with the goal to better include both patients and healthcare professionals in the care provision process (ParkinsonNet, 2012). POHCs open up possibilities for surveillance of professionals’ work, because communication that used to take place one-on-one in the consultation room, or over phone or email, with only the patient or a fellow healthcare professional, now has to be performed on the POHCs in front of a heterogeneous audience. In this context I ask the following research question: how do healthcare professionals enact surveillance in their daily work?

My analysis shows that professionals use different elements of the theater, most prominently the front- and backstages, scripts, and the regulation of others’ performances, to enact surveillance at the micro-level of interaction. Demonstrating the enactment of surveillance allows me to argue that professionals can, to a certain extent, direct how surveillance enters their professional lives, in ways that go beyond resisting or complying with surveillance, in order to benefit their displays of professionalism.

I proceed as follows: I first develop my theoretical framing of professional surveillance in light of dramaturgical work. Thereafter, I discuss my empirical case and methods for data collection and analysis. In the results section, I analyze quotes from interviews with 13 healthcare professionals and from 377 posts obtained through long-term observations of their use of POHCs. In the final section, I position my findings in a broader theoretical context and discuss my contributions, practical implications and avenues for future research.

PROFESSIONAL SURVEILLANCE

In the current ‘audit society’ (Power, 1997) professionals have to deal with surveillance, which has had far-reaching effects on their identities and ways of working (Dent & Whitehead, 2002). As scholars from different fields have shown, professional practices have become more visible and attempts have been made to translate them into procedural rules, protocols, and guidelines (Adler & Kwon, 2013; Fournier, 1999; Walshe, 2002). These guidelines open the door to auditing by the larger public, resulting in a loss of professional autonomy (Adler, Kwon, & Heckscher, 2008; Beddoe, 2010; Leung, 2008; Munro & Hatherly, 1993; Ramirez, 2013). With the introduction of new technologies, this surveillance has become easier and less time-consuming, creating opportunities for making work more transparent, accountable, and monitored (Dennis, 2008; Mann et al., 2003; Petrakaki, Klecun, & Cornford, 2016; Vieira da Cunha, 2013).

Although these macro-level trends are well-documented, less is known about how they play out at the micro-level of daily work. Wider surveillance studies have examined individuals’ reactions to surveillance, often by dividing them into resistance and compliance (Beddoe, 2010; Håland, 2012; Jary, 2002; Knights & McCabe, 2000a; Muzio et al., 2013; Rosenthal, 2004; Sewell, 1998). However, the strict distinction has also been criticized, for instance from a structuration perspective drawing on the duality of structure and agency (Gleeson & Knights, 2006; Thomas & Davies, 2005; Waring & Currie, 2009), or from a labor process theory perspective in which concepts such as ‘accommodation’ or ‘consent’ nuance the division between mindless compliance and active resistance (Thompson & O’Doherty, 2009). Professionals’ responses to changing work environments have been characterized as “dynamic” (Waring & Currie, 2009), “hybrid” (Noordegraaf, 2011), and “relational” or “co-produced” (Gleeson & Knights, 2006), indicating that professionals’ behavior is more complex than resistance or compliance. As Brivot and Gendron (2011) conclude, this means that “resistance and compliance are not diametrically opposed [but] dialectically intertwined” (p. 137). Of course, this view still implies that resistance and compliance are the main responses to surveillance.

I link up with and extend this developing line of research in an in-depth study of professionals’ engagement with surveillance. Exploring the complexities involved in engaging with surveillance requires an analysis of professional surveillance in daily work at the micro-level of interaction. Therefore, I bring
together literature on professionals, surveillance, and the micro-interactional level of organizing with dramaturgical literature. With the integration of insights in these combined literatures I will build an enactive view of surveillance, arguing that professionals do not merely respond to surveillance but actively engage with it (i.e., enact it) in a myriad of different ways. The transition from conceptualizing surveillance as reacted to into enacted is important, because it allows me to theorize how surveillance is not external to one’s professionalism, but constitutes an integral part of it, which is important for our understanding of surveillance as a form of power.

**DRAMATURGICAL PROFESSIONAL SURVEILLANCE**

To develop this enactive view of professional surveillance, I use dramaturgical literature (Goffman, 1959) which adopts elements of the theater to understand micro-level interactions between individuals in everyday life (Dick, 2005; Knorr-Cetina & Bruegger, 2002; Patriotta & Spedale, 2011; Zhao, 2005). Dramaturgical literature, in essence, sees these interactions as performances in which individuals try to maintain order and manage impressions by making positive impressions and avoiding negative ones (Goffman, 1959; Lemert & Branaman, 1997). Impression management is about staging the performance of a ‘self’ that an audience will accept as legitimate. Audiences of various compositions watch actors’ performances and the micro-interactions between and among performers and audience take place both on front- and backstages (Manning, 2008).

Surveillance, implicitly, forms an underlying aspect of dramaturgy: with an audience looking at a performance on stage, its watching eyes are a form of surveillance, one that continuously informs the performer’s performance. Scholars have alluded to the fact that Goffman’s work might pose a valuable viewpoint for understanding surveillance and the impression management that results from it (Brivot & Gendron, 2011; Collinson, 1999; Molstad, 1988; Reid, 2015; Vieira da Cunha, 2013). I extend this use of Goffman’s work by building an innovative theoretical approach that adopts theatrical elements to understand professional surveillance to unleash the full potential of Goffman’s work. More specifically, I draw on the concepts of front- and backstages, scripts, and the regulation of others’ performances. I discuss these concepts below, showing how they illuminate different aspects of surveillance.

**Front- and backstages**

In *The Presentation of Self in Everyday Life*, Goffman distinguishes between different spaces in which performances take place. He defines these spaces as “bounded to some degree by barriers to perception” (1959, p. 106). These barriers distinguish the front- from the backstage. As he argues, some performances occur on a frontstage with a full audience present. Other performances, however, take place on backstages, where individuals are able to perform other versions of themselves, less bound by the strict rules of the frontstage. No longer being watched by a particular audience, the individual is not confined to socially desirable behaviors in relation to that audience. Even though Goffman talks about the presence of ‘barriers’ between the front- and the backstage, other dramaturgical work has shown how these boundaries are, at times, unstable and how the front- and backstage can shift (Brivot & Gendron, 2011). Baralou and Tsoukas (2015) describe the stages as being relative to each other, where one can be on a frontstage that is simultaneously someone else’s backstage. The audiences for different performances are, therefore, also subject to change, and I can start from Goffman’s original concepts to gain a better understanding of how these stages and audiences shift within professional surveillance.

The dramaturgical concept of front- and backstages speaks to transparency, a recurring theme in surveillance literature (Garsten & De Montoya, 2008; Johnson & Regan, 2014; Levay & Waks, 2009; Townley, 1993). The different stages can show how, through making certain things visible and hiding others, professionals decide what content is (in)appropriate for specific audiences. On the studied POHCs, all conversations take place in front of the entire heterogeneous audience of patient and healthcare professionals (i.e., the frontstage) and one-on-one conversations (a former backstage) are no longer possible when communicating through the technology. Previous studies have used Goffman to demonstrate the importance of backstages for the medical
profession, showing that professionals sometimes discuss medical issues and prognoses with fellow professionals hidden from the view of patients (Greener, 2007; Lewin & Reeves, 2011). I build on this work to understand when professionals feel the need to move conversations to a backstage and how that connects with the watching eyes of the heterogeneous audience on the POHCs.

Scripts
Making information visible comes with a requirement that one is able to justify her or his actions. For this justification, criteria for judgment need to be available to ensure that professionals are accountable on them (Giddens, 1984). Accountability is another common theme in surveillance studies (McGivern & Ferlie, 2007; Munro & Hatherly, 1993; Ogden et al., 2006). In the dramaturgical literature, these accountability criteria are located in 'scripts'. When performing, performers make use of scripts to guide them through the performance as they contain all the "rights and duties attached to a given status" (Goffman, 1959, p. 16). Therefore, the script is crucial in knowing how to behave in certain interactions. While being watched by an audience, the performer can turn to the script to make sure that the impression she or he makes is managed correctly.

Professional scripts, in particular, shape and are shaped by individual professionals and constitute "the rules of signification, of power hierarchies and norms of his or her profession" (Hotho, 2008, p. 727). Through the introduction of a new technology to communicate, existing scripts for professional behavior might not be useful anymore. For example, what was once regarded as medically ethical behavior in terms of privacy and communication with or about a patient, could change through the introduction of the POHCs. Scripts, thus, have to be adapted which can occur through performances (Goffman, 1959; Kivisto & Pittman, 2013). Moreover, on the POHCs, professionals can be held accountable on the basis of different scripts used by a heterogeneous audience (i.e., patients and fellow healthcare professionals simultaneously). The change in audience might result in the co-existence of multiple scripts, and the legitimacy of the performance might increasingly depend on the social status and resources professionals can draw on (Lemert & Branaman, 1997). In this chapter, I explore and expand on the notion of scripts by showing how professionals deal with multiple co-existing scripts.

Regulating performances
So far, I have used dramaturgical work to investigate how one performer (a professional) might reflect on her or his own performance in relation to an audience. However, as both dramaturgical and professional surveillance literature describe, performances and surveillance, respectively, also involve external regulation, through mutual monitoring. Monitoring, in the surveillance literature, describes how one individual can regulate the behavior of another (Rosenthal, 2004; Sewell et al., 2012). Similarly, dramaturgical literature describes how performing on a stage involves other individuals, either fellow performers or an audience member, who can regulate a performance while it takes place on the frontstage (Goffman, 1959).

When a performance is flawed in the eyes of the audience or a fellow performer, consequences follow to ensure the recovery of a coherent performance (Kivisto & Pittman, 2013). On the one hand, this monitoring of each other’s performances allows the audience to step in and redirect the performance. On the other hand, it allows fellow performers to interject when their own performance is threatened. When dealing with these threats, professionals can end up with an opportunity for strengthening their professionalism (Brown & Coupland, 2015). Dramaturgical work has referred to these regulatory activities as protective and defensive measures respectively (Goffman, 1959, p. 212).

On the POHCs, with the integration of different disciplines around one client, disciplinary boundaries become more apparent and might have to be monitored through performances. Stepping in after the fact was the only possibility before the POHCs were introduced. As professionals were not present for conversations that took place in other consultation rooms, their only opportunity to regulate others’ performances came up when they would, after the fact, be told what was communicated during those separate conversations. On the POHCs, the opportunities for regulation are more immediately available. Now that I have shown how I connect dramaturgical work to surveillance literature, I will enrich and demonstrate the worth of this new theoretical approach by examining it with the help of empirical data. In the next sections,
I will describe my empirical context, my data collection and methods of data analysis.

METHODS

Case study context
In this chapter, I examine personal online health communities (POHCs) set up on the website www.mijnzorgnet.nl in the Netherlands. Between 2011 and 2013, ParkinsonNet (an organization in the Netherlands attempting to increase the quality of care for patients with Parkinson’s disease) conducted a pilot project, where over a hundred patients were supported in setting up a POHC through the MijnZorgnet website. Four Parkinson’s nurses were appointed to support the patients and their healthcare professionals in gaining access to the website and using the POHC. The Parkinson nurses approached patients who they thought would benefit from using the POHC, but the opposite also occurred, where the patient approached the appointed Parkinson nurse and asked to be included in the pilot. The POHCs were set up in such a way that the patient was the owner of the community and she or he decided which healthcare professionals became part of their POHC. The healthcare professionals received no remuneration for their participation in the project; only the four Parkinson nurses were financially compensated for their time through a grant obtained by ParkinsonNet. The content and use of the POHCs was only visible to those who were invited to join. To ensure the confidentiality of the communities, ParkinsonNet (as the organizer behind the pilot project) did not have access to the content of the POHCs, although it did contact participants with a survey to gain anonymous insight into, and evaluate the success of, the project after it concluded.

The POHC offers a number of options, among which starting a ‘virtual meeting’ and writing in a diary. Patients can give updates in their diary section and healthcare professionals can respond to those diary entries if necessary. Patients (and healthcare professionals) can start a virtual meeting if they think an issue requires an active discussion. The individual who starts the meeting can decide which of the other members within the POHC to invite to participate in the meeting. These invitees will receive an email alert of all entries within this meeting. However, those not invited to the meeting, can still read and participate in the conversations. The POHCs were set up specifically for patients with Parkinson’s disease. Parkinson’s is a chronic and degenerative disease with which most patients are diagnosed at a later stage in their lives (Lees et al., 2009). No cure exists, and because of the chronic nature of this disease, patients build a long-term relationship with their healthcare professionals, most of whom they see on a regular basis. Most patients see their neurologist (generally seen as the principal healthcare professional, because of her or his role in the initial diagnosis and medication prescriptions) once every six months. Neurologists can also direct patients to other healthcare professionals. A range of treatments is available, but physical therapists, speech therapists, occupational therapists, and dieticians are among the most commonly visited healthcare professionals. These healthcare professionals are not, in most cases, in regular contact with each other about a specific patient, and the pilot project is an attempt to stimulate better involvement of these geographically dispersed healthcare professionals and the patient (ParkinsonNet, 2012).

Data collection
For this chapter, I performed in-depth case studies of five POHCs, where I interviewed healthcare professionals and observed them during a period of between 22 and 34 months (see Table 4 for an overview). I observed the online behavior of the five patients and the 19 healthcare professionals involved in their care provision, which led to a dataset of, in total, 377 written posts. Entrance to the five cases was obtained via semi-structured interviews with the patients (only patients have the ability to add others to their POHC, and I contacted them with the help of the Parkinson’s nurse assigned to each region). I selected the five POHCs on the basis of the multiplicity of medical disciplines of the professionals involved, to allow for the best analysis of how surveillance enters healthcare professionals’ daily work. After all, if only the neurologist is included in a patient’s POHC, their virtual context would not be much different from the traditional context of the consultation room, in terms of the
Power to the Patient?

heterogeneity of the audience involved in the surveillance. In total, 19 different healthcare professionals were involved in the five POHCs (four professionals were involved with two or three POHCs in my sample), and they included neurologists, physical therapists, nurse practitioners, occupational therapists and rehabilitation specialists. In addition to the observations of the five POHCs, my dataset includes semi-structured interviews with 13 of these healthcare professionals. I contacted all 19 healthcare professionals involved in the POHCs but six of them declined to be interviewed because of time constraints. I did, however observe postings on the POHCs of all of the 19 healthcare professionals.

I, a white, middle class woman, at that time, in my mid-twenties, conducted the semi-structured interviews face-to-face, although in some cases a telephone interview had to be performed due to time constraints of the respondent. The topic list focused on how healthcare professionals experience the use of a POHC, what they think are the advantages and drawbacks; which subjects are useful to discuss online, and which are not; and in what cases they hesitate when posting messages online. During the conversations, I focused part of the interview on the increased visibility of communication. I explicitly asked the interviewees about their experiences regarding the watching eyes of others, although some healthcare professionals discussed this topic without explicit prompting. Face-to-face interviews lasted between 23 and 66 minutes, while the telephone interviews lasted between 15 and 27 minutes. All interviews were transcribed verbatim. To protect the privacy of healthcare professionals and patients, aliases were used to identify the respondents.

<table>
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<th>Personal Online Health Community</th>
<th>Healthcare professionals</th>
<th>Observation</th>
<th>Length observation in months</th>
<th>Number of posts</th>
<th>Interview</th>
<th>Length of interview in minutes</th>
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<tr>
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<td>69</td>
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<td>32</td>
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<td></td>
<td>X8, occup. therapist</td>
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<td>32</td>
<td>-</td>
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<td></td>
</tr>
<tr>
<td>Total</td>
<td>19 healthcare professionals, 4 in multiple POHCs</td>
<td>Between 22 and 34 months</td>
<td>377 posts</td>
<td>13 healthcare professionals, 4 in multiple POHCs</td>
<td>Between 15 and 66 minutes</td>
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Table 4. Overview of included patients and healthcare professionals in Chapter 4.
Data analysis

The analysis started with reading the interviews with healthcare professionals. In reading those, I noted how professionals were aware that others could see and possibly judge their communications. This realization led me to the concept of surveillance, which also connected to my interest in power processes in health innovations (such as POHCs). I coded passages that made some reference to how communication on the POHCs was affected by the heterogeneous audience present. I started coding these instances first with the general code of surveillance, and then tried to get a sense of which information they were (un)willing to share. During this initial coding, a general distinction came up, as professionals provided reasons for why conversations were (un)suitable for the patient versus why they were (un)suitable for fellow healthcare professionals.

