Interacting Patients

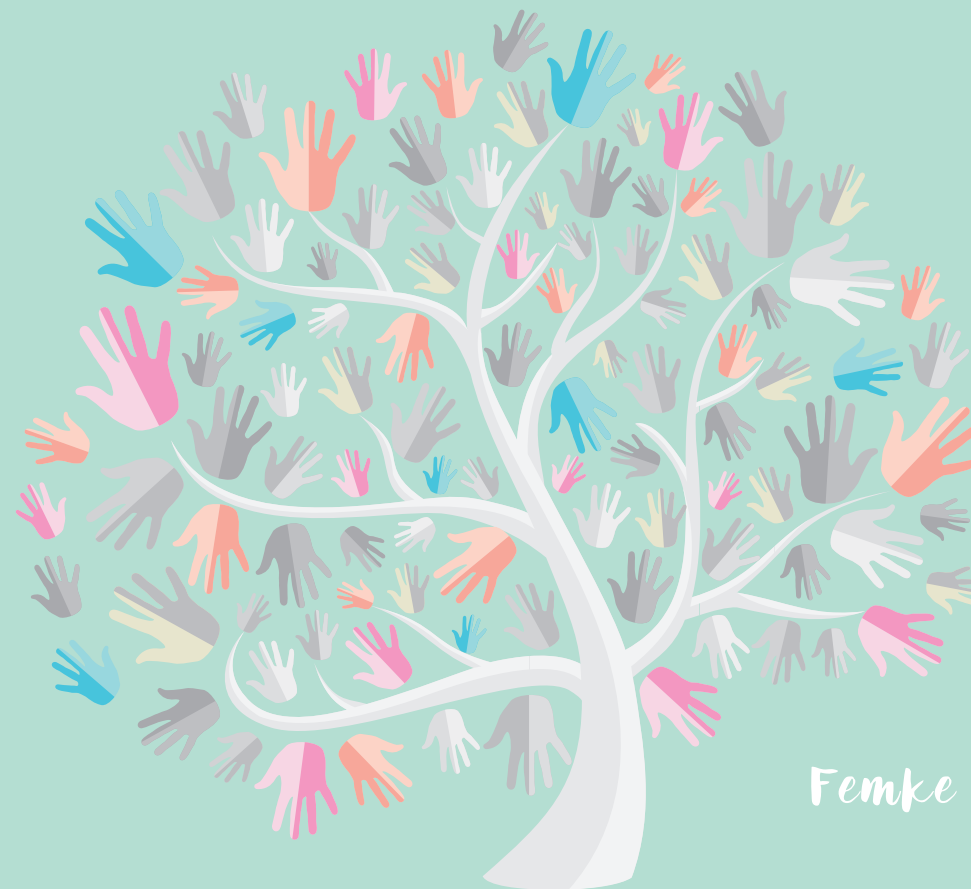## THE CONSTRUCTION OF ACTIVE PATIENTSHIP IN QUALITY IMPROVEMENT INITIATIVES

Femke Vennik

The promotion of active patient participation in healthcare quality improvement projects is an important policy goal in the Netherlands and other Western countries. Healthcare quality improvement is no longer perceived to be an exclusive professional activity; patients, who may be able and willing to participate, are also expected to assume an active role in this respect. For example, they are expected to be actively involved in the improvement of their own healthcare by searching for relevant health information on the Internet and in the healthcare of others by sharing their thoughts with healthcare professionals on how to achieve health service improvement solutions. This book explores how the active role(s) of patients are shaped within these quality improvement initiatives and what this means for the activities expected from patients. It reveals that active patientship is constructed in interaction with other human actors (e.g. healthcare professionals, managers) and non-human actors (e.g. healthcare policy and health IT aimed at facilitating patients' activities) in practice. This finding demonstrates that active patientship is par excellence dependent on the specific context of the patient. Because active patientship involves many different aspects of healthcare (e.g. health IT, professionals' roles, etc.) active patient system might be a more suitable term to use when referring to a more active role of patients in healthcare quality improvement. This book will be of broad interest for those directly or indirectly involved in patient care, like healthcare professionals, patients, policy makers, managers and health technology developers.

Interacting Patients

The construction of active patientship in quality improvement initiatives

Femke D. Vennik

Interacting Patients

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Interacterende patiënten

De constructie van actief patiëntschap in kwaliteitsverbeteringinitiatieven

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INTRODUCTION

CHAPTER 1

The construction of active patientship
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ACTIVE BRAM

Bram is 42 years old and has spent most of his working life at the flower auction but recently became unfit for work due to wear and tear on his joints. Because he was used to working hard and wanted to continue to contribute to society, he decided to take on voluntary work, which included acting as a host at the local hospital near where he lived. After a couple of years, Bram began to display more symptoms and after various examinations he was diagnosed with an illness that can best be described as "closely related to ALS (amyotrophic lateral sclerosis)", but an even more progressive motor neuron disease than ALS, that weakens the muscles, and significantly shortens life expectation. To verify the diagnosis, he searched the Internet and found an expert who could give him a second opinion. The diagnoses turned out to be correct.

Bram continues to do his voluntary work, even though his physical condition causes him to cancel this work more often than not. He regularly visits online forums to find out how best to relieve his illness symptoms and to search for relevant tips and tricks on how best to carry out activities despite the disease. He also shares some tips from his own personal experience on the web.

As his symptoms progress, his visits to the hospital for palliative treatment become more frequent. During one consultation, the doctor invites him to participate in a project on quality improvement of the department. Bram, happy to be useful and maybe make a difference for patients that come after him, agrees to take part in an interview. He also takes part in a meeting with departmental staff and other patients where the care delivery process and points for improvement are jointly discussed and selected. Shortly after, Bram's condition deteriorates and he is unable to carry out any more activities.

Healthcare quality improvement is no longer perceived to be a primarily professional activity. Patients like Bram, who may be able and willing to participate, are also expected to assume a sufficiently active role in this respect (Boivin 2012). For example, they are expected to be actively involved in their own healthcare by searching for relevant health information on the Internet (Wathen et al. 2008), and in the healthcare of others by sharing their thoughts with healthcare professionals on how to achieve health service improvement solutions (Bate and Robert 2007). These expectations illustrate that Parsons' (1951) description of the 'sick role', where a patient only has to focus on getting better and cooperating with physicians (Barbot 2006; Van de Bovenkamp 2010), no longer suffices.

A more active role for patients in healthcare quality improvement is encouraged because of a growing recognition of patients' power to bring about change in healthcare (Hibbard 2003). Presumably as a result of this recognition, quality improvement initiatives which encourage a more active role for patients are increasing rapidly (Donetto et al. 2014).

The expectations of active patientship for healthcare quality improvement, and what the significance of these expectations is for patients' activities, form the motivation for this PhD research, which is dedicated to studying how active patientship in quality improvement initiatives works out in practice.

MOTIVATIONS FOR ACTIVE PATIENTSHIP IN HEALTHCARE QUALITY IMPROVEMENT

Active participation of patients in the realization of healthcare quality improvements is an important policy goal in the Netherlands and other Western countries (Crawford 2002; Dixon et al. 2010; Ministry of Health, Welfare and Sports 2014). Three different arguments underlie the stimulation of an active role for patients in quality improvement, the first and most common reason being that patients, as recipients of care, have unique experiential knowledge that could provide a complementary perspective on healthcare practices to that of healthcare professionals (Boivin 2012). Active involvement of patients could bring to light such refreshing perspectives, which can be used to improve the quality of care. This viewpoint contradicts a previously dominant view on healthcare quality improvement, i.e. that only 'doctors know best' because of their professional education, training and working experience (De Vos 2014).

A second motivation is that patients' activities may produce incentives for providers to improve their quality of care. This is particularly assumed in market-based healthcare systems, such as that in the Netherlands, which include voice and exit mechanisms (Hirschman 1970; Van de Bovenkamp et al. 2013). Voice is an active way to express discontent and dissatisfaction about service delivery (e.g. through active protest or writing a letter), however, voice behavior does not stem from dissatisfaction alone (Van de Bovenkamp et al. 2013). Patients may well be satisfied about service delivery and still express their opinions, for example, to share their thoughts with healthcare professionals on quality improvements. Exit refers to the option to switch from service provider when the service does not fulfill patients' needs (Van der Kraan 2006; Dixon et al. 2010). Policy officers expect that patients' active use of exit and voice contribute to fine-tuning service delivery to individuals' preferences and lead to improved health (Florin and Dixon 2004) and improved healthcare quality in general. In addition, it can trigger a re-distribution of power within the doctor-patient relationship (Roberts 1999), thereby limiting paternalistic views on healthcare in which only doctors govern and decide (Harrison and Mort 1998).

A last and frequently voiced argument for patients' active involvement in healthcare quality improvement is that their involvement could lead to more support for decisions that must be taken (such as the introduction of a new guideline) with the aim of improving the quality of care. This support could increase the implementation chances of decisions, and

patients' awareness of decisions could also put pressure on its implementation (e.g. when patients ask their healthcare providers about the new guideline) (Van de Bovenkamp et al. 2008).

The above arguments for active patientship all relate to improved healthcare quality. To be clear, this theme is the focus of this PhD research but it is not the only reason why active patientship is being encouraged. In addition to being a potential means for improving healthcare quality, active patientship is also encouraged in order to achieve two other goals. First, active patientship is perceived to be necessary for controlling healthcare costs and is a response to the growing demand on healthcare: when patients do more themselves, it lessens their reliance on healthcare services. Second, active patientship is stimulated for the purpose of improving democratic decision-making. Since the democratization movement in the 1960s and 1970s it has been argued that patients, as citizens, have the democratic right to be involved and to have a voice in decisions concerning their care (Van de Bovenkamp 2010). This movement has resulted in the introduction of various patients' rights such as 'informed consent' and 'citizen participation', aimed at strengthening patients' positions. The ideology of improved democratic decision-making could, in turn, also lead to more legitimized decisions, as it assumes a more transparent decision-making process in which all relevant actors have the opportunity to voice their opinions.

Although in theory controlling healthcare costs and improving democratic decision-making can strictly be separated from healthcare quality improvement, in practice these goals are often simultaneously used to stimulate active patientship. In addition, they are very much intertwined: initiatives that stimulate active patientship could, for example, realize the use of lay perspectives to improve healthcare quality and democracy ideals at the same time.

CRITICAL REFLECTIONS ON ACTIVE PATIENTSHIP IN HEALTHCARE QUALITY IMPROVEMENT

Opposed to above expectations, some authors have been skeptical about active patientship in quality improvement initiatives. Their criticism falls into two categories.

First, they argue that patient involvement is often only used instrumentally by healthcare organizations. Harrison & Mort (1998) argue, for example, that patients' opinions are only used to legitimize managers', professionals' or their institutions' preferred course of action. In case of unsatisfactory opinions, patients could easily be set aside as 'unrepresentative', and the outcomes of patient involvement ignored. Others claim that, in practice, organizations' efforts to involve patients are often tools for window-dressing (Coulter 2005) instead of real attempts to engage patients to participate in quality improvement processes. This type

of instrumental use is likely to occur, particularly in market-oriented healthcare systems such as that in the Netherlands, in which healthcare providers have to compete for patients.

Second, authors argue that patient involvement may be asking too much from patients. For example, they have voiced their concerns about the impact of the responsibility to be(come) active in healthcare quality improvement and the necessary skills and competencies patients need to carry out activities, which not all patients will possess (Mol 2008; Tonkens 2003; Trappenburg 2005; Van de Bovenkamp 2010). The burden of responsibility and a lack of skills may have various (negative) consequences for patients and challenge their quality improvement potential. Patients may be able to learn the necessary skills, to develop competences and to professionalize themselves (e.g. by familiarizing themselves with medical language); however, this may include the risk that the valued 'authentic' patient perspective will get lost (Trappenburg 2008; Van de Bovenkamp et al. 2008).

Besides the impact on patients, some authors (Henwood et al. 2003; Van de Bovenkamp 2010) have also emphasized that not every patient wants to be kept informed or take care of themselves, and to actively contribute to improved healthcare quality. Therefore, Grit et al. (2008) argue that active patientship should not be compulsory, but at the same time that these concerns should not stand in the way of patients who might be willing and able to participate.

UNRAVELING ACTIVE PATIENTSHIP IN QUALITY IMPROVEMENT PRACTICES

The motivations and concerns described above illustrate the various assumptions that exist regarding the possibilities of active patientship. These assumptions have led to continuous and uncrystallized debates on what patients' active role(s) in healthcare quality improvement could and should entail. To gain a better understanding of the potential active roles that patients could perform and to steer these debates, researchers have tried to further grasp the 'active patient' idea by differentiating between different *participation levels*, *forms* and *methods*. These distinctions will now be discussed in more detail.

Participation levels

A distinction between different participation levels refers to the macro, meso and micro levels at which patients can be(come) active in healthcare quality improvement.

At a macro level, patients can arrange themselves in patient organizations and be involved in collective decisions concerning government and national policy practices (Boivin 2010; Rabeharisoa et al. 2014; Trappenburg 2008; Van de Bovenkamp 2010). In the Netherlands, government and other actors in the field of healthcare recognize patient organizations as legitimate dialogue partners (Trappenburg 2005; Van de Bovenkamp 2010).

An example of patient involvement in healthcare quality improvement at this level is the participation of patient organizations in national guideline development (see e.g. Boivin 2010; Van de Bovenkamp and Zuiderent-Jerak 2015).

Being active at a meso level refers to patient participation in the governance of healthcare organizations, for instance, through client councils. In the Netherlands, client councils are legally formalized and consequently have the right to give (solicited and unsolicited) advice to a healthcare institution's board of directors, for example, regarding quality issues that affect that institution's clients (Van der Kraan et al. 2008; Van der Meide et al. 2015; Zuidgeest et al. 2011).

At a micro level, a more active role refers to those patients involved in issues related to the clinical (micro) level of healthcare. At this level of care, individual patients interact directly with their own healthcare professionals. A patient who participates in improving the quality of specific health services together with his/her healthcare professionals is one example of this type of participation (Bate and Robert 2007; Tsianakas et al. 2012). Another example is the patient actively involved in his/her own individual care, for instance by keeping a personal electronic health record that is shared with his/her healthcare professionals (Tuil 2008; Aarts 2012).

In this PhD research the focus is on the micro level because it is at this level in particular that new (technological and participatory) initiatives are being developed to actively involve individual patients in healthcare improvement practices. In addition, it is an interesting level to study since active patientship at this level is directly related to the delivery of care to patients, and with that to quality improvements.

However, the identified distinction between participatory levels does not imply that the levels do not interact with each other. National policy can, for example, stimulate patient involvement at both meso and micro levels by making participation compulsory. The opposite is also possible; incorporating patients' perspectives in national guidelines might limit patients' active role at individual level, because users of guidelines may assume that patients' perspectives are already represented (Van de Bovenkamp and Trappenburg 2009). Therefore, to understand the nature of active patientship at the micro level, it is also important to take note of these interactions.

Participation forms

At a micro participation level, various forms of involvement can unfold that provide patients with different degrees of decision-making power. The identification of these different participation forms is another attempt of researchers to provide a better understanding of the active patient notion in relation to healthcare quality improvement. Arnstein's (1969) ladder of participation is perhaps the best known illustration used in healthcare to indicate variations in participation forms. She distinguishes several 'rungs' of citizen participation, ranging from *informing* (i.e. receiving information) to *citizen control* (i.e. having the power to make

decisions). Each rung differs from its predecessor in terms of power; there is a progression from 'hearing' to 'having a voice' to 'making decisions'. The further up the ladder, the more decision-making power citizens have. Arnstein's ladder has also inspired other continuum varieties. For example, Carman et al. (2013, p. 225) differentiate between *consultation*, *involvement*, and *partnership/shared leadership*. Each of these participation forms refers to seeking patients' input, but the continuum's higher end indicates more responsibilities and shared power for patients. Another example comes from Bate & Robert (2007, p. 10) who differentiate between the different forms of participation, i.e. 'complaining', 'giving informa-tion', 'listening and responding', 'consulting and advising' and 'experience-based co-design' (EBCD). The latter refers to an involvement process where patients design healthcare ser-vices together with healthcare professionals. Here too, the higher end of the participation continuum implies more decision-making power for patients.

These continuums provide a clear understanding of the different participation forms patients can exercise. However, they also hold two problematic assumptions. First, they presuppose that more participation, and thus moving to the higher end of the power continuum, is better, when this is not always the case in practice (Van de Bovenkamp 2010). In fact, Van de Bovenkamp (2010) argues that there should be 'limits' to patients' power as more participation or more ways to participate can have negative consequences, such as a disregard for the interests of patients unable to become active (Henwood et al. 2003; Trappenburg 2008; Van de Bovenkamp 2010). Furthermore, these continuums seem to oversimplify how involvement works in practice (Tritter and McCallum 2006). For example, Broer et al. (2014, p. 2) state that "*participation can take many different forms that can and should not be compared to each other solely in terms of client influence.*" Consequently, they argue that "*it would seem crucial to investigate the participation process itself*", to learn more about what participation means in specific settings (Broer et al. 2014, p. 2). Following Broer et al. (2014), it is therefore particularly fruitful to study concrete quality improvement pro-cesses in which patients participate to learn more about the possible active roles patients can and are expected to fulfill.

Participation methods

One way to gain insight into these quality improvement processes is to examine the specific participation methods that are used to involve patients in quality improvement practices. A distinction between different participation methods at each level of healthcare (i.e. micro, meso, macro) is another attempt by researchers to further grasp the 'active patient' idea. At the micro level, the focus of this PhD research, participation methods can be divided into methods that aim to improve the patient care provided by a healthcare department and methods that primarily stimulate the patient's active role in his/her own individual care, in order to improve the quality of care. The former will be discussed first.

Participation methods to improve the patient care provided by a healthcare department

Currently, a myriad of patient participation methods exist aimed at improving the quality of care provided by healthcare departments. These methods range from familiar instruments such as surveys, interviews and focus groups, to lesser known instruments such as mystery guests[1] and patient diaries[2] (CBO 2013). Despite the abundance, new participation methods that lead to different activities for patients are being continuously developed (Locock et al. 2014).

In the Netherlands, different (non-)governmental organizations that try to stimulate patient involvement in healthcare quality improvement have provided overviews of the existing participation methods so that healthcare organizations can choose from several options and know what kind of results they can expect in relation to the method they choose (see for example the website introduced in 2014: participatiekompas.nl ('Participation Compass'), the manual 'Quality Improvement Hospital Care Using Patient Experiences' (Vennik et al. 2013) or the manual 'Patient/Client Participation' (CBO 2013)). Although such overviews are informative because they illustrate possible ways to involve patients, research has shown that in practice, existing methods to involve citizens/patients in participation processes are often adapted to local contexts (Street et al. 2014). This leads to even more varying participation practices (Street et al. 2014), and, presumably, to different results as well.