My second order coding was derived from my theoretical approach. In my linking of surveillance literature to the dramaturgical literature, I distinguished between different aspects of surveillance which also formed my second order codes. These aspects are front- and backstages (or, transparency), scripts (or, accountability), and regulation of others’ performances (or, monitoring). While reading the interviews, therefore, I coded sections that were either discussing making communication transparent, being accountable for one’s actions, and monitoring others’ performances. In this coding, I was particularly interested in the argumentation professionals used for their activities.

After identifying the passages in the interviews that fit the above criteria, I moved my analysis to the observations of the POHCs. The content of the POHCs was also analyzed on the basis of the above mentioned three aspects, but required a different focus. On the POHCs, surveillance was rarely openly referenced; I could only observe the end product (i.e., what they actually wrote down) of the internal process of deciding how to engage with the heterogeneous audience on the POHCs. Therefore, the observations of the medical discussions on the POHCs allowed me to connect what was said during the interviews (about the internal decision-making process) to what was actually communicated on the POHCs. Therefore, the reasons and aspects identified in the interviews guided my analysis of the observation of the POHCs.

With this overview of significant excerpts of both the interviews and observations, I was able to conduct an in-depth discourse analysis. This approach required studying the way language is used by research participants to describe their own account of social reality (Fairclough, 1992). Going beyond the superficial content of quotes and excerpts, I analyzed how healthcare professionals phrase their own accounts, enabling me to reflect on how their language constitutes the framing of their own position on the POHCs and their relationships with others. In my analysis of the text produced by the professionals, I saw the text not as a reflection of a stable reality, but as language created in that specific context in relation to the interviewer (Alvesson, 2010).

In conducting discourse analysis, I used a number of lenses to go beyond the superficial layers of the excerpts. First, I looked at the use of words and sentence constructions; sentences including normative statements (e.g., ‘should’), oppositions (e.g., ‘but’) or hesitations (e.g., ‘might’). Second, I examined the tone of the excerpts (e.g., sarcastic or apologetic). Third, I critically examined the material consequences of what was said, such as excluding others from conversations. Such an eye on details of what is said and how it is said enabled me to take a fine-grained approach to learning how professionals enact surveillance.

All interviews and postings on the POHCs were in Dutch. I conducted my discourse analysis on the original Dutch text and translated the excerpts I used in this chapter to English at the last possible moment. In this translation I focused on containing the meaning and, when relevant, the phrasing used by the professionals. I prioritized containing the tone of the excerpts over the literal word-for-word translation of the text. Moreover, I copied punctuation (errors) observed on the POHCs. In the section that follows, I display the excerpts from the interviews (in italics) and observations (in boxes) that best convey the content of the data as it was collected.

RESULTS

Creating front- and backstages

The POHCs allow the communication between healthcare professionals and
patients to become more accessible for all involved (ParkinsonNet, 2012). In other words, an important aspect of the POHCs is creating more transparency. First, I discuss how professionals experience patients’ presence in the audience to see healthcare professionals perform their daily work:

The advantage [of using a POHC] is that this isn’t going behind the patient’s back. Because you know, as a patient you can also say to the therapist [...] just talk about it with the neurologist, but then he [the patient] doesn’t know what has been discussed with the neurologist. And this way, at least he is aware of the information that is exchanged.

Eric, neurologist - interview

Eric describes that, in his experience, the POHC changed the communication with and about the patient. In the past, patients would sometimes ask one of their therapists (e.g., physical or occupational therapists) to initiate communication with him (as the neurologist). As Eric explains, this way the patient was not aware of the content of the conversation. He phrases this as “going behind the patient’s back”, invoking the image of talking about someone who is near, but nevertheless not included in the conversation. With the introduction of the POHCs, the conversations among professionals became accessible for the patient. Therefore, the transparency created by the POHCs brings communication from the back- to the frontstage.

Although Eric speaks to the advantages of transparency, there are also healthcare professionals who see downsides to the involvement of patients in every aspect of communication between healthcare professionals. The transparency of the POHCs has its limits, as a physical therapist describes:

The patient doesn’t always have to be there when you discuss certain things, because it’s a discussion on a medical level, so to speak. [...] In that case, it’s easier to just go back and forth about if it might be this or that. That might just work a bit easier. But the most important thing is that the patient gives consent for the discussion, and that you feed back the information.

Matt, physical therapist - interview

This excerpt indicates that healthcare professionals construct the ‘ease’ of communication as a criterion for deciding to exclude patients from conversations. Excluding the patient allows for ‘going back and forth’ about possible diagnoses, implying that these conversations are not suitable for patients, even though diagnosing forms an important part of the performance of their daily work. Through Matt’s use of the words ‘medical level’, he positions the patient as not being on the right level to interpret these diagnostic conversations. In his words, conversations about possible diagnoses should be taken to the backstage instead (i.e., communication outside of the POHCs). Ultimately, Matt’s performance of his work in terms of diagnosing “might” be easier on the backstage without the patient’s presence in the audience, because “here the performer can relax; he can drop his front, forgo speaking his lines, and step out of character” (Goffman, 1959, p. 112). He explicitly mentions that after such conversations take place, information needs to be fed back to the patient, who is only able to see the frontstage (i.e., the POHC).

The presence of this backstage for medical conversations also became apparent in the observations of patients’ POHCs. In the following excerpt, we see Katie, a neurologist, talking to a patient about a rash that he described to his healthcare professionals, which he thinks is a result of the skin patch he uses to receive his medication:

Postings on POHC 1

Katie, neurologist
We’ll do some research on your question about the neupro patch. My colleague [Parkinson’s nurse X1] will contact the manufacturer in the coming days. We just discussed it in our meeting. I hope the skin disorder hasn’t gotten worse.

Patient 1
I went to the general practitioner yesterday with a letter to invite him to join the POHC. I showed him the spots and he thought it was a contact allergy.
If the general practitioner thinks you’re experiencing a contact allergy from the patches and it won’t go away, then maybe we should switch to different medication after all. But then, I would like to see you again in the clinic.

As Katie openly explains, she has communicated on a backstage with other healthcare professionals in a meeting, and uses the frontstage of the POHC to relay the next steps of action. The patient, in the meantime, has also gone backstage to ask his general practitioner for advice. This general practitioner is not participating in the POHC yet, however, through the patient, his opinion (that the patches are causing a contact allergy), becomes performed on the frontstage of the POHC. Katie, in turn, acknowledges his diagnosis but argues that if they want to decide to change medication, the patient will have to come into the hospital to have a face-to-face meeting (backstage). This excerpt helps to construct a more nuanced interpretation of transparency on the POHCs; not all communication is made transparent on the POHCs. Rather, both healthcare professionals and patients have offline conversations with other healthcare professionals to ensure the presence of multiple points of view.

The transparency offered by the POHCs is not only difficult with an audience of patients. The healthcare professionals also comment on the difficulties that arise when communication between themselves and a patient becomes available for their fellow healthcare professionals. These difficulties become particularly pertinent when topics of a private nature are discussed on the POHCs. Parkinson’s disease comes with a myriad of debilitating symptoms, some of which are typically considered rather sensitive issues. Although these topics might be hard to address in the consultation room as well, the fact that everyone is able to read about them when discussed on POHCs, makes it more difficult for healthcare professionals to discuss such issues.

I think that private topics, sexual disorders, that people don’t like to discuss that online. But if it concerns the evaluation of certain medication changes, for example. That they could discuss.

Tim, neurologist - interview
again. Through these practices, the boundaries between front and back become blurred as professionals are more transparent about the process of deliberation but not necessarily about the content of these deliberations.

Use of scripts

When deciding what information and communication to make transparent, professionals use and construct scripts that prescribe appropriate communication. We have already seen examples of this with healthcare professionals discussing how medical conversations (based on medical scripts) are not appropriate for patients while performing on the frontstage of the POHCs. Below, I discuss an example of a Parkinson’s nurse who draws on a script of professional conduct between patients and healthcare professionals:

This one lady said “you should just call me Betty”. But then I don’t do that on the POHC, you know. Yeah, I think, the neurologist can also see it in that case. And then I think, yeah, it wouldn’t be really professional if I say “Hi Betty, how are you? How was bingo?” you know? No, I don’t do that [...] yeah but that’s just because others are reading it as well. You just have to have some sort of a professional attitude. Not that you’re not professional when you are in that situation, but here [POHC] you see it in black and white.

Julie, Parkinson’s nurse - interview

Julie explains how, for her, there is a difference in the tone of offline conversations compared to online. Through a dramaturgical lens, we can interpret her behavior as impression management when communicating on the POHCs. The script of professional conduct Julie uses, prescribes how informal she can be when addressing a patient. This script acts as a “means of getting an audience to understand a role” (Kivisto & Pittman, 2013, p. 275). In other words, performing according to this script ensures that the audience (consisting of a patient and fellow healthcare professionals) recognizes her as a ‘professional’. As the quote continues, Julie seems especially concerned with impression management in relation to the neurologist. Whereas she allows herself to address her patient informally during offline conversations (Julie ‘should’ call her Betty), the frontstage of the POHCs changes the script on appropriate ways to talk to patients. The nurse’s construction of professionalism (as constituted in relation to the neurologist) asks for more distance between patient and healthcare professional. Different scripts seem to exist around what professional behavior entails in terms of informal communication. Rather than going along with the patient’s wish to be addressed in an informal way, this nurse prioritizes the neurologist as an audience member over the patient. She chooses to be accountable on the basis of a script of professional conduct she constructs in relation to the neurologist instead of in relation to the patient.

Not only the content, but also the attentiveness one displays through one’s messages is a topic that professionals are accountable for when they communicate on the POHCs. Below we see three postings observed on different POHCs where healthcare professionals explicitly refer to how they provide care while being part of a POHC.

Posting on POHC 4

[The patient initiated this conversation about how she had been doing. The Parkinson’s nurse intervened in the conversation, telling the patient to actively invite the physical therapist for the ‘virtual meeting’ next time so that he’ll get a notification. The patient answers that she though she did. The physical therapist then writes the following:] 

Matt, physical therapist
I did receive a notification. But I just discussed this face-to-face [with the patient]. Next time, I’ll just do it electronically. Of course, that’s what we’re supposed to do :)

Julie, Parkinson’s nurse - interview
Posting on POHC 3
[The patient posted an additional question, after posting a question about a new therapy that was mentioned in the newspaper the day before. The rehabilitation specialist responds to that additional question as follows:]

Becky, rehabilitation specialist
To be honest, I still need to read that article. I’ll do that first.

Posting on POHC 3
[The Parkinson’s nurse started a conversation saying that she had to cancel an appointment last minute. The patient responded the next day, giving an update on how her other appointments had gone. The Parkinson’s nurse responds 2.5 weeks later, starting her posting with the following:]

Tami, Parkinson’s nurse
I am only seeing this message now... don’t always get alerts for postings anymore. So must become more attentive myself!

In these excerpts, healthcare professionals are apologizing for different kinds of inattentiveness. They apologize for a backstage conversation or a lack of response, because they either have not caught up with the newest developments in terms of research or because they missed the alert that notified them of a new post. Through these apologies, they position the POHCs as presenting a new expectation of timely and expert responses that are visible to all. These expectations indicate that the environment of the POHCs alters the scripts prescribing the “rights and duties” (Goffman, 1959, p. 16) of healthcare professionals. However, these scripts, through which they justify actions, are not uniform for everyone. Rather, multiple scripts coexist, as other healthcare professionals do not feel the same pressure to respond quickly:

[I: did you make any agreements on how long you can wait with responding?] No we don’t have any agreements like that here [...] of course it would be nice to not take too long [...] but a response within a couple of days is fine. [...] But it’s one of 40 or 50 emails that I get in a day. So that disappears very quickly from my mind and then I think “oh yeah I still need to do something with that email”.

Tim, neurologist - interview
[talking about Patient 1:] if he needs to wait three days, maybe sometimes a week, for an answer, that might be very frustrating for him. If you think “well, there is a POHC, I can ask my neurologist questions at any given time”. [I: and this is not possible in reality?] No. [...] I just don’t get around to it.

Katie, neurologist - interview

These two neurologists, who are both based at the same hospital, construct a different picture of the response times patients can expect from them compared to the healthcare professionals observed above. They seem less concerned with response time as a topic to be accountable on, as they cite the reality of time constraints. These different quotes construct the existence of multiple scripts that professionals feel accountable on when communicating on the POHCs. One of these is a script of technology, prescribing certain conventions around how to use the possibilities for quick response times that the technology affords. The other script (used by the neurologists above) speaks to the high demands of their profession and the limited time they can spend on individual patients.

Regulating the performance of others
So far, I have examined surveillance as a largely internal process focusing on professionals’ responsibility for their own performances. On the POHCs, however, surveillance is also an interactive process where one can monitor another; by reading each other’s messages and supplementing them where necessary. A physical therapist describes how such monitoring regulates the conversation a patient has with her or his healthcare professionals.
The explanation that the patient gives, they don’t always know what is going on. [...] And when medication is changed because of a particular reason [they say] “yeah, my medication has been changed”. But why? “Well, I don’t actually know”. And some people can articulate this, but a number of them can’t. And in that case, I like seeing [...] what has been done, how did it go [...] and how is going now. And that is easier than having to get all of the information from the patient. Because the patient only talks about how he feels. And what he thinks happened. [I: and that isn’t always correct…?] No

Shelby, physical therapist - interview

According to Shelby (a physical therapist), reading how other healthcare professionals feel the patient is doing, allows for a more accurate description of the patient’s health status, compared to getting the information from the patient (as was common before the introduction of the POHCs). Without direct contact, the professionals could not be sure if this was entirely correct information as the patient only talks about “what he thinks happened”. Therefore, by broadening the audience for healthcare professional-patient interactions, the physical therapist is better able to manage the information from other healthcare professionals. Fellow healthcare professionals in the audience can potentially interfere when the performance a patient gives is going wrong. If such regulating is necessary “poor members of the team, who are expressively inept, can be schooled or dropped from the performance” (Goffman, 1959, p. 112). ‘Dropping’ the patient from the performance by directly communicating with the other professionals could prevent the patient from making a mistake in relaying information from one healthcare professional to another. Below, I discuss an example of monitoring of the patient observed on her POHC.

Postings on POHC 3

Patient 3
My muscles are very sore from the exercises of sitting up straight and balancing on a big ball; could not get one foot in front of the other. Now there is some improvement in my backaches... the quadriiceps and the right foot only really hurt. This is probably muscle soreness and that is a good sign, right? Have been working on it for half a year already. I’m also sitting lop-sided in this chair and every movement is one too many. So I’m keeping it short..

Brian, Parkinson’s nurse
During my visit, I noticed that you were sitting incredibly lop-sided and that you also walk incredibly lop-sided (I’m not a real expert, but it seems to me that somehow you tilt your hip extremely inwards?) I don’t recognize this stance from before. It has been an extreme change in the last 27 months. Hopefully, someone in your team has a solution.

Tyra, physical therapist
I just read Brian’s message. Would it be useful to make an appointment again after all? I would like to look at this with you.

Brian (a nurse practitioner) picks up on some of the hints the patient has left about her ability to sit straight. He communicates his worries about her ability to walk straight and actively asks the other healthcare professionals to present their thoughts on this problem (something the patient has not asked for, as she focuses on the aches she experiences). Through this monitoring, the nurse practitioner supplements the patient’s performance, by emphasizing the severity of her symptoms. His interjection ensures that the patient’s problems are noticed even when she does not emphasize them as much. Tyra’s (a physical therapist) response confirms the worry of the nurse practitioner about the patient’s symptoms, as she suggests it could be useful to make an appointment outside of the POHC, bringing the rest of this conversation to the backstage of
the therapist’s consultation room. We also see Brian acknowledging that he is not an expert in this area. By doing this, he establishes the other healthcare professionals in the audience as the expert performers with regard to this subject, bringing them on the frontstage with him. Acknowledgement of professional expertise becomes more apparent in the next paragraphs, where I discuss the monitoring and regulation of the performance of fellow healthcare professionals.

Similar to my analysis of front- and backstages and the use of scripts, I see that professionals do not only regulate performances of patient performers but also of fellow professionals performing on stage. As I noted earlier, healthcare professionals’ impression management revolves around a script of professionalism, which they perform on stage. In this performance they display their disciplinary expertise. I analyze an excerpt from an interview with Jason (an occupational therapist) who discusses the importance of his disciplinary expertise in the treatment of patients. Patients seeing an occupational therapist often look for adjustments to their homes or workplaces to make their day-to-day life easier. As the occupational therapist describes, although he is responsible for making such adjustments, the neurologist is also often involved in suggesting certain solutions to be made.