Participation methods to stimulate the patient's active role in his/her own care

In addition to participation methods that improve the patient care provided by healthcare departments, methods exist that stimulate an active role of patients in their own individual care. Examples of these are action plans (Turnock et al. 2005), motivational interviewing (Emmons and Rollnick 2001; Miller and Rollnick 2013), shared decision-making (Cribb and Entwistle 2011), personal electronic health records (Tuil 2008) and online health communities (Aarts 2012; Van der Eijk 2015). They all try to stimulate patients' self-management activities for improving individual patient care. With regard to health information technology (health IT) in particular, expectations are high when it comes to the ability to increase the opportunities for patients to become more involved in their own healthcare, and to improve the quality of their care. Over the past decade, a visible result of this expectation is the increased development of patient portals through which patients can access personal health information and various self-management facilities (Otte-Trojel 2015). In addition to

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1   Mystery guests refer to surprise visits by patients or patient representatives, during which situations within healthcare organizations are examined from a customer perspective (see e.g. Adams et al. 2015; Stoopendaal 2015).

2   Patient diaries are patients' written experiences with healthcare that healthcare professionals can read to understand these experiences better (CBO 2013). This is not the same as patients' self-management diaries.

improved self-management activities, health IT is assumed to enhance access to healthcare services, to reduce fragmentation of care and to tailor care to patients' needs (Chaudhry et al. 2006). Due to the ample possibilities that health IT could provide, Chaudhry et al. (2006) even argue that IT is the most promising tool to achieve improved quality in healthcare.

ACTIVE PATIENTSHIP AS A CONSTRUCTION PROCESS

The above overview of participation levels, forms and methods provides more clarity on the multi-faceted nature of active patientship in healthcare quality improvement. These distinctions therefore help to clarify the debate on active patientship. However, to fully understand how active patientship is shaped in the complexity of everyday practice and what the consequences are of that, in-depth studies of participation processes are needed. This way we can further unravel how active patientship is shaped in complex healthcare practices. Knowledge which is important for learning more about the possible active roles patients can and are expected to fulfill.

To further our knowledge about how active patientship is shaped in practice, these practices will be examined from a constructivist perspective. From this point of view it can be argued that active patientship does not emerge naturally (Henwood et al. 2003; Harris et al. 2010), but that it is continuously constructed by interactions with other human actors (e.g. healthcare professionals or managers) and non-human actors (e.g. healthcare policy or health IT aimed at facilitating patients' activities) in practice (Dehue 2014; De Vries 1995; Latour 2005). Following this perspective, it is the interaction between these actors that shapes both the above discussed forms and methods of activeness. This can best be illustrated with the following example.

For example, for patient Bram, a more active role in healthcare quality improvement implies not only a change for Bram but also for his physicians. The invitation to partake in discussions with his physicians on what 'good' quality care is and to become involved in healthcare quality-related decisions of the department, will, for instance, affect the autonomy of the professionals because they now have to share their decision-making power. Consequently, active patientship cannot be seen separately from patients' interactions with healthcare professionals: the willingness of the professionals to acknowledge the importance of Bram's perspective on healthcare and the room they provide for Bram to actually participate (even if it affects their autonomy) will, among other things, determine whether Bram can actively contribute to improved healthcare quality. Presumably, a perceived diminishing of the professional domain or just disagreeing with patient's views could easily influence the willingness of healthcare professionals to embrace and facilitate active patientship, and may even

stimulate debates that bring into question the importance that should be attached to a patient's subjective and lay perspectives, and the desirability of democracy at all levels of healthcare (Harrison and Mort 1998).

Also non-human actors such as health IT can have an influence on whether and how Bram can become active in healthcare quality improvement. As described earlier, some authors describe health IT as the most promising tool to achieve improved healthcare quality (Chaudhry et al. 2006), as it could facilitate the patient's self-management activities. However, when health IT developers underestimate or overestimate the skill set and competencies required by Bram to use the technology (Oudshoorn et al. 2004) or when the technology increases the burden of Bram's self-care rather than increasing self-reliance and consumer control (Lupton 2013), it could also hinder Bram's (expected) activities. Again, active patientship cannot be seen separately from patients' interactions with, in this case, technology. Tensions between users and technologies could easily influence a patient's willingness and potential to become active in practice.

Therefore, from a constructivist point of view, the specific healthcare context plays a very important role in the establishment of active patientship. The example above shows how, in this context, both human and non-human actors can stimulate and hinder patient participation or shape it in certain ways. This line of thought is confirmed by Mol (2008), who acknowledges the importance of interactions and interdependencies within a healthcare delivery context in which patients are expected to become active. She argues that, given the required alignment between patients, professionals, technologies etc., healthcare delivery is 'shared work'. When patients are stimulated to become active, for example, by making healthcare related choices, these interdependencies and interconnectedness continue to exist. In other words, patients are not autonomous individuals but are primarily related to specific actors and technologies in healthcare and, with that, patients' activities are also linked to specific actors and technologies.

This type of approach to active patientship shows the variation of active patientship in practice. Since each healthcare context differs, it follows that different variants of active patientship exist. This implies that the distinction often made in scientific literature between 'active and passive patients' (see e.g. Bångsbo et al. 2014; Brody et al. 1989; Brown et al. 2002; Henwood et al. 2003; Lupton 1997) does not always suffice in practice, as there is much more in between. For example, depending on patients' competences and/or the design of health information technologies, patients can perform certain activities like looking up information but not other activities such as posting questions. In addition, depending on the phase of the disease or context of the patient it is possible that some activities cannot *always* be performed.

Until now, academic researchers and policy practitioners have paid little attention to how interaction processes between patients and other human and non-human actors flourish in patient participation practices and what these interactions mean for the potential of patients to become active in healthcare quality improvement initiatives. As a result, scientific and practical knowledge on the construction and facilitation of active patientship is limited. In policy and practice, for example, this is visible by a focus on either one (type of) human actor (e.g. patient) or non-human actor (e.g. technology) when stimulating active patientship. Consideration for the interaction between the two, for instance by involving patients as end-users in the design of a technology, often remains absent (Langstrup 2013; Oudshoorn and Somers 2006). More insight into the construction of active patientship in participation practices can provide in-depth knowledge on patients' possible active role(s) and activities in healthcare quality improvement, as well as on how these roles and activities can best be facilitated. The focus of this thesis is therefore on empirical research into patient participation processes within quality improvement practices.

ANALYTICAL FOCUS AND RESEARCH QUESTION

The aim of this thesis is 1) to describe how active role(s) of patients are constructed in healthcare quality improvement initiatives at the micro level of care and 2) to explore the consequences and complexities of these construction practices, for example by looking at what it means for patients activities. The central research question is:

How is active patientship constructed in quality improvement initiatives and to what effect?

Answering this question is important as it enhances our understanding of how patient participation works out in practice. This, in turn, provides insight into whether the expectations regarding active patientship (as described above) can be realized and how patients like Bram, who might be willing and able to participate, can be helped to fulfill this active role. To answer the research question, this PhD research examines patient participation processes within two Dutch quality improvement initiatives. Before describing these initiatives in more detail, it will first be explained why Dutch healthcare is an interesting setting to study active patientship.

The context of Dutch healthcare has been selected because the Netherlands is one of the leading countries when it comes to active patient involvement in quality improvement (Donetto et al. 2014). 2006 saw the official introduction of a regulated market system where private care organizations are expected to compete for patients who have a free choice of provider, restricted only by general practitioners who act as gatekeepers, and by insurers that can guide (but not force) patients to use providers with whom they have contracts.

This competition is believed to be an important route not only to increasing efficiency and democracy but improving healthcare quality too (Ministry of Health, Welfare and Sport, 2006), since quality could function as an important selection criterion for patients and health insurers. The implementation of the regulated marked-based model thus promotes the patient's exit option (i.e. choice), but also focuses on increasing the patient's voice (Grit et al. 2008; Van de Bovenkamp et al. 2008). The quality improvement initiatives included in this PhD research, described below, are an example of the latter. Besides the voice and choice options of patients, the participatory rights of patients are secured in various Dutch laws and patients have a supposedly strong position in the triangular relationship with healthcare providers and insurers (Trappenburg 2005). Furthermore, Dutch government policy continues to encourage and strengthen patients' active role(s), which is apparent, for example, in the recent policy impetus for health IT, to stimulate more self-management activities of patients (Ministry of Health, Welfare and Sport 2014). Similar trends can be seen in other countries, for which the Dutch case is interesting to an international audience as well (Adams 2011; Armstrong et al. 2013; Dixon et al. 2010; Donetto et al. 2014; Fudge et al. 2008; Hibbard 2003; Iedema et al. 2010).

To explore how active patientship is constructed in the Dutch healthcare context, this PhD research studies *participation processes*. This focus on processes is derived from the premise that active patientship can take many different forms and shapes, depending on the participation context. Studying processes enables these different forms and shapes to be captured within quality improvement initiatives over time, and provides knowledge on how they are formed by patient interaction with the context. Participation processes within two quality improvement initiatives are studied. The first initiative concerns patients' (expected) use of a new health IT, i.e. a community website. The second case concerns the active involvement of patients in hospital service improvement through a – for the hospital – new participation method. These initiatives have been selected because they both present new[3] ways (i.e. a new technology and a new participation method) to involve patients in healthcare quality improvement. Research into these initiatives provides insights into the latest expectations regarding active patientship. In addition, both initiatives are financially supported by Dutch government, which suggests that the initiatives also represent the latest policy views on active patientship. Furthermore, the technological case (i.e. the website) is specifically included because of the high expectations regarding health IT in supporting patients to take an active role in healthcare (see e.g. Hardey 1999; Harris et al. 2010; Oudshoorn and Somers 2006; Swan 2012; Rozenblum and Bates 2013). More details of each selected case are described below.

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3   ''That what is considered 'new' is situational within a specific historical context'', see the notion of 'situated novelty' (Janssen et al. 2015, p.1981).

Health IT quality improvement initiative

The first healthcare quality improvement initiative discussed in this thesis concerns the development of the Dutch website MijnZorgnet.nl ("my health net"). This case is also referred to as the 'health IT initiative' and was researched between November 2010 and August 2012 (after that, the organization and website under examination no longer existed in the researched format). This website, designed by the organization MijnZorgnet and financed by government, was set up to increase opportunities for patients to actively participate in their own healthcare, to stimulate improved collaboration between healthcare professionals and between healthcare professionals and patients, and to change the current healthcare system into a more patient-centered system (Faber et al., 2012). The website consisted of various online communities that patients and healthcare professionals among others could use to communicate, exchange knowledge and to gather (general and patient-specific) information. Since it was possible to explore the *development* and the *use* of the website simultaneously, it was an excellent way to learn more about how technologies, designers and patients interact, and how this interaction built active patientship in practice.

Quality improvement initiative of hospital departments

The second healthcare quality improvement initiative discussed in this thesis concerns five Dutch hospitals keen to improve the quality of their care provision by using patient experiences. This case, researched between April 2012 and December 2014, is also referred to as the 'hospital departments initiative'. The oncology departments of four hospitals participated in a one-year national government-funded project, in which professional staff of a patient organization, consultants and researchers offered training courses and advice on how to involve patients in quality improvement by means of various participation methods, including EBCD. EBCD is a new service improvement technique that involves patients not only in the prioritization of improvement themes, but also in the realization of improvement solutions, thereby expanding patients' activities. Other innovative elements in this method are the focus on experiences and emotions rather than on opinions, and the use of a short edited film from patients' interviews to illustrate in an impactful way to staff how patients experience the service delivery (Bate and Robert 2007). The hematology department of a fifth hospital that was not included in the national project, but also wanted to use patients' experiences to improve the quality of their services, participated in the training sessions. Within each hospital, project teams designed their own participatory processes, implemented them, and tried to make quality improvements together with patients in the space of a year. As it was possible to study both the *design* and *implementation* of the participation processes within the hospitals, this research site also provided an excellent case to study how active patientship is constructed through interactions in practice.

In both case studies, a qualitative multi-method research design with interviews, document analysis and (online) observations was used (Bowling 2002; Creswell 2003). A detailed description of the methods is described in each individual chapter. The following section presents an overview of the chapters in this thesis and focuses on the studies that are conducted.

STRUCTURE OF THE CHAPTERS

Chapter 2 starts by unraveling how active patientship is constructed in quality improvement initiatives by studying the development of the design of a patient-oriented website. Technologies that attempt to foster patient activities, such as patient-oriented websites, are particularly interesting for studying the construction of active patientship as they carry inscriptions of developers and designers about the users (Akrich 1992; Oudshoorn et al. 2004; Oudshoorn and Somers 2006). By studying these technologies, it is possible to highlight these inscriptions. In this way, the specific ideas and notions that developers have of future users, and the activities these users need to perform, can be examined and clarified. In other words, it reveals the expectations they have for the future active patient/user. In addition to exploring the design aspect, this chapter studies how patients utilize the website. This shows, among other things, that design choices include and exclude certain patients from use, and that the distinction often made between active and passive patients no longer suffices. By including both the evaluation of the website development and its use, interaction processes become clear, illustrating that not only designer but also patient interactions with technology influence the final form of the website. This, in turn, constructs how active patientship takes shape in practice.

Chapter 3 focuses on a specific online space on the website where patients are expected to become active. This chapter examines online health communities (in particular patient-to-doctor communities), where care professionals and patients who generally do not know one another (and thus do not have a formal treatment relationship) meet to exchange information. Such exchanges take place through different features, such as a blog, forum or a wiki, and are stimulated to increase the opportunities for patients to actively participate in their own healthcare. By zooming in (Nicolini 2009) on a specific aspect of the website, this chapter explores the consequences and complexities of the construction of active patientship in quality improvement initiatives in situ. It shows that the website facilitates patients in performing different types of ('new') health activities, but that its use also has challenges, specifically in relation to the reliability of health information, which is used to perform health activities.

Chapter 4 zooms in on another online space on the website, where physicians and patients generally *do* know one another, namely the personal health community. This is a community where a patient – regardless of health condition – can invite care providers and other relevant actors to participate in the exchange of his/her care information. Additionally, the various participants can communicate with one another using diverse features such as an online diary and a forum. This chapter explores how patients and professionals value such new quality improvement initiatives in care and illustrates the consequences of the design and use of such technologies on the roles of patients and professionals in healthcare. It provides insight into the changing roles (with associated skills and activities) for both patients and professionals once patients have been encouraged to assume the (expected) active role in their own care processes.

Chapter 5 shifts the focus to hospital departments that want to involve patients in improving the quality of their care. This chapter explores why hospitals are interested in patient involvement, and studies how hospital project teams design the patient participation processes aimed at improving the quality of care. The chapter illustrates the different motives that hospitals have for involving patients and the various design choices and adaptations they make to existing participation methods, influenced by the hospitals' context. Through these choices, they construct various participation opportunities for patients.

Chapter 6 elaborates further on Chapter 5 and zooms in on the consequences and complexities of the choices made in the design and implementation of patient participation methods. This chapter shows that design choices enable but also limit possibilities for patients and staff to become active and to exchange points of view on healthcare quality, which is necessary to reach informed decisions about which themes to improve. The chapter further illustrates that design choices influence themes and improvement solutions that are selected. Consequently, the question can be raised whether the improvements meet participants' expectations and contribute to the improved quality of care.

Chapter 7 answers the central research question of this thesis. It first describes how human and non-human actors mutually construct active patientship in practice. Subsequently, it illustrates the consequences of these construction practices by zooming in on six different tensions. Furthermore, it discusses the main study implications and presents suggestions for further research.

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HEALTH IT INITIATIVE

CHAPTER 2

Scripting the active patient in online health communities

ABSTRACT

Purpose: The purpose of this paper is to improve the general operationalization of an 'active patient', by examining the specific activities and skills expected of active patients.

Methodology: Expected activities and necessary skills were studied through a qualitative case study into the development and use of an assistive technology (i.e. website) aimed at stimulating active patientship. Interviews, observations and document analysis were used to capture and explore designers' inscribing practices and their consequences regarding expected competences and activities of patients using the website.

Findings: Designers inscribed two 'co-design roles' that active patients were expected to perform on the website (co-designing their own healthcare and co-designing the healthcare of peers), for which at least eight different competencies were needed. The absence of skills or facilities to apply these skills resulted in incomplete use, a different use than intended by designers and non-use of the website.

Practical implications: Technological choices and inscribing processes determine who is able or facilitated to become active and who is not. Due to inscribed co-design roles, it also influences the extent to which already active peers are able to perform health-related activities. Different users with different conditions should be taken into account in the design as specific group characteristics can influence the level of individual activity.

Originality: This study is, as far as the authors know, the first that examines the 'active patient' concept by studying an assistive technology and using scripting literature, resulting in an improved understanding of what it means to become 'active' in terms of skills and activities.

INTRODUCTION

'Passive patients are patients of the past; active patients are the present and future'. This – somewhat provocative and sharply phrased – notion can currently be found in many policy documents and literature on patient participation (Van de Bovenkamp 2010). While 'active patientship' applies especially to the involvement of patients in their own health and healthcare, it also applies to other levels, for example participation in improving the quality of hospital care (see e.g. Vennik et al. forthcoming). Because information and communication technologies (ICT) are seen as enabling instruments that facilitate patients' personal health-related activities (Anderson et al. 2003; Eysenbach 2008; Czaja et al. 2013), expectations for their contribution to active patientship are high. They are expected, for example, to help patients integrate large amounts of complex health information (Baker et al. 2010) and enable self-care (Harris et al. 2010). In recent years, ICT applications that help patients undertake activities that support their own health and care, here further described as patient-oriented ICT applications, have been developed.

Though there is much literature on patients' transformations from passive to active and the stimulating role that ICT could play, this rarely makes explicit what is meant by this changed concept of the patient. What are 'active' patients, or what should they be? What skills do they need, for example, in order to use patient-oriented ICT applications? And is it, for instance, possible to be active in the 'wrong' way? Until now, the description of active patientship has been limited to 'managing your own healthcare' (Henkemans et al. 2010), 'gathering information to be informed about diseases and treatments' (Anderson et al. 2003; Crawford 2006; Henwood et al. 2003), 'participating in medical decision making' (Lee et al. 2010) and 'taking up a healthy lifestyle' (Van de Bovenkamp 2010). Such operationalization gives a general description of activities but remains largely rhetorical (Schermer 2009), as the specific tasks and skills these activities comprise – and the consequences of (not) possessing/utilizing these skills – remain unclear.

To learn more about the content of the word 'active', this paper focuses on the development of a patient-oriented ICT application. Technologies are not neutral tools; they carry various inscriptions of the developers and designers (Akrich 1992; Oudshoorn et al. 2004). For example, the materials used to build cars reflect predictions of the developer and designer about the stresses cars will have to bear (Akrich 1992). By studying these materials, it is possible to explore and explicate designers' specific ideas and notions of (future) users. Applied in this context, examining the development and design of an ICT application, reveals expectations for the (future) active patient, demonstrating which preferences, competencies and activities are inscribed by designers in the technical product (Oudshoorn et al. 2004). The result of the inscribed users' representations in technologies is called a "script" (Akrich 1992, p. 208).