*Neurologists also discuss adjustments and measurements and then he [the neurologist] says “that might be a good solution”. And then I visit the patient and think “that’s really not a good solution”. Then I just put it on the POHC, like “I’ve tried this and this and it didn’t work because of such and such”. And then the neurologist knows this. But you also have to be a bit careful with how you communicate these things to patients, because ‘what the doctor says must be true’. [pretending to be the patient:] “But, actually, my neurologist thinks this is a really good idea”. Then I just say “yeah but if he takes care of the medication, then I stick to my disciplinary background”.*

*Jason, occupational therapist - interview*

This quote constructs the introduction of POHCs as making it easier to monitor and regulate the transgression of professional boundaries: Jason ‘just’ writes on the POHC that he has tried a solution offered by the neurologist, but that it did not work. That direct line with the neurologist is positioned as an advantage of the POHC for Jason. At the same time, emphasized by the word ‘but’, professionals are also careful about the phrasing of such messages. In performing his daily work, Jason is aware that the patient might disagree with his proposed solution (i.e., the patient uses another script) and patients might position him in a different role than he wants to play. As Jason suggests, the patient is used to the neurologist always being right, so she or he might prefer the neurologist’s word to that of the therapist’s. He, rather sarcastically, comments that ‘what the doctor says must be true’, suggesting a sense of irritation toward the idea that his discipline is ranked lower and his opinion is valued less than the neurologist’s. However, because of the POHC, Jason is now able to regulate the performance of both the patient and the neurologist. As the patient is also in the audience on the POHC, Jason needs to (and can) perform his daily work and display his disciplinary expertise to both parties at the same time. He is able to ‘expose’ the neurologist as less of an expert in the area of occupational therapy than Jason is, by indicating that his solution did not work.

Next to the allied healthcare professionals, some medical specialists (in this example, a rehabilitation specialist) also display an awareness of the boundaries between disciplines.

*Imagine that they [patients] have certain symptoms and I think the physical therapist should give a certain type of treatment. In that case I think I should communicate this to the physical therapist first […] because if I would post on the community “well I think your physical therapist should do this and that…” That’s not a decent thing to do. That’s a collegial code that you adhere to. […] It’s great that everything is now visible for everyone, but it also means that some things are not possible and that you should be aware of that.*

*Becky, Rehabilitation specialist - interview*

Drawing on a script of professionalism (a “collegial code”), Becky argues
that it is not "decent" to discredit a fellow professional's work in front of the patient. Using the word 'should', she emphasizes the existence of (unwritten) norms (i.e., scripts) around how you approach disciplinary boundaries in a collegial setting. When we compare the responses of Jason (the occupational therapist) and Becky (the rehabilitation specialist) we see that they are both aware of the fact that disciplinary autonomy and expertise exist and should be handled carefully. Notably, Jason talks about these disciplinary differences from the viewpoint of monitoring his own performance. Becky, on the other hand, discusses it from the viewpoint of monitoring someone else’s performance, constructing a hierarchical difference in whose performance needs regulation on the frontstage and with what goal. The rehabilitation specialist, similar to the neurologist, is part of a group of specialists with a higher number of years of formal education than the allied healthcare professionals (the group Jason, the occupational therapist, belongs to). The allied healthcare professional fears a transgression into his territory where the specialist is not confronted with similar issues, and instead has to be careful not to embarrass someone in a lower hierarchical position. Dramaturgical literature refers to this as 'defensive' and 'protective' practices, respectively (Goffman, 1959, p. 212). These defensive practices are used by professionals when their own performance on the frontstage is threatened, whereas protective practices are used by the audience or fellow performers to save the performance occurring on stage. These practices, and the different use of them by different professionals, are an important way through which healthcare professionals enact monitoring.

DISCUSSION

Point of departure for this study was the development of a dramaturgical approach to professional surveillance, by asking the question as to how professionals enact surveillance in their daily work. Professional surveillance has intensified and is increasingly conducted in new configurations such as networks or by clients and other non-professionals (Adler & Kwon, 2013; Bogard, 2006; Mann et al., 2003). Literature on surveillance has argued that the existing dichotomy between resistance and compliance does not do justice to how professionals respond to these new forms of surveillance (Collinson, 1999; Gleeson & Knights, 2006; Levay & Waks, 2009; Shapiro & Matson, 2008; Thomas & Davies, 2005). I extend this conversation with my developed dramaturgical approach to professional surveillance that shows how professionals enact surveillance at the micro-level of interaction. Although my empirical analysis is specific to the context of healthcare provision, I argue that it speaks to more general processes of the intensification of watching eyes on professionals’ work (Adler & Kwon, 2013) and organizing through network structures (Oberg & Walgenbach, 2008).

In my examination of professional surveillance, I brought together literature on professionals (Adler & Kwon, 2013; Dent & Whitehead, 2002; Noordegraaf, 2011), surveillance (Ball, 2010; Collinson, 1999; Ramirez, 2013), the micro-interactional level of organizing (Knorr-Cetina & Bruegger, 2002; Larson & Wikström, 2007; Patriotta & Spedale, 2011), and dramaturgy (Brivot & Gendron, 2011; Moeran, 2005; Patriotta & Spedale, 2011). The framework I built on this combination of literatures uses various theatrical elements to understand different aspects of surveillance showing how professionals actively engage with (i.e., enact) the watching eyes of multiple audiences rather than react to them. Using this framework in my empirical analysis highlights a main theoretical contribution of this study which is that reconceptualizing 'surveillance as enacted,' shows that surveillance is not external to one’s professionalism, but constitutes an integral part of it, as I will discuss in more depth below.

The analysis shows the interrelations between surveillance and elements of the theater, looking at transparency on various stages, script-based accountability and monitoring through regulating others’ performances. On the frontstage (the POHC), transparency exists as performances are played out in front of an audience. Around the frontstage, multiple backstages exist where performers hide performances from different audiences. Professionals manage the watching eyes of specific audiences through playing with the different stages. Goffman (1959) suggests that front- and backstages should always be understood in reference to a particular performance. Although I have depicted the POHC as a frontstage, the backstage activity that takes place (for example, a
neurologist discussing diagnoses with his team of colleagues) can be regarded as another frontstage (if you take the point of view of the neurologist or his colleagues). My analysis thus shows that one performer’s backstage can, from the perspective of certain audience members or fellow performers, simultaneously be a frontstage. Furthermore, eliminating the backstage (creating total transparency) is often not possible as professionals find a way to organize the backstage in again (Johnson & Regan, 2014; Van den Brink, Benschop, & Jansen, 2010). My analysis allows me to demonstrate that professionals mostly create this backstage to make the content of conversations invisible to allow for more efficient communication on a ‘medical level’. However, the process and the fact that backstage communication takes place are made transparent by these professionals. This finding of the difference between content and process transparency might be embedded in or prescribed by medical ethics (a form of a professional script). In these ethics, privacy and handling information in a sensitive manner remain important values while involving patients in the process of care is becoming increasingly important (Car & Sheikh, 2004).

Dramaturgical scripts provided a basis for the accountability, a common theme in professional surveillance literature (McGivern & Ferlie, 2007; Munro & Hatherly, 1993; Ogden et al., 2006). The rules and regulations, and the (speaking) lines that are (implicitly) present in scripts allow professionals to be judged by the members of the audience on the POHCs. As my analysis suggests, multiple scripts can exist at the same time, especially as professionals have only recently started using this technology and need to adjust to the eyes of a heterogeneous audience. Being accountable in front of a heterogeneous audience requires improvising and changes to existing scripts which are not easily made (Greener, 2007; Ramirez, 2013). Dealing with conflicting scripts plays a larger role in surveillance and impression management than has been hitherto acknowledged, and forms an important way in which professionals enact surveillance beyond compliance or resistance.

In literature on surveillance, monitoring is often positioned as revealing a dark side of organizations, zooming in on the negative consequences for professionals who will be judged on their faults (Ball, 2010; Brivot & Gendron, 2011; Knights & McCabe, 2000a). Such a focus is connected to a recent surge of chapters in organizational literature on the (unquestionably important) ‘dark sides’ of organizations (e.g., Skinner, Dietz, & Weibel, 2014; Willmott, 2013). However, my dramaturgical approach allows me to illuminate a ‘brighter side’ of the monitoring and regulating of performers/professionals. I can see how healthcare professionals get a stage on which to display their professionalism, and on which they can monitor transgressions of their professional boundaries. To some extent, this echoes Waring and Curie’s (2009) conclusion that changes to professions can sometimes be used or converted to secure legitimacy. Moreover, referencing Goffman, others have shown that repeatedly watching each other’s daily work, for example in operating rooms, can contribute to smoother organizing processes (Riley & Manias, 2005). My study contributes the idea that monitoring (and surveillance in general), seen through a dramaturgical lens, can become a resource for professionals, rather than only a liability.

Bringing these three aspects together in one framework that reconceptualizes surveillance, enables me to answer my research question of how professionals enact surveillance in their daily work. I show how professionals create backstages, use different scripts for their interactions with different audiences, and defend or protect performances to manage professional impressions. Thus, they engage in different activities that make surveillance an integral part of their daily work and their sense of professionalism. For example, as the Parkinson’s nurse is performing on the frontstage, she reconsiders the scripts that are used for establishing her professionalism and, on the backstage, she hides more informal behavior. This is an active process in which some audience members are prioritized over others. The fact that the Parkinson’s nurse is more concerned with displaying her professionalism in relation to the neurologist compared to the patient is not a simple matter of complying or resisting the watching eyes of the heterogeneous audience, but an active engagement with them. Professionals enact surveillance and how it is a part of their professionalism, as they are aware of the possibilities for surveillance and decide how they can engage with this surveillance in such a way that it improves their daily work and the impressions they make. As surveillance becomes a part of professionals’ daily work (they need to reflect on how they come across to a heterogeneous audience), professionals also become part of and drive
the surveillance possible in the POHC (by deciding what is visible, how that is judged and how performances can be regulated). Based on these empirical findings I have contributed an in-depth, micro-interactional conceptualization of surveillance.

*Enacting surveillance, enacting power*

This reconceptualization of surveillance shows the ways in which different actors influence their own and each other’s performances, but a deeper analysis of power within the framework is warranted. A reactive view of surveillance tends to locate power in the reactions to surveillance, by for example, focusing on professionals avoiding, defying and manipulating surveillance (Sewell, 1998; Shapiro & Matson, 2008). Some authors emphasize that professionals, in reaction to this surveillance, exercise agency in an attempt to maintain their autonomy and position of authority (Gleeson & Knights, 2006; Levay & Waks, 2009). I take this analysis of power one step further through my dramaturgical approach that zooms in on and highlights how surveillance is enacted as a form of power at the micro-level of interaction. Therefore, I can show in more depth how enacting surveillance enacts power, and how hierarchies are played with. To make these points, I return to the theatrical metaphor and employ the dramaturgical concepts of audience placement and lead and supporting roles.

In the theater, an important aspect is the placement of audience members, where seats are available further from and closer to the frontstage. I bring this idea of placement of audience members as an extension to Goffman’s work to show how it can be linked to surveillance as a form of power in multiple ways. First, for the audience members, their seat affects the (in)visibility of the performance. Going back to transparency, I have seen that some audience members got to see more or got a better view than others. Those audience members who were given the front row seats had the best view, revealing the power processes involved in the theme of transparency. Second, for the performers, the placement of audience members affects who they can see most clearly, as it shows who professionals feel accountable to. My analysis shows that, especially for lower ranked professionals, other professionals (in particular the higher ranked ones) are on the first row; these professionals are the ones for which the performers on stage are trying the hardest to put on a good performance, displaying their professional expertise. Back seats are much less visible to the performers on stage, suggesting that when audience members are placed in those seats professionals behave less accountable to them in that context and are less concerned with them watching their performance. This division reflects the importance of impression management when performances are subject to subordination and insecurity (Collinson, 1999).

The placement of audience members works differently for higher ranked professionals. In their discussion of what to make (in)visible they seem to position the patients on the first rows. Higher ranked healthcare professionals might have an easier time assigning the best seats to patients, because their professional expertise is not as much a topic of debate as it is for lower ranked professionals. They can, as it were, ‘afford’ to prioritize the patient over their fellow professionals, as their professional identity is not in the same way at stake in relation to the other professionals present. Expertise of higher ranked professionals seems to be self-evident from the longer years of training and status assigned to their discipline (Dent & Whitehead, 2002). Although the evidence in my data is not conclusive, it does suggest that being watched by a heterogeneous audience might pose a bigger risk to one’s professional status for lower ranked professionals than for higher ranked.

At the same time, lower ranked professionals can also gain the most from performing in front of a heterogeneous audience as we can see through the second metaphor drawn from the theater: the aspect of lead and supporting roles. The use of the POHCs makes it visible who leads and who follows in a performance. Some professionals are given the lead roles over others by the performer(s) on stage. As multiple roles are available to individuals, performers sometimes have the flexibility to play with and switch roles (Greener, 2007). Using the concept of lead and supporting roles to the themes of surveillance, I note that monitoring allows professionals to change who leads and who supports. The therapist was
able to assign himself the lead role through regulating the performances of the patient and the neurologist when the neurologist encroached on his disciplinary boundaries. With this regulation he moved the neurologist to a supporting role.

These examples show that linking surveillance to dramaturgical concepts adds to our understanding of surveillance as a form of power. Rather than linking the exercise of surveillance to control on the one hand, and separating that from linking (agentic) reactions to this surveillance on the other hand, my developed framework shows that by enacting surveillance, power is also enacted. Such an enactive view of power brings to the foreground how professional hierarchies are performed and constructed through daily work, and departs from seeing professional hierarchies as a cause for or effect of reacting to surveillance.

Implications and future research
To end this chapter, I move on from my theoretical contribution and discuss the practical implications of the framework. The surveillance of medical professionals exists parallel to discussions about patient-centered care provision. These discussions advocate a more prominent role for patients in medical decision-making, requiring more openness and transparency from the healthcare professionals (Berwick, 2009). Linking my discussion of professional surveillance to patient-centered care, suggests that the total transparency and accountability expected in patient-centered care is hard to achieve because of the management of impressions done within the enactment of surveillance. As long as healthcare professionals associate certain scripts to their professional status (such as those about medical deliberations and the formality of tone of conversations), healthcare professionals will try to achieve and manage a particular impression in front of their audience. The heterogenization of the audience (an important aspect in recent calls for integrated care (Kodner & Spreeuwenberg, 2002)) makes this process of impression management even more difficult. Professionals who are attempting to provide more patient-centered care should critically reflect on the limits of this ideal in terms of the professional identity that they construct for themselves.

Furthermore, I would like to comment on an avenue for future research. I note that patients did not gain a central role in my analysis. My focus on surveillance of professionals was chosen purposefully because they underwent the greatest transition, in terms of surveillance, through the introduction of the new technology (they were not used to being able to be judged by different parties, whereas patients were already subjected to watching eyes of their multiple healthcare professionals). However, patients might also struggle with the question of what information they can post when it is read by all healthcare professionals at the same time. For example, patients might phrase their experiences with and opinions about medication changes differently to their neurologist compared to their physical therapist. Therefore, it would be interesting for future research to include these perspectives in an examination that looks at how patients (or, more generally, clients or customers) can enact surveillance, and how this might differ from professionals.

I believe that the insights I developed may inspire research in other organizational contexts. In line with a discourse of co-creating services and products, other sectors are also implementing similar network structures, such as online brand communities, where multiple audiences are brought together (Harryson, Dudkowski, & Stern, 2008; Wiertz & de Ruyter, 2007; Wood & Ball, 2013). In these contexts, whether online or offline and whether inter- or intra-organizational, watching eyes of others will force organizational members to engage with increased surveillance. In these contexts, similar to the POHCs, what information is made transparent, what individuals are accountable for, and what monitoring takes place will play out within the interactions between the different actors.
CHAPTER 5

MAT(T)ERIALIZING BODIES IN ORGANIZING

Understanding power in organizing from the materiality-turn*

* This chapter is based on a single-authored article that is currently in a first round of review at Organization Studies. A previous version of this article was presented at the Academy of Management Conference of 2014 in Philadelphia, USA.
In this chapter, I argue that the recent ‘materiality-turn’ has underexplored potential for understanding power in organizing. Drawing on agential realism’s idea of agential cuts, I coin the concept of matterializing (with two Ts) to reposition agential cuts (temporary separations between subject and object) in explicit power terms. This concept demonstrates how agential cuts enact how (certain) matter comes to matter. I explore the concept of matterializing in the context of (patients’) bodies which leads to my empirical contribution: highlighting the entangled material-discursivity in the case of bodies, as bodies have traditionally received attention for their discursive constructions at the expense of examining the materiality of bodies. I make these contributions in relation to my empirical data, observations of online communication between patients and healthcare professionals. Based on this data, I show that through these actors’ postings bodies matterialize in such a way that they allow certain bodies to ‘become’ and exclude others.

INTRODUCTION

Advocating an increased emphasis on materiality is the focal point of a current movement of organizational scholars who question the relationship between discourse and materiality (Dale & Latham, 2015; Dameron, Lê, & LeBaron, 2015; Fotaki, Metcalfe, & Harding, 2014; Nyberg, 2009; Orlikowski, 2010; Robichaud & Cooren, 2013). Where traditionally discourse (including, but not limited to, the meaning we give to certain physical objects) has gotten most attention in Organization Studies, this ‘materiality-turn’ is speaking out against this narrow focus, arguing for the need to better include materiality (including, but not limited to, the physical object) in our examinations of organizational processes (Ashcraft, Kuhn, & Cooren, 2009; Carlile, Nicolini, Langley, & Tsoukas, 2013; Reed, 2000). This emphasis on materiality has an (underexplored) effect on how we understand power in organizing, which, as methods such as critical discourse analysis show, has often remained in the realm of language.

The way forward regarding the inclusion of materiality in examining organizing seems less self-evident, which has resulted in ontological debates around materiality and its relation to discourse (for an overview of the different positions in these debates, see: Hardy & Thomas, 2015; Orlikowski & Scott, 2015; Putnam, 2015). Agential realism, conceived of originally by Karen Barad (1998, 2003, 2007) and translated to Organization Studies most prominently by Orlikowski & Scott (2007, 2010; 2008), presents, perhaps, the most radical ontological consequences for how both discursivity and materiality are involved in organizational processes, and therefore, power in organizing. This theoretical stream argues that the discursive and material are ontologically entangled (Barad, 2003; Iedema, 2007; Nyberg, 2009; Orlikowski, 2010; Orlikowski & Scott, 2014). As such, agential realism opposes a more common view held by others that discourse and matter are two separate entities with an independent core where one pre-exists the other (Hardy & Thomas, 2015; Leonardi, 2011; Zammuto, Griffith, Majchrzak, Dougherty, & Faraj, 2007).

The usefulness of agential realism for Organization Studies has been a topic of debate. Those who are skeptical argue that it presents a too vague, abstract, and philosophical body of work, and, when it comes to empirics, impossible to translate from its origins in physics (i.e., waves and particles) to the social sciences (i.e., social processes in organizing) (Leonardi, 2013; Mutch, 2013). Proponents of this new ontological perspective state that it allows for showing how “the world is always in the process of becoming; it is enacted in practice” (Orlikowski & Scott, 2015, p. 704). Sympathetic to this latter perspective, I set out to explore agential realism’s potential for understanding power in organizing. I unleash this potential by drawing on Barad’s idea of ‘agential cuts’, which, I argue, provides an (underexplored) entry point into understanding power.

Barad describes agential cuts as enacting temporal separations between the subject and object (e.g., the individual and the body). In other words, agential cuts produce a separation between different components of a phenomenon that are otherwise entangled (and therefore, indistinguishable). Although these separations are not ontologically ‘real’, they do allow certain understandings of a phenomenon (in this case, bodies) that drive our activities. Simultaneously, they exclude other understandings of phenomena from ‘becoming’. As this chapter demonstrates, when and how these separations, and thus understandings, are enacted is a process of power. In short, I will examine
agential cuts in the context of patients’ bodies and demonstrate that agential cuts enact separations between the ‘subjective’ discursive (e.g., expressions and interpretations of feelings and sensations) and the ‘objective’ material (e.g., symptoms and medication) of the body. I coin the concept of ‘matterializing’ (with two Ts) as a way to reposition agential cuts in explicit power terms. These separations are embedded with power, because of the particular understanding of the body, and the simultaneous exclusions, they enact, as the decoupling of the ‘subjective’ interpretations from the ‘objective’ symptoms allows for rejecting certain bodies. As such, I move beyond an understanding of power (related to bodies) in organizing captured in the discursive (what we say and how we say it) to captured in the material-discursive. Moreover, I show that attempts made to separate the material and discursive add another layer of power as these cuts allow for certain bodies to mat(t)erialize and not others.

While I construct this theoretical concept of ‘matterializing’, I will, from the start, position it in an empirical context. Bringing in the empirical straight away will help to make Barad’s work and concepts more concrete (which addresses the criticism of Barad being applied in vague ways). To work through agential realism’s ontological approach (entangling matter and language), and consolidate its relevance for understanding power in organizing, I will embed it in empirics from the start. Therefore, this chapter will take an unorthodox approach to developing its main contributions: rather than perpetuating the abstract explanations of agential realism, I will discuss its main concepts by applying them directly to my data.

The empirical context in which I work through and apply agential realism is so-called personal online health communities (POHCs) that allow patients and their own healthcare professionals to interact online to discuss a patient’s health. In this virtual context, patients’ bodies are central to care provision and they need to be materialized online to be able to make medical decisions around a patient’s health. In this context, I ask the following research question: how do agential cuts enact the matterializing of patients’ bodies?

With this chapter, I make a number of contributions. The most important theoretical contribution is the consolidation of the underexplored potential for studying power in organizing of the ‘materiality-turn’, by mobilizing agential realism and its concept of agential cuts. As a product of this agenda, another (conceptual) contribution of this chapter is the development of the theoretical concept of ‘matterializing’. This concept allows for engagement with an explicit material-discursive perspective on bodies in organizing. Bodies offer an exemplary empirical foundation through which the historical dominance of discourse and language in understanding organizational processes comes to light (Ashcraft et al., 2009; Hardy & Thomas, 2015). As such, a last (more empirically focused) contribution of this chapter is that it highlights bodies in organizing beyond their relation to discourse (e.g., norms, symbolic representations, and the use of certain language), and positions them as simultaneously co-constituted by discourse and materiality; in other words, bodies in organizing are phenomena enacted through entangled material-discursive practices.

The chapter will now continue with an overview of the case and the methodological approach taken to the empirical data. Thereafter follows the theoretical discussion weaved together with the empirical in order to reach my aim for this chapter, which is to bring an in-depth power lens to the use of agential realism and to demonstrate the material-discursive entanglements involved in enacting bodies in organizing.

RESEARCH CONTEXT

In this chapter, I analyze an empirical context where patients interact with their healthcare professionals through a new communication technology. The so-called personal online health communities (POHCs) provide a place in which chronically ill patients can discuss all kinds of issues related to their disease with their healthcare professionals. Although bodies are not physically present in the conversations on the POHCs, they are central to the organizing of care on the communities, as the conversations center on the patient’s body and its illnesses. The POHCs that I examined were part of a pilot project set up by ParkinsonNet, a Dutch organization that aims to improve care for patients with Parkinson’s disease. The POHCs were one of multiple projects that they had set up in hopes of getting the patient and her or his healthcare professionals involved with and up to date about the patient’s care (ParkinsonNet, 2012).
The technological system of the POHCs provides patient and healthcare professionals with a menu of options. To examine the concept of materializing, I focus on the ‘virtual meeting’ section, where patients or healthcare professionals can start a ‘virtual meeting’ and invite specific healthcare professionals to participate. These virtual meetings can be on any disease-related topic, but often involve conversations about medication changes. Similar to face-to-face consultations, the ‘virtual meeting’ space allows for back-and-forth interactions between patient and healthcare professional(s). Only those invited to the meeting receive an email notification of the start of the meeting and any subsequent postings. However, the meetings are still openly accessible to anyone who is part of the patient’s ‘virtual team’. Those who are not actively invited are not notified, but can still see and participate in the discussion.

Data collection
I draw on data that was collected by observing patients’ POHCs. In total, I observed the POHCs of 14 patients, to which I got access by being added to the ‘virtual team’ of the patients’ communities. For this chapter, I use one example of an online conversation to be able to zoom in on the way the patient’s body mat(t)erializes in the POHC. I present one case, that of Luke (a pseudonym), as his POHC illustrates much of the use of other patients’ communities as well. I specifically chose Luke as almost the entire conversation was conducted online. Other patients had similar conversations, but they were often shorter. What generally happened in those situations was that their healthcare professionals chose to move the conversation offline, because they, for unstated reasons, preferred discussing these issues over the phone or in person. Although this one patient reflects a larger sample of patients, generalizability is not the core goal of this chapter. Rather, my goal with this analysis is a theoretical and empirical exploration of agential realism’s main concepts for understanding materiality and their impact on understanding power in organizing.

Data analysis
After collecting the data, I commenced analyzing the collected material. I initially came to the data being interested in the patient’s body, its position on the POHCs, and the power processes embedded in this process of providing care to virtual bodies. I started with collecting relevant quotes from the observations of all patients’ POHCs, noting any reference to the body. All references to the body, be they explicit references to symptoms or more implicit mentions in reference to ‘other’ bodies, were coded using the ATLAS.ti program. While I was coding these references, I was also immersing myself in the academic literature on bodies. I started with Foucault (1978, 1988), but because my data was simultaneously leading me to a more material perspective, my reading moved on to Butler (1993), and ultimately to Barad (2003, 2007). This journey led me to my interest in the entanglement of the material and discursive with regard to bodies. Noticing the lack of an explicit vocabulary to understand the power embedded in these ‘material-discursive bodies’, I then pinpointed my theoretical contribution in advancing an explicit power perspective to develop the materiality-turn’s underexplored potential for understanding power processes in organizing.

I realized quickly that to really develop this perspective, I should choose one conversation to allow for an in-depth, integrated story, rather than a disconnected analysis derived from multiple POHCs. This realization led me to select Luke’s case, and one back-and-forth conversation with healthcare professionals about his body and the symptoms it was going through. After selecting this conversation, I analyzed the content of this conversation more thoroughly, and focused specifically on the agential cuts enacted in the conversation. I used Barad’s definition of agential cuts as separation and enacting resolutions as a guide to findings these cuts. I looked for separations enacted between the material (e.g., symptoms or medication) and discursive (e.g., expressed feelings) and the ways in which these separations constituted moments of comprehension and compromise and then analyzed these sections from an explicit power perspective.

The conversations I analyzed were all written in Dutch. Before displaying the conversation between Luke and his neurologist in English, the text was analyzed in Dutch. I analyzed the text in Dutch, because translation inevitably entails a loss of meaning and by analyzing the text in the original language I hope to have captured as much of this meaning as possible. In the
translation from Dutch to English I focused more on translating the meaning than the literal translation of each word. The conversation displayed in the next section is somewhat shortened (by taking out greetings and endings) to limit the space used for displaying the conversation.

MATTERIALIZING THE PATIENT’S BODY

Luke, the patient I focus my analysis on, is a 73-year-old man, who was diagnosed with Parkinson’s eight years ago. The timing of when you start medication, which medication you take and how much at which stage are generally considered important questions within the doctor-patient relationship for Parkinson’s disease (Lees et al., 2009). In the early stages of his disease he decided not to take medication, but six months after his diagnosis he did make the decision to start his medication. During the interview, Luke described how a year and a half ago he started noticing that the pills he was taking were not effective anymore. His experiences with his medication were also laid out on the POHC. The excerpt below is part of a recurring conversation to find the right medication regime. In this excerpt, I see Luke and the neurologist in a back-and-forth process, discussing how the medication needs to be changed to make the patient more comfortable.

Luke
On Thursday April 4th 2013, I had a really bad day and night. Getting up and walking was almost impossible. I couldn’t get up the stairs, I took the regular dosage of medication this morning half an hour earlier. This worked until about 10.00. After that, things worsened again [1]. I am keeping myself to the prescribed dosage of medication again. Please advise.

[...]

Neurologist
Other illnesses/diseases can increase the signs of Parkinson. This could be a urinary tract infection, but also the flu or, for example, severe constipation. Next to that, Parkinson itself often shows fluctuations, there are good and bad days [2]. Every once in a while this can be pretty bad, while it goes back to normal after that [3].

What counts for every symptom: if it’s temporarily a bit worse, there is no reason to change anything about the medication. [3]

Luke
In the evenings after 7 pm, when I start getting tired, I don’t get around that well in the house. I keep falling asleep. My wife needs to keep waking me up. A hopeless task. The weird thing that happens is that if I, for example, go grocery shopping after 7 pm, it doesn’t happen.

Neurologist
The sleepiness for the most part will be a side effect of the medication, mostly from Sifrol, but maybe also a bit from levodopa (sinemet). If this continues to be a problem, we could consider slowly phasing out the Sifrol. Maybe the effect of this medication has started to decrease at this point. Often times, phasing out is possible with a slight increase of Sinemet.

Will you let me know if you want to try the phasing out? In that case you will have to have Sifrol pills of a lower dosage to start the phasing out. [4]

[...]

Luke
[description of recent history of changes in medication]. In response to an email on 30-06-2013 and a phone conversation on 02-07-2013; we have, in mutual agreement [5], decided to change the medication a bit. This did not have the effect that was hoped for. I did not sleep at all Thursday, Friday, Saturday, and Sunday night. (tremor in limbs, slowly or not at all be able to move, balance, etc.) I have since had the feeling that the overall condition, through the phasing out of Sifrol, suddenly strongly decreased. Do you have a solution for this, or could we maybe reverse the phasing out of Sifrol.

Neurologist
Of course, it shouldn’t be the case that the phasing out of the medication is causing you so much trouble. If this remains, there’s no other solution than to reverse the phasing out of Sifrol.

However, I would like to ask you to try something else [6], in the hopes of subduing the annoying side effects. My advice is to keep using a low dosage of Sifrol (2 x 0.375), but to take this in the evenings around 6 pm. The medication does work for 24 hours, but in the first period there is a stronger effect than at the end of the 24 hours. Will you let me know how this works out?

* Numbers in brackets refer to a quote that I come back to in my analysis.
I have two goals regarding what I want to illustrate with this analysis. The first goal is to work through agential realism’s main ideas by embedding it in empirical data. The second (and main) goal of this analysis is to zoom in on agential cuts as a way to develop the materiality-turn’s potential for understanding power processes. As I will explain, I offer the concept of materializing (with two Ts) as a way to reposition agential cuts in explicit power terms, by focusing on the mat(t)erializing of the patient’s body.

Material-discursive practices

Central to agential realism is the concept of material-discursive practices. The centrality of this concept points to two important aspects of agential realism. One is that bodies (or phenomena in general) are material-discursive, not material and discursive (the hyphen is crucial here). In other words, the material and discursive of phenomena are inseparable (although they are separated for the clarity of this sentence); they are entangled together. The second aspect is that of practices. Using the word ‘practices’ points to the importance of activities, and the constant (re)production of these activities, for the becoming of phenomena. Below, I will further explain these aspects and relate them to my data.

Starting with the material-discursive aspect, agential realism argues that the two are entangled, where “to be entangled is not simply to be intertwined with one another, as in the joining of separate entities, but to lack an independent, self-contained existence” (Barad, 2007, p. ix). Drawing on a physics example which argues that light can be both a particle and a wave; Barad argues that all phenomena carry such ontological indeterminacy, meaning that phenomena such as bodies are simultaneously material-discursive. With introducing this hyphenated concept, agential realism explicitly criticizes a long history of discursive domination in scholars’ examinations of the world. However, analyzing empirical data in a ‘hyphenated way’ is proven to be quite difficult (Leonardi, 2013). This difficulty lies in the fact that it requires us to think beyond the distinctions that we so easily make; for example, between me and the keyboard on which I am typing right now, or between Luke’s body, the medication he takes, and the way that makes him feel.

Moving to my empirical data, I see the neurologist and patient in constant communication about Luke’s body. They discuss symptoms and the effects of medication, and therefore, bring matter into this typed-out conversation. From the viewpoint of agential realism, it is important to understand that these symptoms are not separate from how they are experienced and talked about (although, lacking an appropriate vocabulary, I separate them in this sentence). Rather, using that perspective, we can understand Luke’s body as a phenomenon that is simultaneously enacted through material-discursive practices. The symptoms do not exist separately, prior to being experienced, interpreted or spoken about. By the same token, the meaning and language embedded in the symptoms do not exist without their attachment to the materiality of the symptoms. One clear example of this entanglement can be seen in the first posting when Luke says that “things worsened again” [1]. This (written) sentence enacts both a physical experience (body’s matter deteriorates) and an expressed experience of feeling worse. But one does not pre-exist the other; they are enacted in concert when writing this sentence, allowing Luke’s body to materialize (for now, with one T) as in need of help. But Luke is not the only one who enacts material-discursive practices that materialize his body; the neurologist engages in similar practices, when he responds and writes that other illnesses can (temporarily) affect his bodily functioning, but that this is something that will go away on its own.