In this paper, we aim to examine the 'active patient' concept further, by studying how designers' expectations regarding patients' competences and activities are reflected and scripted in patient-oriented ICT applications. The research question guiding this paper is: *How is the 'active patient' scripted in the design of a patient-oriented ICT application?* Insight into this question is scientifically and practically important as it explicates professionals' and policy-makers' expectations of patients' skills and activities and it results in an improved conceptualization of what is currently expected from patients (Boivin 2012). This will sharpen the scientific and policy debate of active patientship.

This paper begins with a brief overview of active patientship literature. This is followed by an explanation of the scripting concept and how it is relevant to this case. In the methods section we describe the research design, and in the results section we illustrate the scripting activities that took place in the development of a patient-oriented ICT application. In the discussion and conclusion we reflect on the consequences of these scripting activities, in light of the 'active patient' concept.

ACTIVE PATIENTSHIP

The involvement of patients in their own health and healthcare has always been a social practice. However, through the years, different institutions and developments have influenced the extent to which patients have been stimulated to become 'more' or 'less' active. Steele et al. (1987) provide an overview of the active patient concept starting from the mid-eighteenth century. At that time, writers stressed the search for self-help alternatives due to broad societal interest in personal freedom, autonomy and personal responsibility combined with a growing distrust of medical authority. These ideas flourished into the nineteenth century but became less discernible when, among other things, major advances in medical technology were realized (e.g. the discovery of X-rays), along with new ways to treat and prevent diseases (e.g. with improved vaccines). This resulted in increased medical authority at the beginning of the twentieth century (Steele et al. 1987). This increase, however, did not last long; professional authority was again challenged in the second half of the twentieth century when socio-political critiques "called for more egalitarian power-sharing within the clinical consultation", to move away from paternalistic physician-patient relationships (Boivin 2012, p. 10) where doctors govern and decide. In this period, patients' rights such as 'informed consent' and the right to participate in decisions concerning their own health were introduced (Steele et al. 1987). According to Van de Bovenkamp (2010), these rights strengthen the position of patients. At the same time, they also (legally) place emphasis on a more active patient, who makes individual health choices or decisions together with healthcare professionals and manages his/her own health (Boivin 2012).

Besides the more democratic argument, that patients have the right to be involved in decisions concerning their lives, there are also other arguments for stimulating an active patient and to move the boundaries of patient skills and initiatives, such as to enhance the legitimization and quality of decisions (Van de Bovenkamp 2010). Moreover, active patient involvement could, for example, potentially lead to improved dialogue during medical consultations, as patients give opinions and ask questions, resulting in a more complete information exchange and ultimately improving the quality of care (Steele et al. 1987). Finally, stimulating patients to become active and do more themselves could control costs by reducing the burden on health systems; an important argument at a time when healthcare costs continue to rise and the chronically ill population continues to grow. These arguments illustrate that there are multiple reasons for not being excused from an active role in society when one is ill.

Professionals and policy makers anticipate that not every patient is able to become more active on his/her own and search for ways to support patients in assuming a more active role. In this respect, much is expected from ICT applications, which are seen as important instruments to facilitate patients in health-related activities (Adams and De Bont 2007). Technological developments in this area, such as the availability and accessibility of health information through the web, have stimulated more (intense) possibilities for patients to become active, possibly leading to other tasks and responsibilities of patients, as well (Hardey 1999).

SCRIPTING USERS IN TECHNOLOGIES

To gain a better notion of the 'active patient' concept, it is particularly suited to study healthcare-related technological developments aimed at involving patients in their own health and healthcare, as studying these technologies makes it possible to distill designers' inscribed vision of the skills, behavior and activities of (future) users of the technology. Designers have a specific configuration of the user in mind (Akrich 1992), which determines how they shape the technology of a product in terms of materiality, layout, functionalities, etc. By studying design practices and thus by looking at these different aspects, the user configuration becomes explicit, which makes it possible to deepen our understanding of what it means to be(come) an 'active' patient.

A study by Oudshoorn et al. (2004) illustrates that designers' "inscribing" processes – i.e. the translation of the designers' vision of the competencies, actions and responsibilities of the user into the design (Akrich 1992, p. 208) – are influenced by both the environment in which they find themselves ("macro dynamics") and their own personality ("micro dynamics"), and that these dynamics influence the inclusion and exclusion of users. Regarding the macro dynamics, they showed, for example, that the initial wish of designers in their

study to include a diversity of users gradually became overruled by a more marketing-related focus of having an innovative product. To be 'innovative,' this study showed, meant not lagging behind in using the latest computer software programs. Because this software was not accessible to every user, specific (types of) users were excluded. This illustrates that when differences between users are not taken into account, certain competences and wishes of specific segments of the populations are excluded, making it impossible to design for 'everybody' (Oudshoorn et al. 2004). When designing a patient-oriented ICT application, the diversity in patients groups should thus be taken into account, which means avoiding categories of users that are too broadly defined (Van Loon et al. 2014).

The inclusion and exclusion of users is also influenced by micro dynamics, specifically by the use of the "I-methodology" (Akrich 1995): a concept referring to designers' tendency to take their own "preferences and skills as major guides in the design" (Oudshoorn et al. 2004, p. 53). Applying I-methodology can lead to an overestimation of the skill set of the more 'average' user. Consequently, this further contributes to the inclusion and exclusion of specific users. In addition, taking the self as a representative model could result in the exclusion of users based on certain aspects, such as gender: the work of predominantly male designers may lead to a masculine design style, primarily attractive to, and thus used by, men (Oudshoorn et al. 2004; Rommes et al. 2011). Though many studies explore so called gender-scripts (e.g. Ravneberg 2012; Shade 2007; Van Oost 2003), similar studies on scripted roles of 'active' patients were not found in the literature.

Although design influences the inclusion and exclusion of users and is able to govern user behavior, for example by technically stimulating or limiting certain (inter)actions, it does not mean that users are passively submitted to a certain script (a view also known as technological determinism) (Akrich 1992; Oudshoorn and Pinch 2003). Contrary to a more linear notion of technological innovation where the agency of designers is placed above that of users, users can better be viewed as co-designers who "may slightly modify the scripts, they may drastically transform them, or they may even completely reject them and create new meanings and uses of the objects or become nonusers" (Oudshoorn and Pinch 2003; Oudshoorn et al. 2004, p. 55). Examples of such modified scripts are ICT applications that are used in a different way or for a different purpose than intended by designers. Scripts could thus reinforce existing user behavior but could also create new behavior. It is therefore possible that users (and technologies) take on different roles in practice than what the designers had envisioned.

Given the above, it is important to look at design practices in their entirety when studying inscribing processes and scripts related to the active patient. This means that it is not only vital to focus on the design of a product, but also to take into account the broader context in which the product is (being) built. Additionally, not only designers' points of view have to be taken into account, but also the view of users of the technological product (Akrich 1992). These views should be alternated continuously, to fully understand how a

behavioral architecture (i.e. the technological design that stimulates certain user behavior) is actually inscribed and (co-)created by both designers and users.

METHODS

Case study

To explore how the 'active patient' is scripted in the design of a patient-oriented ICT application, an in-depth qualitative case study was performed into MijnZorgnet ('my health net'). This was a Dutch organization engaged in building an assistive technology: the patient-oriented website (www.MijnZorgnet.nl). This website was a web-based community platform where patients and physicians could communicate and exchange knowledge. When the organization started (2009), the idea of MijnZorgnet was proclaimed by the Minister of Health, Welfare and Sports (VWS) to be a pioneering healthcare initiative; the initiative received four-year funding from VWS and the Radboud University Medical Centre. It was initiated by two healthcare professionals who wanted to increase opportunities for patients to actively participate in their own healthcare processes, to stimulate better collaboration between physicians and between physicians and patients, and to change the current healthcare system into a more patient-centered system (Faber et al. 2012). The past tense is used because the organization and website under study no longer exist in the researched format. To be clear, the aim of this paper is not to provide an explanation for this ending. This paper aims to examine the 'active patient' concept, by studying how designers' expectations regarding patients' competences and activities are reflected and scripted in patient-oriented ICT applications.

As described above, studying inscribing processes meant studying MijnZorgnet from a broad perspective. We included both the design of the product and the context in which it was being built into the study. In addition, as recommended by Akrich (1992), we continuously alternated between the organization MijnZorgnet, the website they were building, and end users (i.e. patients), using a variety of data collection methods: observations, document analysis and interviews.

Observations

The main research method used in this study was observation. Observations were conducted by the first author during weekly meetings held by MijnZorgnet's team between November 2010 (when the website was launched) and August 2012 (when the organization stopped in its current structure by a shortage of financial resources). MijnZorgnet's team consisted of approximately 14 employees (male and female), each focused on a different aspect related to the website: technological development, product and support, marketing and sales, research and business management. Examples of observed meetings are:

- 'The round': morning rounds at the end of every week in which each employee recited the activities he/she had performed that week.
- 'Deliverable of the month': sessions in which employees presented the achievements and activities of that month.
- 'Colloquia': sessions once a week in which employees or external guests gave presentations on certain topics related to the organization's work.

During these meetings, current and future (technological) developments regarding the website and organization were discussed, under the leadership of two directors (the healthcare professionals who started the initiative). Every employee was free to voice his/her opinion regarding this development process.