This change in understanding of Luke’s body (from being in need of help to getting better on its own) brings me to the other aspect of agential realism, referred to before: the ongoing open-ended aspect of material-discursive practices. Bodies are always ‘becoming’ when looked at from the agential realist perspective of material-discursive practices. The body is not just there, waiting to be interpreted, but is brought into (temporary) existence through material-discursive practices. In my data, this aspect is illustrated by the fact that Luke’s body constantly changes.

In the first posting, Luke’s writing enacts material-discursive practices that materialize a body that is not responding well to medication and needs help [1]. Further into the exchange the material-discursive practices enacted by the neurologist materialize a body that is, first, experiencing ‘normal’ fluctuations in symptoms for a patient with Parkinson’s disease [2] and later needs less medication [4]. In their exchange, it becomes apparent that Luke’s
body is not a static object, but a living and changing phenomenon that is always becoming and depends on specific material-discursive practices to materialize. The body is not just there, but enacted through the postings of the patient and the neurologist. As Introna writes, the separate moments where the body is enacted in the conversation are just “one event in that incessant flow of becoming of this heterogeneous assemblage” (Introna, 2013, p. 334). Therefore, the different materializations are not different representations or viewpoints on the same static body; they are, as it were, different bodies altogether. Mol (2002) has referred to this as the ‘body multiple’, where the different bodies together form a connected whole that is constantly on the move, rather than being disconnected and fragmented.

By describing these aspects of agential realism (entanglement and becoming), I have been able to provide a material-discursive perspective on bodies that helps to further establish a movement in Organization Studies toward explicitly including materiality in examinations of bodies. With this empirical exploration of agential realism’s main concepts, I move to the next section, where I focus on agential cuts and bring in the concept of materializing to construct an understanding of the power embedded in bodies and organizing.

Agential cuts
I now move to the main point of this chapter; bringing a more explicit power lens to the materiality-turn in Organization Studies by drawing on agential realism and the idea of agential cuts as enacting a temporary separation between the objective materiality and subjective discursivity (Barad, 2007). Even though I posit that a ‘real’ separation between the material and discursive is not ontologically possible, the agential cuts that enact a ‘sense’ of that separation still do have a ‘real’ effect, especially with regard to which bodies materialize. In other words, the fact that I have shown the material-discursive entanglement and becoming of bodies does not mean that the patient and neurologist treat Luke’s body as such. Rather, their postings make agential cuts to separate the (material) object and (discursive) subject, which helps them in their quest to find common understandings of how to best care for Luke’s body, as I will show below.

Barad uses the word ‘resolution’ in relation to her description of agential cuts, when she writes that agential cuts enact “a local resolution within the phenomenon of the inherent ontological indeterminacy” (Barad, 2003 2815). Although Barad does not specify her definition of the word ‘resolution’, in the realm of physics, a resolution denotes a division into component parts (even though ontologically, this division is impossible). Therefore, reading Barad’s definition from such a perspective, agential cuts produce that (‘sensed’) division between the (inseparable) ontological components of the body. This word ‘resolution’ is, thus, essential to understanding agential cuts. However, looking at the word solely from a physics perspective (which fits Barad’s background) might be too limited. A more common sense understanding of ‘resolution’, as solving a dissonant issue, further adds to our understanding of agential cuts, especially from a power perspective. Using this common sense understanding, agential cuts are also a way to reach a compromise and a moment of comprehension (or, intelligibility (Barad, 2003, p. 824)) about certain phenomena. As such, a commonsense understanding of resolution positions agential cuts as enacting a compromise from an unlimited array of possible materializations of the body. This compromise stems from specific configurations of material-discursive practices that are temporarily enacted.

Combining the physics definition (division into component parts) and the common sense definition (solving a dissonant issue) of ‘resolution’, provides a rich foundation for bringing an explicit power lens to agential cuts, and more broadly, the focus on materiality in Organization Studies. In other words, such an analysis of agential cuts gives access to the temporary division between subject/(discursive) and object/(material), but also to how this separation is achieved through compromise and mutual comprehension. To expand on and illustrate this point, let me go to the data again.

For example, the neurologist’s material-discursive practices materialize Luke’s body through writing that his body’s symptoms are fluctuating (“there are good and bad days” [2]), while at the same time disagreeing with the patient’s interpretation of it, as this fluctuation is normal and Luke was apparently worried about his body without that being necessary (“no reason to change anything about the medication”[3]). Here, the neurologist separates (i.e.,
enacts an agential cut) the ‘objective’ material symptoms from the ‘subjective’ discursive experiences that the patient writes about. In that separation the neurologist enacts a temporary understanding of Luke’s physical symptoms in relation to Luke’s expressed feelings and interpretations of them, creating a division between these two component parts required for the neurologist to comprehend how to materialize Luke’s body.

Simultaneously, this agential cut also allows the neurologist to bring in his own (subjective, discursive) interpretation of Luke’s bodily functioning, to reach a moment of compromise with regard to how Luke’s body is doing and how to proceed. The compromises enacted through agential cuts are most clearly present when Luke uses the phrasing “in mutual agreement” [5]. This phrasing displays how the agential cut made in that specific context helped him and the neurologist resolve the ‘indeterminacy’ between the objective material symptoms and the subjective discursive experiences, materializing a contextualized body from the array of possible materializations. Here [5], temporarily, Luke’s body materializes as a body needing a change in medication regime. At this point, I would like to introduce and explain the concept of materializing (with two Ts) as a way to capture the power involved in the materialization of bodies.

As the conversation as a whole develops, there is a sense that Luke’s body, as enacted through the neurologist’s material-discursive practices, matters in different ways than Luke’s enactment of his own body in Luke’s postings. The neurologist’s materializations of Luke’s body seem to be regarded as more legitimate (more ‘materializing’) than Luke’s body as it materializes through the patient’s postings. The agential cuts enacted present an understanding of Luke’s body, where the patient makes a larger compromise in disregarding his understanding of his body than the neurologist, as the neurologist tries to make the patient comprehend rather than the other way around. Although there is no complete disregard of the materialization of Luke’s body through Luke’s own material-discursive practices, there is the sense that the neurologist’s materialization matters more than Luke’s, as he dismisses Luke’s interpretations of his experienced symptoms. As agential cuts mat(t)erialize specific, localized bodies, they simultaneously exclude other materializations from becoming, and therefore, mattering. In other words, agential cuts materialize certain bodies over others. The becoming and excluding of bodies captures another layer of power. As the neurologist describes Luke’s ‘worsening’ body as being part of a regular Parkinson’s disease trajectory (“there are good and bad days”[1]), he excludes the materialization of Luke’s body as something to take immediate action on (for example through medication changes). This becoming and exclusion of bodies is possible precisely because an agential cut is made between the objective material symptoms and the subjective discursive experiences. The agential cut is therefore a process of power because it allows certain bodies to ‘become’ and excludes others.

Important to note here is that agential realism brings a material-discursive perspective on this becoming and excluding. This perspective entails a number of consequences for understanding bodies in organizing. First, within a traditional Foucauldian perspective (i.e., discursively oriented), these interpretations of the body would have been examined as discursive struggles over a static site (i.e., a stable body), whereas a material-discursive perspective shows how the discursive and material are entangled. This creates a perspective on the becoming and excluding that is much more profound as it shows how the postings create different mat(t)erializations of the body altogether, where Luke’s body feels, behaves and needs differently based on the enactment of the changing material-discursive practices. For example, as soon as the neurologist posts that good and bad days are part of Parkinson’s disease, Luke’s body changes from a sick Parkinson’s patient’s body, to a normal Parkinson’s patient’s body, in a way that is discursive-material, not just discursive.

Second, the concept of ‘materialization’ does not just point to materializations that compare the postings of the patient versus the neurologist; there is an infinite array of possibilities present that are excluded through both these individuals’ postings. One can, for example, think of materializing the body in a more holistic way, explicitly bringing together the mind and body in discussions of care. Even though such exclusions are constantly enacted, drawing on agential realism also allows for future enactments where what was once excluded will be included. As such, excluded materializations are not permanent, as Barad describes that “possibilities are reconfigured and
DISCUSSION

To reiterate, this chapter makes a number of contributions. The most important one is that I contributed to a current movement to bring a materiality perspective to Organization Studies, specifically as I explored its potential for understanding power in organizing. I made this contribution in the context of bodies in organizing, which is an area of research mentioned many times for its potential for moving beyond the discursive (Ashcraft et al., 2009; Hardy & Thomas, 2015). Drawing on agential realism and the specific idea of agential cuts (Barad, 2003, 2007), I coined the concept of ‘matterializing’ to make these contributions.

What I am doing with the concept of matterializing is to bring a more explicit vocabulary to discuss the power processes embedded in agential cuts. As such, this chapter makes three points regarding the materiality-turn’s (and, more specifically agential realist’s) potential for understanding power in organizing. The first is that power is not just embedded in language, but in entangled material-discursive practices.

The second point is that agential cuts add a layer to this power analysis, because they show the power enacted when those separations between the material-discursive are made. Precisely because we tend to (try to) separate the material and discursive, we enact certain understandings of phenomena that create exclusions and inclusions of phenomena that (temporarily) determine how we understand, experience, feel and use those phenomena (not just how we talk about them).

The third point speaks to agential realism’s emphasis on the open-ended becoming of phenomena. Although the POHCs ‘reconfigure the possibilities’ (Barad, 2007) for mat(t)erializing (e.g., because the neurologist cannot visually observe the body, the patient gains more control and responsibility for materiality the body), these possibilities are not endless as restrictions on what appropriate care looks like remain in the specific time and place in which materializations are enacted. Therefore, the temporality of these possibilities and restrictions show the open-ended becoming not just of the bodies themselves (or, more generally, material-discursive phenomena), but also of the exclusions and inclusions of certain bodies. Within the agential realist framework, there is an infinite amount of opportunities for (agentic) change, as Barad writes: “what matters is marked off from that which is excluded from mattering but not once and for all” (Barad, 2007, p. 181). Such a framing of ‘reconfiguring possibilities’ has effects on how we conceptualize agency in relation to power in organizing, as I will explore in more depth in my concluding chapter.

I now move on to my second contribution where I introduce a more explicit material perspective on bodies and organizing. Bodies have been positioned as an exemplary case for understanding materiality in Organization Studies, because bodies (perhaps unlike other organizational phenomena such as inequality or bureaucracy) have such a self-evident tangible materiality (Ashcraft et al., 2009; Hardy & Thomas, 2015; Orlikowski & Scott, 2015). Limiting the examination of bodies to the language we use to talk about them ignores the fleshy and sometimes tangible aspects of bodies in organizing. Even though bodies have been positioned as an avenue for future research regarding materiality in Organization Studies, such statements have not yet led to a real increase in studies examining materiality in-depth in relation to bodies in organizing.

Studies that do take into account the materiality of bodies do so in a number of ways: some scholars state it as fact (i.e., ‘the body is a material entity’) (Bryant & Garnham, 2014; P. Y. Martin, 2002), others focus on ascribing materiality to objects or things that interact with a (material) body (Dale & Latham, 2015; Godfrey, Lilley, & Brewis, 2012), often drawing on Merleau-Ponty’s work to focus on bodies in our surrounding material world (Natalia Slutskaya & De Cock, 2008; Yakhlef & Essén, 2013). Another group decenters materiality of bodies by relating it to a very specific theme, such as gender or queer performativity (Courtney, 2014; Ozturk & Rumens, 2014), ethics (Dale & Latham, 2015), or embodied knowledge (Hindmarsh & Pilnick, 2007; Natalia Slutskaya & De Cock, 2008). Embodiment, in general, forms a vibrant stream of literature where the body, its experiences and the way it is put to work, takes center stage in analyzing organizational processes (Gärtner, 2013;
Wolkowitz, 2006). Although this work presents some promising explorations of the importance of materiality of bodies, I have argued that – to fully take the materiality of bodies in organizing seriously – we can draw on agential realism to radically change our ontological perspective on bodies. By bringing in the materiality of bodies, in entanglement with the discursive, I have shown how bodies are part of organizational practices beyond a distinction between a stable, fleshy, observable, and touchable body and the way we use language to speak of that body.

This chapter also speaks to wider issues around the applicability of agential realism’s insights to Organization Studies. With this chapter, I have linked up and contributed to other scholars’ attempts to bring agential realism to Organization Studies (Jedema, 2007; Nyberg, 2009; Orlikowski & Scott, 2014, 2015), and addressed criticisms of these attempts articulated by others (Leonardi, 2013; Mutch, 2013). I have contributed, by embedding it in empirics, an application of this theoretical framework to Organization Studies that provides a different perspective of power. Whereas the concept of agential cuts has been applied in other work (Nyberg, 2009), it has not yet been appropriated for the examination of power (in relation to bodies) in organizing, which further establishes the theoretical framework’s potential for understanding organizing processes.

In thinking through the usefulness of this concept of agential cuts and how they enact the mat(t)erializing of bodies, it is also important to understand where agential cuts are not made. In other words, which bodies (or, more generally, phenomena) do not materialize? I believe that this question constitutes a fruitful basis for future research, where scholars might look at certain things like body language that will be hard to translate to the online space of the POHCs. The idea of ‘body language’ itself links materiality and discursivity into one concept and would, therefore, present an interesting opportunity to further explore material-discursive practices. Moreover, in the mat(t)erializing of bodies, body language might play an important role, but the possibilities for that are limited without visual observations of bodies. A further exploration of how space and material-discursive practices connect to each other could unpack the spatial aspects of bodies in organizing and simultaneously help to further build on the topic of space in Organization Studies from an agential realist perspective (Beyes & Steyaert, 2012; de Vaujany & Mitev, 2013).
CHAPTER 6
CONCLUSION
In this final chapter, I return to my main research question. By drawing on my empirical analyses in concert with insights from theory, I will answer this question below. In later sections of this chapter, I will develop further theorizations from this answer to contribute an overall perspective on power processes in organizing. This perspective will focus on conceptualizing change in relation to power processes in organizing, because the idea of changing power processes stood at the basis of this dissertation.

**ANSWERING THE RESEARCH QUESTION**

My main research question was formulated as follows: how does organizing care through personal online health communities affect power processes in care provision? Each chapter has provided unique insights into answering this question. First, using terms such as ‘choice’ and ‘making demands’ to reflect patients’ expected active and empowered role in care provision, the personal online health communities (POHCs) position patients as consumers. I have shown that such macro-level consumerization processes (re)produce inequalities and hierarchies of patients along the lines of intersecting social categories. Patients who are older women, cognitively disabled and of a lower class background seem to be the farthest removed from the identity of the patient-consumer, and, therefore, most impacted in terms of their access to care. Second, I zoomed in on the patients who are able to use the POHCs and who are, therefore, presumed to fit the patient-consumer identity of an active and empowered patient. This zooming in allowed me to see how patients were regulated by ‘organized emancipation’ and how this affected their individual identity work. I noted that their identity work presents moments of disciplining as well as micro-emancipation. Ultimately, the POHCs provide space for patients’ voices but also bring an added sense of responsibility for patients who need to construct and know what a ‘good patient’ is in relation to the ambiguous space of the POHCs. The idea of emancipation moves away from a ‘right’ that individuals possess to a ‘duty’ that they themselves are made partly responsible for. Third, on the side of the healthcare professionals, a large transition for them lay in the increased possibilities for surveillance of their daily work. I concluded that they enact surveillance in ways that make surveillance an integral part of their sense of professionalism. This enactment reveals the ways in which some watching eyes (fellow healthcare professionals) are prioritized over others (patients). This prioritization of (certain) fellow healthcare professionals’ eyes reveals that they are the group it is most important to make a good impression in front of. Fourth, further engaging with this concept of enactment as an entry into power processes, I developed an analysis of the enactment of patients’ bodies, where patients and healthcare professionals both engage in the materializing of the patient’s body through their postings on the POHCs. In this materializing of the patient’s body the material and discursive are entangled in a constant process of ‘becoming’. As I demonstrate, the practices enacted by the patient and healthcare professional allowed for certain bodies to mat(ter)ialize, and not others. Through using POHCs patients might have gained more control over the information flowing from their bodies (due to limited visual observance by others), but their materialization of their bodies also often seemed to matter less compared to the healthcare professional’s.