During the observations, the researcher was primarily focused on speech (e.g. what was said), visual aspects (e.g. facial expressions) and the activities performed (e.g. adjustments to the website). In addition, during observation moments, informal interviews with employees of MijnZorgnet were conducted. The observations and informal interviews provided insight into how MijnZorgnet employees wanted to design the patient-oriented website, their views of patients (i.e. their roles, skills, etc.), and how they thought that patients should use the website.

During all observations, extensive field notes were taken and worked out into thick descriptions. The field notes were divided into descriptive notes, reflective notes (i.e. personal thoughts) and demographic information such as time and place of the observations (Creswell 2003). Some observations were recorded with permission and transcribed verbatim. During the observations, the employees knew that the researcher was present to collect data.

Document analysis

In addition to observations, relevant 'documents' (in the broadest sense of the word) were analyzed by the first author. Examples are PowerPoint presentations given by MijnZorgnet staff, strategy documents compiled by the organizations' Board of Directors and the website that was being built. Regarding the latter, different aspects of the website were observed and analyzed, including the layout, the login, the available (instruction) information and the help desk. Specific attention was paid to designers' language use and the usability of the site. To gain more in-depth knowledge of how the website was used by patients, five online health communities on the website, accessible for anyone with internet access, were observed for eight to 21 months (between December 2010 and September 2012). See Vennik et al. (2014) for a detailed description of the selection of these communities. Discussion themes of these communities included Parkinson's disease, cerebrovascular accident and fertility care, and the communities consisted of different information and communication functionalities including blogging applications, forums and wikis. The aim of observing the communities was to find out how the different functionalities were used and whether that

corresponded to the intentions of the designers, which was possible to compare due to the data obtained by the observations described above. The website analysis (including patients' use of the website) was performed by taking screenshots of the website and analyzing all the content and visible aspects present while making descriptive and analytic notes (Bernard 2006).

Interviews

Lastly, the first author performed semi-structured interviews with MijnZorgnet employees and website users (i.e. patients). Interviews were held with a selection of MijnZorgnet staff (N = 5) (i.e. one director, project coordinator, marketing and sales employee, implementer and a process manager support and technology). The selected key persons were interviewed to deepen and validate some more general findings of the observations and document analysis. During the interviews, staff members were invited to talk about the development of the organization and website, their own role, their vision on the website and on the patients' role. The interviews were conducted face-to-face at the organization MijnZorgnet and lasted approximately one hour each.

Semi-structured interviews with users of two of the five observed online communities were also conducted (N = 17). The two communities, about Parkinson's disease, were selected because they had the longest life span of the five observed communities and a relatively high number of members, which increased the possibility of activities and postings within these communities, giving a clearer picture of how the communities were used. Additionally, the users of these communities – chronically ill patients under age 50 – were according to the directors of MijnZorgnet the ideal target group of MijnZorgnet.nl. The users (nine male, eight female; between the ages of 39 and 65; time since diagnosis of Parkinson's disease ranged between one and 18 years) were contacted through forum and private messages, with permission from the community managers. During the interviews they were asked to explicate their experiences with the website and were invited to talk about why, how and when they used the website. With the exception of four telephone interviews, the interviews were conducted face-to-face at the respondents' houses and lasted 73 minutes on average.

Data analysis

The interviews were tape-recorded with permission and transcribed verbatim. All transcripts, field notes and documents were analyzed qualitatively. First, all data were carefully read and data related to the role and activities of patients were selected and labeled. Second, labels that shared a commonality, for instance activities that an active patient needed to perform, were clustered and formed into categories. As a final step, themes were created by selecting the core category (i.e. active patient) and to link this category to the other categories (i.e. aim of MijnZorgnet, expectations of patients using the website and experiences of patients

with this website) (Creswell 2003). This process of analysis continued until no new codes, categories and themes emerged (Bowling 2002) and was performed by the first author and checked for consistency of application of the codes to the data by the second author.

Ethical considerations

Permission to perform the interviews with employees and the observations at the organization was given by the directors of MijnZorgnet. In addition, permission was obtained from the Committee on Research Involving Human Subjects (in Dutch: Commissie Mensgebonden Onderzoek Regio Arnhem-Nijmegen) to interview users of MijnZorgnet.nl. The content of this website was available for scientific research as a result of the user agreement. To respect the privacy of the participants in this study, pseudonyms are used (Creswell 2003).

RESULTS

In this section, we first describe the healthcare changes that the staff of MijnZorgnet had in mind and illustrate how they wanted to reach this envisioned change, by introducing MijnZorgnet.nl. Then, we describe which skills the organization expected patients to have/ develop and how these translated into specific activities on the website. Finally, we discuss patients' experiences with the website and compare these experiences with the designers' vision, to illustrate the consequences of scripting activities.

Changing healthcare by patients using online communities

MijnZorgnet was an organization aimed at changing the current healthcare system into a more patient-centered system, by stimulating personalized care and reducing fragmentation of care. Building a patient-oriented website (i.e. MijnZorgnet.nl) with the technological design of online health communities facilitated by communication functionalities such as blog, wiki, forum and the option to exchange files, was seen as a way to reach this goal. The underlying idea was that by using different types of online communities, illustrated in Table 1 [4], in which patients have an 'active' role (see the following section for an elaboration on what this 'active' precisely means), the health network of the individual patient becomes transparent, which could stimulate (improved) collaboration and communication between healthcare professionals and between professionals and patients, thereby reducing fragmentation of care. Additionally, the health network could provide access to relevant (personal) health information leading to better-informed patients.

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4   Since the choice for the communities and their characteristics was made prior to this study, it is beyond the scope of this paper.

Personal health community
* Content is only visible for community members.
* Community of one person who is surrounded by his/her physicians and other relevant actors to his/her health (see also Aarts et al. 2015).
Private hospital community
* Content is only visible for community members.
* Patients and physicians of a specific hospital ward are gathered.
Public general community
* Content is visible for everyone with Internet access.
* Patients and physicians that generally do not know each other are gathered (see also Vennik et al. 2014).
Private general community
* Content is only visible for community members.
* Patients and physicians that generally do not know each other are gathered.

Table 1. Community types on MijnZorgnet.nl.

The choice for the type of website was motivated by the positive experience of one of the directors with the use of online communities in healthcare. However, making this choice also shaped the first user representation: the user was configured as someone with access to a computer and working internet connection. At that time, this meant almost everyone in the Netherlands (European Commission 2014). This was in line with the target group MijnZorgnet envisioned: 'every Dutch citizen' could create a profile on MijnZorgnet.nl, after which he/she could focus on his/her own health by participating in different health communities (see the list above). They configured the user thus as 'everybody'. Within this group of 'everybody' they expected particularly most activity and enthusiasm from chronically ill patients under age 50 (observation March 18, 2011).

Scripted expectations of active patients in online communities

Every patient was expected to be able to and actually use the website, because, "From the beginning we [of MijnZorgnet] created something that is generically available for anyone" (Director 1). One of the community types on the website was the PHC and patients were expected to use this community in the following way:

"Here [in the PHC] the patient creates his own team of healthcare professionals or even loved ones, family, children, people who are involved in your care; you can organize and decide it yourself. This creates a personal community in which the patient is in the lead and this way you give others access to all sorts of information about your healthcare, that provides them with insight, and they can also add information. Well, the ultimate goal of this is of course shorter lines, no fragmentation and patient-centeredness." (Product manager, transcribed observation January 21, 2011).

The PHC contains the notion that 'transparency' is a necessary precondition to improving communication and coordination in care, whereby it refers to the visibility of individuals involved in a patients' care process and the information they can contribute. These individuals include physicians but also other relevant actors in the patients' social network such as family members, and must have access to the same online space (a PHC) where they can 'gather' and where all relevant data are stored. Coupled on this, MijnZorgnet gave individual patients the responsibility to manage this space by selecting and inviting relevant people in their network and by controlling the content of the community. With this, the reframing of the patient as having a more active role in healthcare becomes apparent. It illustrates that patients, in partnership with healthcare professionals, family members and/or (patient) peers, become (more) integrally bound up in care-related activities, thereby 'co-designing' their own healthcare.

The envisioned active co-design role was, however, not limited to the PHC, it applied to all community types on the website. In private hospital communities and general communities, patients were, for instance, expected to gather information (e.g. about treatment options) by searching for relevant content and posing questions to physicians and peers. In addition, patients were expected to provide meaningful and transparent information to help (unknown) others (e.g. about coping strategies). Patients were thus also asked to co-design other patients' health, by becoming (more) integrally bound up in activities related to the care of others.

These two scripted co-design roles required specific skills and competences, which became visible by looking at the design of the website. For example, the activity 'gathering information (e.g. about Parkinson's disease), by searching on the website for relevant content and posing questions to physicians and peers', meant that patients first had to have Dutch reading and writing skills, as this was the main language used on the website. In addition, as some applications on the website (such as 'community' or 'blog') were referred to in English, patients also needed to have some understanding of the English language and what these terms mean with respect to the functionality of those sections of the site. Furthermore, finding relevant information on Parkinson's disease required using the website's search and, by default, typing relevant search terms. In the search process, patients saw a list of information available on the website related to these terms (the more information, the longer the list and anything on the website could 'pop-up' including community themes, physicians working on that specific subject, forum, blog or wiki messages and PDF's). Next it was up to patients to select the relevant item(s) from the list and to evaluate the information in terms of reliability and appropriateness/relevance to their personal health situation. When patients could not find the information they were looking for, questions could be posted within a community, implying that it was first necessary to find the right community. Every user could start a community on the website and related to Parkinson's disease there was, for instance, a community for young patients with Parkinson's disease (i.e. patients under age 56) and

a community for questions about Parkinson's disease and having a job. Patients needed to have found both communities in order to know that work-related questions could best be posted in the latter community, as the former in general concerned the same target group, but did not discuss work-related subjects. Once the right community was selected, it was necessary to find the correct area (e.g. blog or forum theme) within the community to formulate the question.