The different chapters of this book form thick descriptions that allow for a comprehensive analysis of the complex power processes, involved in using a new technology, for all users (both patients and healthcare professionals). The complexities are produced by a range of disciplinary and (micro-) emancipatory practices. Disciplinary practices can be found when patients do not want to come across as a complainer or when healthcare providers avoid informal talk in front of other (higher ranked) healthcare professionals. But, POHCs also create a space for (micro-) emancipatory practices as easier access to healthcare professionals has become a reality and new opportunities for displaying (professional) expertise arise to benefit one’s position in the medical hierarchy. This ambiguity in the use of POHCs sits at the basis of my Foucauldian perspective on power, where power processes “exist [...] in action” (Foucault, 1982, p. 788), resulting in volatile and fluid practices, that cannot be classified as either restrictive or empowering.

Zooming out from the practices themselves, a Foucauldian perspective also allows a better understanding of the structures that underlie these practices. The power processes that operate within the POHCs are not located within one
figure or institution. Foucault argues that power is located in the distribution of knowledge, and as such, power and knowledge are closely intertwined (Foucault, 1978). This power/knowledge drives how individuals understand themselves, through the (re)production of norms about ‘appropriate’ behavior, making existing inequalities resilient to change (Knights, 2009). Next to the discursive, normative aspects of power/knowledge, the design of the POHCs also drives the behavior of the users, because it restricts certain behaviors (e.g., transparent conversations in front of all users around sensitive topics) and encourages others (e.g., writing often in a diary but also creating easier access and control over information that flows from the patient’s body).

The norms embedded in and the design of the POHCs, thus, create certain expectations for both patient and healthcare professionals. In their desire to work with the POHCs and reap their benefits, patients and healthcare professionals become tied to their understandings of themselves (as patients to be empowered, or professionals that need to collaborate) and discipline themselves and create opportunities for micro-emancipation according to those subjectivities. The fact that POHCs are expected to change power processes is, therefore, an act of power itself, as it creates a renewed power/knowledge structure around the ‘appropriate’ use of POHCs that limits the ‘conditions of possibility’ (Hardy & Clegg, 2006), rather than destroying such a structure altogether. The expectations and technical possibilities for changing power processes that users are provided with still come with an (unconscious) obligation to behave in certain ways, and users discipline their behavior accordingly. Although the POHCs present some instances of changing medical hierarchies they also tie their users further to the expectation that all users should be empowered individuals, activated so that they can become their own best self which will improve care provision. With that expectation they simultaneously exclude a large group of patients (and possibly healthcare professionals) who do not fit this mold.

Ultimately, POHCs affect power processes in organizations in such a way that POHCs exist in a kind of twilight zone. In their ambition to change existing power processes through empowerment, the POHCs focus on individuality. By limiting the conceptualization of power processes to liberated selves who ‘possess’ power, the POHCs neglect the wider societal power processes that influence all the interactions on and with the POHCs. That power processes go beyond the individual becomes clear when you realize that the healthcare professionals that I talked to were all wonderful professionals that spoke enthusiastically about their willingness to give their patients a more active role. Similarly, the patients that I spoke with, displayed an interest in this active role. Both groups saw the ways in which the POHCs had potential to achieve this goal. Still, this group of ‘enlightened’ individuals could not radically change the power processes in their daily care provision practices. They remain in an in-between state because their individual willingness is not accompanied by a larger societal and systemic shift, because the POHCs do not (and cannot) provide this. This dissertation has made initial steps to lay bare the wider societal power processes that become internalized and reproduced by the POHCs’ users and influence care provision practices. Understanding those processes provides a first step in changing healthcare for the better.

Therefore, rather than looking at power as an individual possession, we should focus on the ambiguity and messiness of power processes. Below, I will continue exploring power processes in organizing (care provision) as I move onto the theoretical contributions of my dissertation and develop my theoretical perspective on changing power processes in organizing.

THEORETICAL CONTRIBUTIONS

After showing in my analyses that power processes are ambiguous and messy, I can safely conclude that the same can be said of academic examinations of them. I have embraced this messiness in my work, which shows from the different power concepts I adopted. In the sections below, I will first reiterate my contributions to each of these power concepts separately. Afterwards, I will show that my journey through these concepts has made apparent that combining these literatures lays bare two debates in the ‘power in organizing’ literature that I will then use to develop my own perspective on changing power processes in organizing. Let me start by reiterating the theoretical contributions that each sub question has allowed me to make to that specific body of literature.
Whereas consumerization has mostly been criticized for its potential for exploitation and new forms of control, I contributed (in Chapter 2) a critical analysis of the tacitly assumed universal abilities to behave as a consumer. Using an intersectional approach (Cho et al., 2013; Verloo, 2013), I provided an understanding of the patient-consumer identity and its exclusionary practices, showing how it leads to unequal access to care between individuals of different intersecting social categories. Connecting those findings to consumerization processes in a wider societal context, I argue that consumerization is a potentially dangerous strategy for increasing the quality of care or service provision. Because there often is an absence of recognition of the political nature of these exclusionary practices (Calás et al., 2013; Garland & Darcy, 2009), the dominance of consumerization processes becomes part of the ‘systemic dynamics of power’ through which already existing inequalities and privileges become further institutionalized (Rodriguez et al., 2016, p. 202).

Zooming in on the patients who do have access to the care provided through POHCs, I have (in Chapter 3) coined the concept of ‘organized emancipation’ to understand how patients’ identities are regulated by an explicit attempt to emancipate them. Whereas emancipation is often seen as achieved through bottom-up identity work (Alvesson & Willmott, 2002), I offered the concept of ‘organized emancipation’ to understand how organizing that aims to achieve emancipation (like POHCs) affects the identity work of organizational members. I contributed the concept of ‘organized emancipation’ to the literature on identity work (especially the literature that focuses on identity work in changing environments) arguing that in these contexts, the idea of emancipation moves away from a ‘right’ that individuals possess to a ‘duty’ that these individuals are made partly responsible for. This duty to emancipate is shared with the organization, constituting an ambiguous environment for emancipated identities to be constructed. As such, identity regulation through organized emancipation leads to identity work that entails a complex web of practices where especially the responsibility for this emancipation becomes a space for contestation.

Moving to the healthcare professionals (in Chapter 4), I have contributed an enactive view of professional surveillance to the surveillance literature. Using a dramaturgical approach (Goffman, 1959) I have shown how professionals enact, rather than react to surveillance, in such a way that the watching eyes of others become an integral part of their sense of professionalism. Moreover, I have demonstrated that surveillance, seen through a dramaturgical lens, can become a resource for professionals to display this professionalism, rather than only a liability. With their enactment of surveillance, professionals can play with hierarchies and, therefore, also enact power.

I further explored this enactive view (in Chapter 5). Drawing on a literature on the importance of materiality, I examined its underexplored potential for understanding power in organizing, by analyzed bodies from a material-discursive perspective. More specifically, I drew on agential realism’s (Barad, 2007) idea of agential cuts to coin the concept of ‘materializing’. This concept involved three points regarding our understanding of power in organizing: power processes are not just embedded in what we say, but also in materiality; materializing points to the importance of certain materializations of bodies over others, and in this materialization lies both an exclusion of other bodies to materialize, but also the possibility for those other materializations to be enacted in the future.

Ultimately, the strength of this dissertation lies in the combining of otherwise compartmentalized concepts of power (Tsoukas, 2016). Using different concepts allowed for illuminating different organizational practices, which, analyzed together, make it impossible for us to point to clear examples of linear changes to power processes that create more equality. Instead, this dissertation contributes an exploration of power processes in their conflicting and temporary manifestations. At the same time, this dissertation shows the conflicting and temporary academic understanding of power processes in organizing.

In the next sections, I will reflect on the different power concepts I have used and how they overlap and/or conflict. I discuss how they reflect my journey through the literature, which, in terms of social theories, started with a discursive focus based on Foucault, with limits on agency, to a more materiality informed perspective on power, derived from Barad’s agential realism, which intertwines agency and structure in practices. This journey shows that, there
are two poignant central theoretical debates that are sewn into this dissertation, which I have not explored in-depth yet: (1) the older debate around agency versus structure and (2) the contemporary ontological debate with regard to the material and discursive (and how they relate). After discussing separately how the different chapters of my dissertation address these two debates, I will argue that discussing these debates in concert, and my insights gained on them, allows me to make a contribution to the literature on power processes and organizing from the specific perspective of change.

**Agency-structure**

The agency-structure debate has a long history in Critical Management Studies (Ashcraft et al., 2009; Heugens & Lander, 2009; Reed, 1997; Volkoff, Strong, & Elmes, 2007; Whittington, 1994; Willmott, 1994). In this long history, structure and agency have been seen as two opposites as well as operating together, transcending the dualism between agency and structure (Gleeson & Knights, 2006; Reed, 2003). Some have argued that structure has received too much attention in Organization Studies at the detriment of an understanding of agency (Fairclough, 2005; Whittington, 1994; Willmott, 1994). Others warn against a strong focus on agency because of its tendency to lose sight of larger societal processes (Reed, 2006).

In my dissertation, I have been on different sides of the debate. While drawing on intersectionality literature to examine the consumerization of patients, I showed how, at the macro-level, social categories provide structural barriers for certain patients in their access to care. Intersectionality literature can be used to examine fluid and agentic identification practices, but is also often adopted with a rather structural and stable view of social categories and their role in organizing the world, and I have done the latter in Chapter 2, where I most explicitly use this approach. Bringing identity constructions to the micro-level (in Chapter 3), brought in a more explicit discussion of agency. Agency was present in the form of micro-emancipation through identity work, while also recognizing the disciplining done in relation to the structural regulations embedded in the ‘organized emancipation’ through POHCs. When moving to professional surveillance, structure was mostly represented in the dramaturgical scripts that provided the guidelines for professional behavior. In this fourth chapter, I developed an enactive view of surveillance and I expanded on this idea of enactment in the fifth chapter of my dissertation in which I further developed an enactive view on bodies, using agential realism’s framework, to examine practices in which agency and structure are entangled rather than two opposite and separate practices confined to a dichotomy.

This dissertation represents my own journey through the literature, in which I have increasingly added complexity to the agency-structure debate. Moving from a solely structural focus (which we often find in Foucauldian-inspired research projects), to one where structure and agency are rather separated to a perspective on agency and structure as simultaneously enacted, based in agential realism. This journey has consequences for how I understand changing power processes in organizing, which I will explore below, after I discuss the debate on materiality and discursivity.

**Material-discursive**

The dominance of discourse has recently become a point of debate in Critical Management Studies (Ashcraft et al., 2009; Hardy & Thomas, 2015; Putnam, 2015), with scholars arguing that not everything can or should be reduced to language. Instead, they call for more in-depth examinations of the role of materiality in relation to discourse (Orlikowski & Scott, 2015). Materiality has since been applied to different organizational topics, of which technology is, perhaps, the most prominent (Beane & Orlikowski, 2015; Labatut, Aggeri, & Girard, 2012; Orlikowski & Scott, 2008). Moreover, the debate around the importance of materiality has been taken up in different ontological directions, where some see matter as a stable entity that frames and is framed by the social (Leonardi, 2011; Zammuto et al., 2007) and others argue that neither materiality nor discursivity are ever stable and the two are inseparable from one another (Orlikowski, 2010; Orlikowski & Scott, 2008).

Similar to the agency-structure debate, the different sections of my dissertation engage in this debate in different ways, reflecting my own journey through the literature. When discussing the inequality produced by consumerization processes at a macro-level, my focus was mostly on the
Power to the Patient?

Discursive aspects of this process (i.e., how it is talked about), although examined the material effects this discourse has on different patients (e.g., unequal access to care). Materiality of the POHCs is brought in, in Chapter 3, when I discussed patients’ identity work. This examination positioned the design of the POHCs as a rather stable matter influencing the behavior of individuals. The fourth chapter, again, is more discursively-oriented, by analyzing how professionals talk about being watched and write on the POHCs while being watched, and how these discursive practices enact surveillance. In the fifth chapter, where I hone in on bodies, I theorized materiality as entangled with the discursive, rather than seeing them as two separate entities (Barad, 2003; Butler, 1993). Materiality in this chapter is conceived of as a generative force rather than a stable and pre-existing entity. Thus, the chapters take different ‘sides’ in this current debate around the role of materiality in organizing. My dissertation moves from a discursively-oriented literature to one where materiality becomes increasingly important, but as a separate entity, to ultimately, a literature where materiality and discursivity are rendered ontologically inseparable.

In the section below, I will integrate the insights from both the material-discursive and agency-structure debates as the two combined allow me to make a contribution to the literature on changing power processes in organizing.

**Theorizing changing power processes**

Both the agency-structure and material-discursive debates are important to consider when conceptualizing change in relation to power processes in organizing. After all, change has everything to do with space and ability for change (agency-structure) and the ‘consistency’ of change and where to locate it (material-discursive). The different chapters have (implicitly) provided different perspectives on change, each emphasizing different aspects. In this section, I bring the two debates together to carve out my own position based on insights I gained during my journey through these literatures.

Similar to travelling across physical spaces, inevitably, a journey through literature must also come to an (temporary) end. At the end of this journey you end up staying in one particular place. For my perspective on power processes, this means that I must locate myself in a specific theoretical perspective, a destination as it were, and it makes sense for me to end where I arrived in my last empirical chapter. In this fifth chapter, where I used agential realism, there is underexplored potential for integrating debates around material-discursive and agency-structure into a perspective on changing power processes in organizing. However, just like with traveling, even though I cannot fully be in multiple places at the same time, I still take my experience with previous destinations with me to my (for the purpose of this PhD journey) ‘final’ destination.

Within agential realism’s focus on constant enactment, there is space for (momentary) disruption, for example, of medical hierarchies. With a focus on doing and actions, agential realism positions agency (and the ability for changing power processes) as embedded in material-discursive practices rather than individuals (Nyberg, 2009). Therefore, it is not the individual her- or himself that actively changes the world around her or him, it is a web of entangled practices that provide, or even forces, the ability for change. This conceptualization of agency provides the possibility that, as Introna writes, “at any moment it [any phenomenon] could also be otherwise.” (Introna, 2013, p. 337). Agential realism focuses simultaneously on the micro- and macro-level, as on the one hand, it zooms in on the possibilities for small, everyday changes, but also focuses on the larger interconnectedness and entanglement of the world. I can usefully draw on this perspective for my conceptualization of changing power processes in organizing.

Such a perspective of agency, where the ability to change power processes (but also to reproduce them) is embedded in material-discursive practices rather than individuals, links up with my use of Foucault’s conceptualization of power as existing in action (Foucault, 1982), rather than possessed by individuals. After all, if power is not individually possessed, then agency is not either. Foucault is often referenced in Barad’s development of her framework of agential realism (Barad, 2003, 2007) and he is also seen as an inspiration for material scholarship (Lemke, 2015), even though his work is often taken up in a solely discursive way. Agential realism, however, further develops the agency-structure and material-discursive debates by extending Foucault’s points around these debates and making them more explicit (Juelskjær & Schwennesen, 2012).
Still, we see little theorizing of agency that is not human-centered. Discussions of agency are often centered on individuals’ abilities to yield their agency (Ashcraft et al., 2009; Caldwell, 2007; Labatut et al., 2012; Mangen & Brivot, 2015). Agency has thus become linked to the subject, the agent who makes intentional choices. Historically, however, agency comes from the Latin word ‘agere’, meaning ‘doing’, where the focus is put on the verb, the actual action of agency (i.e., ‘power existing in action’). The desire to link agency and individual intentionality is understandable: it allows us to feel that we are in conscious control over our lives and, therefore, can act, as Caldwell (2007, p. 780) describes, as a ‘vaguely therapeutic device’. However, when I reposition agency and the ability to change power processes to the realm of practices, a large space of possibilities to see changes is opened up, because there are an infinite amount of practices that could change power processes (Barad, 2007; Caldwell, 2007). This practice-based perspective combines agency and structure in practices, entangling the two together.