This example reflects the assumption on the part of MijnZorgnet employees that the user was someone similar to them: predominantly highly educated, young professionals between the ages of 26 and 40; a group familiar with the use of computers and internet, who are able to easily find information and who use social media sites such as Twitter and Facebook where the use of English terms is customary (see the following section for whether or not this corresponded with the actual users). In addition, the example illustrates that 'being active' not only means that you have to perform different kind of activities; you also need to have the right (level of) skills to perform these activities. To unravel the 'active patient' concept, it is thus not only important to focus on the scripts of activities that users have to perform, it is also necessary to take into account the role descriptions of required skills and competences to perform a script (to remain in the theater metaphor).

Based on the observations, document analysis and interviews, we distinguish at least eight different skills that users should possess: technical computer skills (e.g. to use different functionalities within the online communities); reading and writing skills (i.e. Dutch proficiency and a general understanding of English); intellectual skills (e.g. to formulate a question); information skills (i.e. to search, find, critically analyze and process various sources); reflective skills (e.g. to translate information into the own healthcare context); leadership skills (e.g. to initiate writing information in different types of communities); management skills (e.g. to organize relevant information in the PHC); and relational skills (e.g. to invite physicians in one's PHC). There is an implicit expectation that these skills are already present and that they will automatically flourish regardless of the context, or that they can be developed in every patient. However, when this is not the case, it means that certain users will be excluded or 'scripted-out' of using the website.

Users' experiences with and consequences of using the website

Having illustrated designers' expectations regarding active patients, it is time to explore users' experiences with the website, to see whether these correspond. Interviews with users of the website have shown that patients indeed experienced benefits using online communities on MijnZorgnet.nl. General communities were, for instance, used to performing medical activities (e.g. to prepare for the consultation with the doctor), emotional activities (e.g. to gain recognition) and lifestyle activities (e.g. reading tips on how to combine working with having a disease) (see Vennik et al. 2014). Regarding the PHCs, potential benefits were identified relating to the organization of care (e.g. better collaboration between physicians) and care experience (e.g.

reducing stress) (see Aarts et al. 2015). The extent to which these benefits could be achieved was, however, strongly related to the usability of the website and thus to the technological design. Some patients experienced difficulties with that.

The majority of users experienced two types of difficulties in particular. The first was navigating the website. This concerned not only the technology to go from one hypertext link to another on the website, but also how available information was structured. Some users did not understand where to 'click' to see the information they were searching for. Others found it difficult to find the way back to their starting point once they had 'clicked through' the website. Most users found the information inconveniently arranged, for example because of the dissemination of information about a particular subject within various communities (which was possible as every user could create a community and was able to post content wherever he/she wanted). Because of this, navigating to relevant information was no minor issue. The website designers scripted patients with technical computer and information skills, but users' experiences illustrate that these competences were not adequately present in the actual users or facilitated by the website.

The second difficulty related to navigation concerned the functionalities for information provision and exchange. The designers had chosen to include different functionalities within the communities, each for a different and distinct purpose. A blog, for instance, was described during one of the observations as a place to "inform every member about something that you, as a community owner, find important", whereas the forum functioned as "a place for discussion" in which everyone could participate (product manager, transcribed observation January 21, 2011). However, for some users, neither the purpose of the different functionalities, nor how to use them was entirely clear:

"All those other terms and 'community', I thought, what should I do with it? Because, well, my English is not so good and then you have all those other terms that you never use in ordinary everyday life." (Female user, 65 years).

"The man asked "how do I post a message" and I also sometimes have problems with that. Then I think yeah why am I making such an effort? I'm already giving something of myself, so if it takes too much effort I'm done with it." (Male user, 60 years).

The interviews revealed that some users did not know the difference between certain functionalities; they experienced them as similar, did not know what they were meant for or how to use them. An instruction on how to use the functionalities was also not immediately visible on the website. To find this information, users had to go to the help desk for which they first had to register by e-mail address or Twitter account.

For other users the functionalities were (more or less) clear, but they sometimes faced other challenges: they did not know what to post or felt insecure in writing a message. This

implies that providing a technological website is not enough to make a user/patient active on the website, as they still might not have the right level of skill or face other challenges:

"The aim [of a wiki] is clear I guess, working together on a question [...]. But what kind of information should I add and which theme should be selected? That, I wouldn't know." (Male user, 47 years).

"I find it rather difficult to post something because I'm very dyslexic and then I'm not sure how to write it down. Those [doctors] are so highly educated and then I find it sometimes difficult to ask a question. Even if I want to, it does not mean I'll always do it." (Female user, 49 years).

The combination of navigating difficulties, technologically unfamiliar functions and patients not knowing what to add in terms of content or how to write it, resulted in 'empty' functionalities within various general communities. Especially content in blogs and wiki's remained absent for a long period, sometimes permanently. Not all users could meet the inscribed competences of patients, resulting in a non-use of certain aspects of the website.

Moreover, some users used the website differently than envisioned by the designers. For example, questions and experiences were posted in unintended places. Accordingly, both patients and designers tried to actively steer users' actions to ensure that the website was used in the 'proper' way. Users explained, for instance, to one another where to post information, while the organization MijnZorgnet adjusted the technology:

"You see that also on MijnZorgnet.nl; someone posts a message and somebody else tells you it's better to move it. [...] So I guess it is difficult for a lot of people." (Female user, 57 years).

The help desk receives different kinds of questions. An employee in control of the help desk says that the new help desk arrangement should stimulate users first to search for solutions themselves, instead of "randomly shooting things into the help desk". He says that the current contact option is too easy to access and that when it's removed, questions can be better controlled. One director asks the employee how one can force people to ask less questions. The employee suggests: 1) by making it more difficult to ask questions, 2) by posting a proper frequently asked questions list, and 3) by introducing a help button. (Observation, May 27, 2011).

Although asking questions was one of the envisioned elements of the active patient, the observation above illustrates that asking questions about how to use the website was not what MijnZorgnet was aiming for. This implies being active might be different from what

was expected and viewed as a 'wrong way' or in a 'wrong place'. To stimulate the 'right' way and place, in this case to find solutions for problems themselves first on the website, the technology was adjusted and reshaped by the designers to steer users in a different direction. Prior user behavior contributed to this design change, which illustrates that patients also functioned as co-designers of the website.

However, it should be noted that being 'wrongly' active is not always visible for designers who study user behavior by (solely) observing the use of the technological design. During the interviews, some respondents indicated that they connected with peers on MijnZorgnet.nl (e.g. by using the forum), but that they soon made use of their own e-mail address instead of the website to exchange experiences with peers. The complicated log in process (by using DigiD, the identification method of the Dutch government to identify internet users) compared to e-mail and the limited time they had on the website (approximately 15 minutes) before they were automatically logged off due to security reasons, were reasons for users with Parkinson's disease (who in general have coordination problems) to make this shift. Due to this shift, the premise of transparency and idea that patients could co-design the health of many others were both replaced by co-designing the health of an individual in another web space. An understanding of a different use of the website than intended could, in this case, only be made visible by interviewing users. In order to steer (and eventually script) user behavior, designers must therefore actively include actual users (instead of proxy users such as professionals, which often occurs) in the development of the website; MijnZorgnet only included actual users in limited fashion (i.e. in relation to certain developed technological aspects of the website).

DISCUSSION AND CONCLUSION

With this study, we explored how the 'active' patient is scripted in the design of a patient-oriented website. By studying the organization creating the website, the website itself and users' experiences with the site, this study provides in-depth insight in inscribing processes and co-construction of assistive technologies such as information platforms intended to support 'active patients'. The results show that designers inscribed two co-design roles that active patients were expected to perform on the website: co-designing own healthcare and co-designing the healthcare of other patients. To perform these roles, patients needed to have at least eight different competencies, including technical computer skills and information skills. The consequences of these inscriptions will be further discussed in this section.

We illustrated that the target group of MijnZorgnet.nl was every Dutch citizen (with specific expectations regarding chronically ill patients under age 50). However, the question is whether the aim to script everybody in the design of the website was supported by

the technological choices that were made. This is an important question because it has implications for who is facilitated to be active and who is not, which is also of normative consequence – especially in the case of healthcare.

The technological choices seemed to be based on both macro and micro dynamics (Oudshoorn et al. 2004). The wish to change the current healthcare system into a more patient-centered system, by stimulating personalized care and reducing fragmentation of care, was an influencing macro dynamic that fit within broader healthcare policy. It resulted in the idea to create a website that, through use by active patients, would make the health network of the patient visible, leading to improved coordination and communication between physicians and between physicians and patients. However, the website design was also influenced by micro dynamics, namely the I-methodology: designers own competences were used as a point of reference in the creation of the website. The combination of these dynamics resulted in a scripted website design that could be used optimally when patients had at least eight different types of skills and were facilitated to use these skills. However, not all users had these competences or had conditions, for instance leading to coordination problems, that influenced their ability to use the website. As a consequence, users did not use certain aspects of the website, used the website in a different way than intended, or were even scripted-out (i.e. excluded from use) (see, e.g. Wyatt et al. 2002), which makes it problematic to suggest that the website was built for every Dutch citizen. It also makes clear that designers cannot only underestimate users' competences, leading to frustrated users who experience feelings of discrimination, as Ravneberg (2012) has illustrated, but that they can also overestimate users' competences, thereby influencing users' ability to use the website. The level of design of assistive technologies must thus take different users with different conditions/(dis)abilities into account, as the specific characteristics of these groups can influence their degree, level or pace of 'activity' (Czaja et al. 2013), and often ask for specific website design requirements (see, e.g. Fischer et al. 2014). The importance of focusing on individuals and their interaction with computer systems, and thus on the functionality and usability of websites, is also confirmed in human-computer interaction literature (Shackel 2009).