Focusing on practices, rather than human intentionality also gives rise to a more materiality focus. Understandings of human agency are often built around the use of language and the discourses individuals draw on or reject. In contrast, with a focus on practices, I move away from a sole focus on the speaking, meaning-making human, providing more space for seeing materiality, entangled with discursivity, in these practices. Uniting material-discursive and agency-structure debates in this perspective on material-discursive practices, I offer a framework for theorizing changing power processes in organizing. This framework could be fruitful for Critical Management Studies because of its focus on reconceptualizing change, rather than focusing on where change does not happen. This shift in focus responds to a current criticism of Critical Management Studies that, as a field, is good at finding persisting inequality, but has less well-developed ways of understanding and articulating change toward more quality and ‘just’ organizing (Klikauer, 2015; J. Martin, 2003; McKenna & Peticca-Harris, 2016). The theoretical points made above might form a fruitful foundation for understanding change toward greater equality in organizations.

To illustrate that point, let me briefly return to my case of the healthcare sector to highlight and build the first pillars for this foundation. Based on the above, it will not be the will of patients and healthcare professionals that will change care provision; it will be the enactment of phenomena, such as consumerization of patients, their identities, professional surveillance, and patients’ bodies, that holds this agentic potential. These phenomena, and their enactment through particular material-discursive practices, have the ability to change care provision for the better. The boundaries and exclusions (e.g., who is considered a patient(-consumer), what is made visible to be surveilled, and which bodies matter) that are (re)produced while enacting these phenomena can shift, opening (temporary and ambiguous) spaces for more inclusive boundaries where multiple positions, knowledges, and expressions of ‘good behavior’ can coexist. These shifting boundaries and exclusions are not the result of intentionally ‘choosing’ individuals who attempt to change power processes for good, but the result of a specific configuration of practices allowing for such actions toward change. Thus, my theoretical perspective on changing power processes does not show how new power processes will ultimately become stabilized in the POHCs, but rather focuses on how different phenomena (such as consumerization processes, identities, surveillance, and bodies) are agentially intervening in power processes, rendering hierarchies fluid, becoming, and ambiguous. Looking at Mol’s (2008) work, who has written a great deal about (‘good’) care practices, embracing this ambiguity is actually a central aspect of her vision for care provision, which she refers to as a ‘logic of care’. In this ‘logic of care’ patients are not positioned as emancipated actors who make choices, but as part of a configuration of practices where adaptability, attentiveness, and ‘shared doctoring’ are central components of both patients’ and healthcare professionals’ daily care provision (Mol, 2008). Implementing such a ‘logic of care’ demands that we move from a focus on empowering individuals to creating a system in which care is central, allowing for practices that will improve the lives of patients and the healthcare professionals involved in their care.
REFLECTING ON LIMITATIONS AND FUTURE RESEARCH AGENDAS

In this section, I take a reflexive, interpretive perspective on the traditional limitations section of a dissertation. This means that I reflect on my own position as a researcher and what my position has allowed (and driven) me to see and what it has not. As a researcher, I am not just responsible for ethically engaging with interviewees but also for the enactive effects of my writing. In other words, while writing I enact a certain version of my data and this enactment has consequences (Barad, 2007). In this respect, (Mol, 2008, 2010) has been an inspiration in terms of her unforgiving reflection on and honesty about what her research does and does not do. In my case, for example, I reiterate the existence of categories of patient and healthcare professionals, in that way enacting the separation between them. Acknowledging that my position, and the wider context in which I work, influenced the creation of this book, means that I locate myself in a specific time and space, which will help the reader understand the value of my work rather than erase it.

One way to work through these enactments is to think about alternative versions of my writing (Alvesson, 2010). This has the simultaneous effect of reflecting on the limitations of this research and providing avenues for future research. There are certain aspects of my data that I chose not to focus on. Although the technology of the POHCs stands at the basis of this dissertation, the object of analysis was how patients and healthcare professionals were using it. Centralizing the technology as an actor could have provided a conceptualization of the POHC as a non-representational space (Lefebvre, 2014); as an active player in the material-discursive practices of care provision. Future research could put more emphasis on the technology, its design, intended functions and the different stages of development it went through, contributing an even more complex configuration of practices, which could connect to academic conversations around space, technology, and power processes (Müller, 2015).

Another active player in these practices is insurance companies. Although they have hardly been mentioned in this dissertation, insurance companies, of course play a large role in the financial playing field of care provision (Schäfer et al., 2010). Insurance companies are important players in healthcare, and attempts to make it more financially efficient, but they were not considered in this dissertation. If, or when, they put financial consequences on the use of POHCs (which was not the case during the pilot project but has been discussed since) they further complicate power processes as economic arguments would become increasingly important. Adding this layer of actors and their practices to my current focus on patients and healthcare professionals could enrich future research, providing more information on the exclusions and possibilities enacted through the POHCs with the involvement of insurance companies.

PRACTICAL IMPLICATIONS

My research participants are not the only ones who have constructed their identity throughout this PhD. I have also noticed myself engaging in identity work to further establish a Critical Management scholar identity, which was (partly) regulated by the department in which I work and the conferences and summer schools I attended. For me, this means that, at times, I join other critical management scholars in being "more articulate about what [we] are against, than what [we] are for" (Adler, Forbes, & Willmott, 2007, p. 154). This is a characteristic that would make for a terrible consultant or any job position working in a more practice-oriented environment and makes this section of my dissertation harder to write. As a Critical Management scholar, I like to think that my role is to challenge practitioners to think beyond their immediate environment and the ways in which we have all been taught the world ‘just’ works. For my dissertation, this means that I would like to convey that power is a process, rather than a possession. This perspective moves practitioners (and patients) away from an individual focus toward a wider understanding of their social context.

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3 What I have not seen is nearly impossible to identify, because I can, most likely, still not see it. Therefore, I am basing this section on comments, received through presenting at conference and journal submissions, that I have been unable to incorporate.
When I think in such large systemic changes, the ideal of eliminating inequalities between and among patients and healthcare professionals might go hand in hand with eliminating other inequalities as well. Some, such as Naomi Klein (2014), have argued that attempting to radically change one inequality (in her case environmental) would be an (exciting) opportunity to eradicate other forms of inequality as well. Under the neoliberal zeitgeist, where patients are positioned as consumers, professionals as service providers, and the market rules, a radical change would entail overthrowing these capitalist ideals and instead implementing a logic of care (Mol, 2008). In that new logic, racial, gender, disability, and class inequalities (that still persist in the use of POHCs as I showed in this dissertation) can be changed as well. However, stating that such a system needs to be implemented in practice might not sound very practical at all, and I cannot avoid addressing where the individual idealistic healthcare professional, patient or web designer should begin.

As part of this larger system change, one could think of practices that ‘tinker’ (Mol, 2008, 2010; Mol et al., 2010) with our current care provision process. Tinkering points to situations where one can, in the moment, make small changes. As Mol suggests, this tinkering can be driven by moments of friction, but these are localized in time and space. To provide an example of what this tinkering might look like, I will connect it to the concept of patient-centered care, which I also discussed in my Introduction. Patient-centered care strives for transparency and accountability with regard to care provision. As my fourth chapter on surveillance shows, realizing that goal is made difficult through the existence of internalized rules around professional conduct. As long as healthcare professionals associate certain scripts to their professional status, they will try to achieve and manage a particular impression in front of their audience. The heterogenization of the audience (an important aspect in calls for patient-centered care (Kodner & Spreeuwenberg, 2002)) makes this process of impression management even more difficult, but this configuration of practices also creates a moment of friction to inspire tinkering. Professionals who are attempting to provide more patient-centered care should critically reflect on the limits of this ideal and relate it to the professional identity they construct for themselves. On the basis of this reflection, new care practices might become available that will allow for tinkering with the care provision process.

Another practice to be implemented is one of reflexive, open dialogue between designers, healthcare providers, and patients about their expectations and wishes with regard to using the POHCs. This dialogue might create a space to discuss the internalized norms they have regarding each other’s and their own use of the technology. Although I have no illusions that such conversations would be devoid of power processes, they might make each party more aware of the (implicit) assumptions they hold about the abilities the other parties have in terms of using the technology. This awareness of internalized norms can be a first step toward changing them. Another step would be to address power processes and implicit norms in the training of young professionals during their medical curriculum; providing them with more awareness of the wider societal context in which they provide care might open up possibilities for different care practices.

With regard to the technological design, I suggest changing the system to encourage two-way knowledge exchange. In their current state, the POHCs mostly promote the information provision by patients, without a clear way for them to gather information from their healthcare providers, other than the occasional knowledge exchange taking place during a virtual meeting. For example, one might think of adding a section where healthcare providers can post general information relevant to the disease stage the patient is in, or to share information about the latest possible treatments, for patients to look at. Gaining this information could give patients additional possibilities for playing an active role in their own care.

Moving beyond the healthcare sector, the lessons learned from my dissertation also extend to other organizational contexts, such as organizing that is done through network configurations, a way of organizing that has become more common as independent organizational entities work together on one goal (Gittell & Weiss, 2004), similar to the set-up of the POHCs. Even beyond that context, any organizational context dealing with issues of consumerization, organizational identities, (professional) surveillance and bodies (i.e., basically every organizational context) can learn from this dissertation about the impact of new ways of organizing through technology.
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English Summary

For a non-academic audience*

We hear in the media about the changing role of patients as a result of the introduction of the Internet. Those discussions mention the so-called ‘doctor Google’ phenomenon (googling your symptoms to participate in diagnosing your illness and offering possible treatments), but the Internet is also used in care provision in more advanced and integrated ways. One example of this trend are so-called ‘personal online health communities’. These are secured online forums (from here on: ‘online communities’), where patients can securely and privately communicate with their own network of healthcare professionals. These online communities have been dubbed a ‘Facebook of healthcare’ and are expected to give patients more insight into and control over their own care, which will ultimately lead to more emancipated patients. Therefore, online communities are assumed to cause a shift in power, offering an entry into ‘the future of patient-centered healthcare’. But is it really that easy?

I put this assumption of shifting power to the test in my dissertation. Although we know quite a lot about the potential of such online communities from academic literature, we know a lot less about the actual use of them, let alone if they achieve shifts in power. To study the use of online communities, I analyzed a pilot project in which patients with Parkinson’s disease were supported in setting up an online community for two years. In this online community, their network of healthcare professionals (e.g., neurologist, physical therapist, dietitian, and/or general practitioner) was involved. On the one hand, my analysis of this pilot project consisted of interviewing patients and healthcare professionals who gave up their valuable time for an interview. On the other hand, data collection also consisted of observations, as almost all patients gave me permission to observe their online communities. The latter

* For an academically-oriented summary, please go to Chapter 6: Conclusion
meant that I was added to their online communities so that I could observe and analyze all the communication (also past posts). These diverse forms of data collection led to a broad dataset of 18 interviews with patients, 13 interviews with their healthcare professionals and a total of 691 analyzed posts (written by 14 patients and their 32 healthcare professionals).

The most important point that I can make with my dissertation is that the assumptions around online communities are based on a specific definition of power that does not do enough justice to the complexity of power processes in care provision. Within this specific definition, power is conceptualized as a possession: some people have power and others do not. Translating this to healthcare, the medical specialist (in the case of Parkinson’s disease, the neurologist) possesses the power with which she or he can dominate the patient who possesses no, or very little, power in the care provision process. With my dissertation, I argue that, by using this definition, it is difficult to let the online communities (as a stand-alone intervention) achieve the future it envisions; one where patients are emancipated, and where they take up a central position within their circle of equal healthcare professionals. Based on this definition, one would only need to bring together healthcare professionals who are willing to transfer their power to patients who want to receive it. Although the pilot project does exactly this, we still do not see a major shift, which urges us to look for more complex ways of understanding power. In the following summary of my dissertation, I discuss how I bring more complexity to this prevalent definition of power-as-a-possession through drawing on Foucault’s definition of power as a process. On the basis of that definition, I have applied and developed various concepts from the so-called Critical Management Studies literature in relation to my collected data.

POWER IN HEALTHCARE

Foucault, an important French social theorist from the second half of the twentieth century, locates power in action rather than in the hands of specific individuals, groups, or institutions. Power is, therefore, not something that a person possesses and can transfer to another, but power is a process that is present in every interaction, in which certain norms prescribe accepted behavior. Critical Management Studies, as an academic subfield within Organization Studies, draws on that Foucauldian definition, as this subfield looks at ways of organizing from the perspective of power processes and inequality. Using this definition of power as a process, we see that power within healthcare is better defined as a process, a process that is intertwined with everything patients and healthcare professionals do. As a result, shifting of power is not the result of one moment where one person (the medical specialist) transfers a part of her or his power to another (the patient). Shifting power is instead connected to how patients and healthcare professionals communicate and behave on the online communities; it is in everything they do.

The field of Critical Management Studies analyzes these power processes from a broad range of concepts, of which I selected four that apply to my empirical case. To analyze my data, I have studied how power processes are involved in the following four concepts. First, ‘consumerization’ of patients; the patient is no longer positioned as a person with a specific disease receiving care, but as a consumer who can make demands from healthcare professionals who are seen as care suppliers. Second, patients’ identities; the self-censoring that patients engage in to ensure their identification as a ‘good patient’. Third, professional surveillance; the possibilities for surveillance facilitated by the online communities and how healthcare professionals deal with these increased possibilities for watching each other’s work. Fourth, bodies; how bodies materialize within the virtual world of the online communities.

The patient-as-consumer?
The online communities position patients in an explicit role of consumers. This means that patients are expected to, according to the rules of the market, demand products and services that healthcare professionals are supposed to supply. But such a role is not available to all patients. My analysis shows that only a very select group of patients can live up to the expectations of a ‘patient-as-consumer’. A patient needs to possess many skills and abilities to be able to behave as an active consumer in relation to her or his care. For example, a ‘patient-as-consumer’ should be able to work well with computers, have insight
into their own care process, and be able to articulate their needs regarding this process. The fact that online communities only reach such ‘low-hanging fruit’ (the patients that are already quite active, in multiple areas of their lives) that possesses these skills and abilities, is made even more problematic as I argue that these skills are often determined by structural background characteristics such as class, gender, and ethnicity.

Patients’ identities
For those patients that do fit this patient-as-consumer position (they are on the online communities), I have analyzed how they construct their identity in relation to the online communities. My analysis shows that existing norms around what care provision is supposed to look like are resilient, and that patients try to adhere to those norms when constructing their identities as ‘good patients’ on these online communities. More specifically, I show that although patients mention that they appreciate the new possibilities to contact their healthcare professionals, they also mention their hesitations around coming across as complainers and too demanding when they use their online communities regularly. Moreover, the specific design of the online communities ensure that postings in certain sections (i.e., the ‘virtual meetings’) are experienced as more invasive - because they create automatic notifications to healthcare professionals - than others (i.e., the diary). As a result, patients are more hesitant to post their questions in the virtual meetings compared to writing daily updates in the diary section. As a result, patients censor themselves based on their ideas about how often a patient should or can contact her or his healthcare professionals, and about which issues.

Professional surveillance
But patients are not the only ones who struggle with the new opportunities provided by the online communities. Healthcare professionals also experience a change in their work practices as a result of the introduction of the online communities. Where before, they had one-on-one contact with their patients, their communication can now also be watched by other healthcare professionals. Simultaneously, this also counts for their communication with healthcare professionals; where before it was easier to have one-on-one conversations about patients with fellow healthcare professionals, they now have to think about how to conduct such conversations when a patient also has access to them. My analysis shows that healthcare professionals consciously think about how and what they communicate on the online communities, and that this sometimes leads to a hiding of communication rather than transparency. For example, healthcare professionals talk less informally with their patients in the presence of other healthcare professionals. Furthermore, they less freely discuss possible diagnoses or treatment options and certain sensitive issues in the presence of the patients. On the other hand, the online communities and their new possibilities for surveillance also provide possibilities for healthcare professionals in a lower position in the medical hierarchy (i.e., non-medical specialists) to display their expertise around certain issues (e.g., physical therapy treatments or devices that can provide support around the house). The surveillance possibilities, therefore, have both positive and negative effects for care provision.

Materializing bodies
On the online communities, it is impossible for healthcare professionals to directly observe their patients’ bodies. To receive the right information about the wellbeing of their patients, healthcare professionals have become dependent on the descriptions the patient her- or himself posts on the online communities. As a result, the online communities have given patients more say about which information flows from their body. However, my research also shows that existing norms still prevail that determine whose expertise (bodily experience or educational knowledge) is deemed most worthy for decision-making. On the basis of these norms, the initiative for making decisions around the bodies of patients often still remains with the healthcare professional.

CONCLUSION AND VISION FOR FUTURE
Based on the prevalent definition of power-as-a-possession, online communities only need healthcare professionals and patients willing to give up and receive
power respectively, for patient-centered care to arise. However, those are exactly the willing users involved in the pilot project I studied and even within this group we note complications that prevent an actual power shift. My results show that positioning new innovations as improved ‘care of the future’ (to create more emancipated patients) needs nuancing. Although patients do have easier access to their healthcare professionals, there are still structures in place that prevent patient-centered care from being implemented. Online communities, and other innovations geared toward emancipating patients, should therefore be embedded in a larger social-cultural change where norms about abilities, knowledge, and expertise that patients and healthcare professionals need, are transformed. Changes in the education of healthcare professionals could, for example, play a large role in this transformation, as well as conversations between healthcare professionals and patients where they openly discuss their assumptions and internalized norms. Such conversations could lead to a decrease of the censorship that patients and healthcare professionals put upon themselves. Moreover, the technological design of the online communities could also be more explicitly geared toward encouraging two-way knowledge exchange, in contrast to the current information exchange mostly initiated by the patient. Two-way knowledge exchange (e.g., healthcare professionals updating the patient on relevant innovations in the field) could give patients additional resources to gain more control over their own care.

NEDERLANDSE SAMENVATTING

Voor een niet-academisch publiek*

In het nieuws lezen we veel over de veranderende rol van de patiënt door de opkomst van het Internet. Daarbij wordt bijvoorbeeld ‘dokter Google’ aangehaald (je symptomen googelen en op basis daarvan zelf participeren in het aandragen van diagnoses of behandelmogelijkheden), maar het Internet wordt ook op steeds verdergaande manieren ingezet in de zorg. Een voorbeeld daarvan zijn zogenaamde ‘persoonlijke zorggemeenschappen’. Dit zijn besloten online fora (vanaf hier: online communities) waar patiënten met hun eigen kracht van zorgverleners communiceren. Een dergelijk ‘Facebook van de zorg’ wordt geacht patiënten meer inzicht en controle over hun eigen zorg te geven en uiteindelijk meer geëmancipeerde patiënten te creëren. De online communities zouden dus een machtverschuiving teweeg moeten brengen, die de toekomst van de zorg zou moeten inluiden. Maar is het wel zo makkelijk?

Ik stelde deze assumptie van machtverschuivingen ter discussie in mijn proefschrift. Alhoewel we vanuit de wetenschappelijke literatuur veel weten over de potentie van dit soort online communities, weten we nog maar weinig van het echte gebruik ervan, laat staan van het oomachtverschuivingen opleveren. Om het gebruik van online communities te onderzoeken heb ik een proefproject geanalyseerd, waarbij patiënten met de ziekte van Parkinson gedurende twee jaar ondersteund werden in het opzetten van een online community waarin hun netwerk van zorgverleners (bijvoorbeeld neuroloog, fysiotherapeut, diëtist en/of huisarts) aanwezig was. Mijn analyse bestond aan de ene kant uit het interviewen van patiënten en zorgverleners die hun kostbare tijd ter

* Voor een wetenschappelijk georiënteerde samenvatting, verwijs ik u naar Chapter 6: Conclusion
beschikking stelden voor een interview. Aan de andere kant heb ik observaties gedaan van de online communities, nadat bijna alle patiënten ook toestemming gaven om mij te laten observeren binnen hun online communities. Dit laatste betekende dat ik werd toegevoegd aan hun online communities, zodat ik al hun communicatie (ook de posts uit het verleden) kon observeren en analyseren. Deze diverse vormen van dataverzameling hebben geleid tot een brede dataset van 18 interviews met patiënten, 13 interviews met hun zorgverleners, en een totaal aan 691 geanalyseerde posts (geschreven door 14 patiënten en 32 van hun zorgverleners).

Het belangrijkste punt dat ik met mijn onderzoek kan maken is dat de online communities op een bepaalde definitie van macht zijn gestoeld die onvoldoende recht doet aan de complexiteit van machtsprocessen in de zorg. Binnen deze definitie is macht een bezit; sommige personen bezitten macht en andere niet. Dit vertalende naar de gezondheidszorg heeft de medisch specialist (in het geval van de ziekte van Parkinson, de neuroloog) de macht waarmee zij of hij de patiënt kan domineren, omdat die laatste weinig of geen macht bezit. Met mijn proefschrift beargumenteer ik dat, door deze definitie te gebruiken, het lastig is om de online communities (als op zichzelf staande interventie) die toekomst te laten realiseren die ze beogen; één waarin patiënten geëmancipeerd zijn, en waarin zij een centrale positie innemen binnen hun kring van evenwaardige zorgverleners. Op de basis van deze definitie van macht hoeft iemand alleen maar zorgverleners die hun macht willen overdragen samen te brengen met patiënten die deze macht willen ontvangen. Hoewel het proefproject deze partijen inderdaad samen brengt, zien we alsnog geen machtsverschuiving plaatsvinden, wat ons aanspoort om macht op een meer complexe manier te definiëren. In de hiernavolgende samenvatting van mijn proefschrift zal ik uiteenleggen hoe ik deze definitie van macht als-bezit meer complexiteit heb gegeven door me allereerst te baseren op Foucaults definitie van macht als een proces. Op basis van die definitie heb ik verschillende concepten uit de zogenaamde Kritische Management Studies (Critical Management Studies) literatuur toegepast op en ontwikkeld aan de hand van mijn verzamelde data.

MACHT IN DE ZORG

Foucault, een belangrijke Franse denker uit de tweede helft van de twintigste eeuw, positioneert macht in activiteiten, in plaats van in de handen van specifieke individuen, groepen of instituten. Macht is daarom niet iets wat een persoon bezit en kan overdragen aan een ander, maar macht is een proces dat zich in elke interactie bevindt, waarin bepaalde normen geaccepteerd gedrag voorschrijven. Critical Management Studies als wetenschappelijk subgebied binnen organisatiewetenschappen, baseert zich op deze Foucaultiaanse definitie van macht omdat het naar organiseren kijkt met een oog op machtsprocessen en ongelijkheid die daar een rol in spelen. Gestoeld op deze herziene definitie van macht zien we dat macht binnen de zorg veel beter als een proces gedefinieerd kan worden, een proces dat verwezen is met alles wat patiënten en zorgverleners doen. Machtsverandering is dan niet een moment waarbij één persoon (de medisch specialist) een deel van haar of zijn macht overdraagt aan de ander (de patiënt). Machtsverandering is dan verbonden aan hoe patiënten en zorgverleners communiceren en hoe ze zich gedragen op de online communities; in alles wat ze doen.

Het vakgebied Critical Management Studies analyseert dit soort machtsprocessen vanuit een groot scala van concepten, waaruit ik een viertal heb geselecteerd. Om mijn data te analyseren heb ik gekozen naar hoe machtsprocessen werken rondom de volgende vier concepten. Ten eerste, het ‘klantificeren’ van patiënten; de patiënt wordt niet langer gepositioneerd als een persoon met een bepaald ziektebeeld die zorg ontvangt, maar een klant die behandeling kan eisen van behandelaars die als zorgaanbieders worden gezien. Ten tweede, de identiteit van patiënten: de zelfcensuur die patiënten op zichzelf uitoefenen om zich als ‘goede patiënt’ te identificeren. Ten derde, inspectie van professionals; de inspectiemogelijkheden die online communities faciliteren en hoe zorgverleners met zulk toegenomen toezicht omgaan. Ten vierde, lichamen; hoe de lichamen van patiënten gematerialiseerd of ‘verstoffelijkt’ worden binnen de virtuele wereld van de online communities.
De patiënt als klant?

De online communities plaatsten patiënten in een expliciete rol van klant. Dit betekent dat van patiënten verwacht wordt dat zij, volgens de regels van de markt, producten en diensten mogen eisen die zorgverleners dan vervolgens aanbieden. Maar niet voor elke patiënt is een dergelijke rol weggelegd. Mijn onderzoek toont aan dat slechts een zeer selecte groep aan zulke ‘patiënt-als-klant’ verwachtingen kan voldoen. Een patiënt moet veel vaardigheden en mogelijkheden tot haar of zijn beschikking hebben om zich als een actieve klant richting haar of zijn zorg te gedragen. Een ‘patiënt-als-klant’ moet bijvoorbeeld goed met computers om kunnen gaan, inzicht hebben in het eigen zorgproces, en behoeften rondom dit proces goed kunnen verwoorden. Het feit dat de online communities alleen maar het ‘laaghangend fruit’ bereiken dat deze vaardigheden en mogelijkheden heeft (de patiënten die al actief zijn, in verschillende gebieden van hun leven), wordt nog problematischer door het besef dat deze vaardigheden vaak gestuurd worden door vastliggende achtergrondkenmerken zoals klasse, gender en etniciteit.

Identiteit van patiënten

Voor de patiënten die wel voldoen aan deze ‘patiënt-als-klant’ positie (de patiënten uit mijn onderzoek zitten ten slotte op de online communities), heb ik geanalyseerd hoe zij hun identiteit construeren in relatie tot de online communities. Uit mijn analyses blijkt dat normen rondom hoe zorgverlening er uit ‘hoort’ te zien, weerbarstig zijn en dat patiënten proberen te voldoen aan deze normen terwijl ze hun identiteit als ‘goede patiënt’ construeren op de online communities. Meer specifiek laat ik zien dat, hoewel patiënten aangeven de nieuwe mogelijkheden tot contact leggen met hun zorgverleners te waarderen, ze ook huiverig zijn om als klagerig en te veeleisend over te komen als ze met enige regelmaat gebruik maken van de online communities. Daarnaast zorgt het ontwerp van de online communities ervoor dat berichten in sommige onderdelen (zoals de ‘virtuele vergaderingen’) als meer invasief ervaren worden - omdat ze automatische notificaties versturen - dan andere onderdelen (zoals het ‘dagboek’). Dit ontwerp van de online communities zorgt ervoor dat patiënten meer aarzelen over het plaatsen van hun vragen in de virtuele vergaderingen in vergelijking tot het plaatsen van (dagelijkse) updates in het dagboek. Op deze manier leggen patiënten een bepaalde zelfcensuur op die bepaalt hoe vaak een patiënt contact mag of kan opnemen met haar of zijn zorgverleners en over welke onderwerpen.

Inspectie van professionals

Maar patiënten zijn niet de enigen die worstelen met de nieuwe mogelijkheden die de online communities hen bieden. Ook zorgverleners ondervinden een verandering van hun werkproces door de introductie van de online communities. Waar ze eerder één op één contact hadden met hun patiënten, kan hun communicatie nu ook geïnspecteerd worden door andere zorgverleners. Ditzelfde geldt ook voor hun contacten met andere zorgverleners; waar het eerder makkelijker was om in één op één gesprekken over hun patiënten te praten, moeten ze nu nadenken over hoe deze gesprekken eruit moeten zien als de patiënt daar ook toegang tot heeft. Uit mijn onderzoek blijkt dat zorgverleners daardoor bewuster nadenken over hoe en wat ze communiceren en dat dit leidt tot een verhulling van sommige communicatie in plaats van een transparantie ervan. Zorgverleners praten bijvoorbeeld minder informeel met hun patiënten in het bijzijn van andere zorgverleners. Daarnaast bespreken ze minder vrijelijk mogelijke diagnoses of behandelingsmogelijkheden en bepaalde gevoelige problemen in het bijzijn van de patiënt. Tegelijkertijd bieden deze nieuwe inspectiemogelijkheden ook mogelijkheden voor zorgverleners met een lagere positie in de medische hiërarchie (niet-medisch specialisten) om hun expertise over bepaalde onderwerpen (fysiotherapeutische behandelingen of hulpmiddelen voor in huis) te etaleren. De inspectiemogelijkheden hebben dus zowel negatieve als positieve gevolgen voor de verhoudingen binnen de zorg.

Materialiseren van lichamen

Op de online communities is het niet mogelijk voor de zorgverleners om de lichamen van hun patiënten direct te observeren. Om de juiste gegevens over het welzijn van de patiënt te verkrijgen, zijn ze dus afhankelijk van de beschrijvingen van de patiënt zelf. Dit heeft meer zeggenschap bij de patiënt tot gevolg omdat die beter kan bepalen welke informatie er vrijkomt vanuit haar
of zijn lichaam. Echter, mijn onderzoek laat ook zien dat bestaande normen nog steeds overheersen die bepalen welke expertise (ervaringskennis of medische kennis) als meest belangrijk wordt gezien voor het maken van beslissingen. Op basis van deze normen blijft het initiatief voor de beslissingen rondom de lichamen van patiënten nog altijd overwegend bij de zorgverlener liggen.

CONCLUSIE EN VOORUITZIEN NAAR TOEKOMST

Op basis van de veelvoorkomende definitie van macht-als-bezit, zou men denken dat online communities alleen maar welwillende zorgverleners en patiënten nodig hadden, die macht wilden opgeven of ontvangen. Echter, de online communities die ik bestudeerd heb, bevatten exact deze personen en nog zien we complicaties die voorkomen dat er een verschuiving van macht plaatsvindt. Mijn resultaten laten zien dat het positioneren van nieuwe innovaties als een verbeterde ‘toekomst van de zorg’ (om zo meer geëmancipeerde patiënten te creëren) nuance nodig heeft. Alhoewel patiënten makkelijker contact krijgen met hun zorgverleners, blijven er structuren bestaan die de vrije emancipatie van alle patiënten in de weg staat. Online communities, en andere innovaties gericht op het emanciperen van de patiënt, moeten daarom ingebed zijn in een grotere sociaal-culturele verandering waar normen over de vaardigheden, kennis en expertise die patiënten en zorgverleners nodig hebben, aangepast worden. Dit zou de activiteiten van patiënten en zorgverleners zodanig kunnen veranderen dat zij op meer evenwichtige voet zouden komen te staan. Veranderingen in de opleidingen van medisch personeel zouden daarbij voorbeeld een rol kunnen spelen, alsmede open gesprekken tussen zorgverleners en patiënten waarin zij hun assumpties over elkaar en hun geïnternaliseerde normen openlijk bespreken. Dit zou kunnen leiden tot een vermindering van de censuur die patiënten en zorgverleners zichzelf opleggen. Daarnaast zou het technische ontwerp van de online communities ook meer gericht kunnen worden op het tweezijdig uitwisselen van kennis, anders dan de huidige informatie-uitwisseling die voornamelijk van de patiënt richting de zorgverlener loopt. Tweezijdige informatie-uitwisseling (bijvoorbeeld zorgverleners die de patiënt informeren over nieuwe innovaties in hun veld) zou patiënten middelen kunnen bieden om meer controle over hun zorg te krijgen.
Laura Visser was born on July 17th, 1988. She received her high school diploma (Gymnasium) from the Oosterlicht College in Nieuwegein in 2006. After that, she went on to pursue a Bachelor’s in Sociology at the Radboud University, which she completed in 2009. In September 2009, Laura started a Master’s of Sociology at Northeastern University in Boston, the United States. She completed this program, with a focus on Gender Studies, in 2011, which eventually resulted in a publication in *Studies in Higher Education* on gendered patterns in international research collaboration in 2015, co-authored with a professor (Dr. Kathrin Zippel) and fellow graduate student (Dr. Katrina Ugly).

In 2011, Laura started her PhD trajectory at the Institute for Management Research at Radboud University. So far, her project has resulted in one published article (in the medical journal *BMJ Open*): a summarized version of her main findings, written for medical scholars, and co-authored with her supervisors and Professor of Neurology Bas Bloem. Numerous of her dissertation chapters are in (advanced) rounds of review at high-impact management journals.

During her time as a PhD Candidate, Laura was involved in many other activities, such as co-writing and managing a large public-private partnership project (a 2 million EFRO-funded project called ParkinsonNeXt), for which she received a one year extension on her PhD contract. She was also actively involved in the PhD community by acting as the PhD representative for the Institute for Management Research in the university-wide PhD network (PON). Lastly, Laura co-founded and still chairs the Halkes Women Faculty Network Nijmegen, a women’s network at the Radboud University. During her PhD trajectory, she also received the Frye Stipendium, which allowed her to spend three months at Monash University in Melbourne, Australia in the spring (or, their fall) of 2016. Oh, and she also taught in the five years of her PhD, among others tutorials on Research Methods and supervising Master’s theses.

When Laura’s PhD contract ended in August of 2016, she got the fortunate opportunity to start as an Assistant Professor at the Strategic Human Resource Management department within the Business Administration program at Radboud University. She has since been teaching multiple courses within the Strategic Human Resource Management curriculum and is developing a research agenda around postfeminism in organizations.