The consequences of scripted designs not only have implications for the inclusion and exclusion of users, but also for the roles patients were expected to perform. Active patients were to become more integrally bound up in their own care, as well as in the care of others. They, for instance, had to help other patients by providing experiential knowledge, a process in computer sciences also known as 'social scripting' (Lau 2007). However, if patients do not know where to post their experiential knowledge (as they did not always knew the difference between functionalities), or when they do not use the website in the 'right' way (e.g. when they shared experiences through private e-mails instead of public messages), they could not contribute to the care of (many) others. Technological choices thus not only determine who is facilitated to be active and who is not, but they also influence the

extent to which already active peers are able to perform health-related (self-care) activities. To meet the high expectations of ICT applications in healthcare, it is therefore important to keep monitoring whether technological choices still correspond with the goals that technologies have to establish.

The scripting literature of Akrich (1992, 1995) and Oudshoorn et al. (2003, 2004) used in this paper is helpful to illustrate that designers' technological choices and inscribing practices influence who is able or facilitated to become a (more) active patient and who is not, which is important to take into account in the active patientship debate. However, using this literature also illustrates another important aspect for this debate: by creating 'scripts' patients are also able to deviate from these scripts (Akrich 1992; Oudshoorn et al. 2004), potentially leading to a 'right' or 'wrong' way to be active and doing the right kind of activity, but in the wrong place. Thus, the often-made distinction between 'active' and 'passive' in the active patientship debate, we argue, is insufficient for understanding daily practice, as there are more gradations to make. Because an understanding of activities that should be avoided or performed elsewhere could also clarify which types of activities could and/or should be performed (Eldh et al. 2008), future research could focus on these kinds of activities to learn more about the active patient.

Designers adapted the website according to 'incorrect' use of it by active patients. As patients' actions led to reshaping the technology, it illustrates that patients also function as website co-designers. Although co-design activities to change and improve services usually take place by talking to users to bring their experiences to the fore to indicate improvement areas and solutions (Bate and Robert 2007), co-design can thus also take place 'indirectly' when technologies are adjusted on basis of observed user behavior. However, as our results indicate that it is not always possible to observe the 'wrong' use of the website and to reshape the website accordingly, it remains crucial to include patients within the development of a technology, for example by interviewing them, to ensure better alignment between intended and actual uses (Eisma et al. 2004).

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2

CHAPTER 3

Expert and experiential knowledge in the same place: patients' experiences with online communities connecting patients and health professionals

ABSTRACT

Objective: To explore patients' experiences with online health communities in which both physicians and patients participate (i.e. patient-to-doctor or 'P2D' communities).

Methods: A qualitative content analysis was conducted, based on observations in five P2D communities ranging from 8-21 months, and semi-structured interviews (N = 17) with patients.

Results: Patients consider information from physicians and peers as two distinct sources, value both sources differently and appreciate accessing both in the same web space. According to respondents, physicians can provide 'reliable' and evidence-based information, while patients add experience-based information. Patients use this information for multiple purposes, including being informed about scientific research and personal reflection.

Conclusion: Patients find P2D communities beneficial because they help patients to collect information from both medical experts and experiential experts in one place.

Practice implications: Patients use P2D communities to perform medical, emotional and lifestyle activities. The presence of physicians in P2D communities may inadvertently suggest that the quality of information used for the activities, is controlled. When information is not officially being checked, this should be stated explicitly on the website and supplemented with a statement that information is only indicative and that patients should at all times contact their own physicians.

INTRODUCTION

In the past few years, virtual communities have rapidly increased in prevalence (Demiris 2006; Nambisan 2011a, 2011b). Virtual communities are social networks facilitated or formed online (Wellman 1997), "where people with common interests gather 'virtually' to share experiences, ask questions, or provide emotional support and self-help" (Eysenbach et al. 2004, p. 1). Online communities are used in various sectors including healthcare, where they usually form around health-related conditions or goals, such as losing weight, living with back pain, or coping with disease.

Research on health-related online communities has explored how they are used and how users (mostly patients) experience them (Coulson et al. 2007; Frost and Massagli 2008; Malik and Coulson 2008; Van Uden-Kraan et al. 2008; Van Uden-Kraan et al. 2009; Ziebland and Wyke 2012). Research on this topic primarily focuses on communities where *patients or family members* share experiences, also known as online patient support groups or peer-to-peer (P2P) communities. These studies indicate that patients who use P2P health communities are better informed about symptoms and treatments (Van Uden-Kraan et al. 2008; Van Uden-Kraan et al. 2009; Wicks et al. 2012; Ziebland and Wyke 2012), receive guidance on coping strategies (Coulson and Knibb 2007), and find patient peers (Wicks et al. 2012).

Online communities in which *patients and physicians* are linked (here defined as patient-to-doctor (P2D) communities) also exist (Heldoorn 2008; Van der Eijk et al. 2013), but are currently under-researched. In these communities, patients and healthcare professionals are able to communicate with each other regardless of geographical location or the professional's institutional affiliation. An offline medical treatment relationship between the members of the community is generally absent, with the focus being on self-help rather than provision of health services. Although knowledge exists on the consequences of using P2D communities (see e.g. Himmel et al. 2005; Umefjord et al. 2003; Umefjord et al. 2006), most studies focus on 'ask the doctor forums', rather than interfaces where questions can be posted to and answered by both patients and healthcare professionals.

This paper reports the results of a qualitative study of patients' experiences with on-line self-help communities in which both physicians and patients participated. The research question was: *How do patients experience the use of online P2D health communities and what are the consequences of such use*? The research reported here addressed this question in relation to the Dutch website MijnZorgnet.nl ('my health net'), an online platform where patients and healthcare professionals communicated and exchanged knowledge within online health communities. The insights gained in this study are relevant for practice because patients are increasingly obliged to stay informed about health matters (Wathen et al. 2008), which potentially leads to greater use of online health communities for this purpose. More information about how patients experience both participation in P2D communities

and consequences of such participation, enable reflecting on the informed patient discourse (Henwood et al. 2003) in light of practical experiences.

METHODS

Observations of online health communities

Qualitative research was conducted on a single case in the Netherlands: the website MijnZorgnet.nl. MijnZorgnet.nl provided an online platform where patients and healthcare professionals within online health communities could communicate and exchange knowledge, and was online from late 2010 to late 2013 (Aarts 2012;Van der Eijk et al. 2013).The communities were supported by several applications, including blogging applications, forums, private messaging and wikis.These applications enabled end-users to produce and publish text, images and/or emoticons on MijnZorgnet.nl, in the absence of official moderators.

The first author observed five web-based 'open' health communities on MijnZorgnet.nl for 8-21 months (between December 2010 and September 2012). 'Open' means that the community's content was visible to anyone who had Internet access. Registration to join these communities was only necessary when a community visitor wanted to respond to an existing message or post a new one.The online health communities on MijnZorgnet.nl were selected for maximum variation in disease subjects, community manager's background (i.e. patient or physician), community lifespan and number of community members. See Table 2 for the characteristics of the selected communities. In order to understand the use and value of online P2D communities for patients, screenshots were taken and archived of all content in the selected P2D communities, and the following aspects were examined and described in field notes using thick description: architecture (i.e. functionalities, such as blogs and wikis), how people converse (i.e. treatment), the content of the conversations, how people present themselves, and the contributions of the community manager. Data saturation was reached after seven months of observations and confirmed by the 14 remaining

Subject of community	Number of members	Background of community manager(s)	Online since	Followed for
Parkinson's disease and labor	158	Physicians (1 medical officer and 1 occupational therapist)	22-Dec-2010	21 months
Parkinson's disease in young patients	61	Patient	21-Jan-2011	20 months
Cerebrovascular accident	95	Patient	20-Feb-2011	19 months
Fertility care	2	Physician (gynecologist)	02-Feb-2011	8 months
Self-care for pregnancy and birth	18	Physician (obstetrics nurse in training)	09-May-2011	16 months

Table 2. Characteristics of the selected communities on September 19, 2012.

months. This extended period with different observation moments was chosen because newly created communities need time to mature (Hansen 2007).

Interviews

The observations led to an initial understanding of how P2D communities are used by patients and for what reasons. To gain more insight in how patients experience such communities and the consequences of using them, semi-structured interviews (N = 17) were conducted, by the first author, between June and October 2012 with patients from two of the observed communities: 'Parkinson's disease and labor' and 'Parkinson's disease in young patients'. These communities were selected because they have the longest lifespan of the five communities shown in Table 2 and a relatively high number of members, which increases the possibility of more activities and 'traffic' (i.e. postings) within these communities. Content-wise, these two communities are also interesting as they involve patients with Parkinson's disease (PD): a chronic and progressive movement disorder whereby patients arguably search for information at different moments in time and during an extensive period (i.e. for the rest of their lives). Patients were recruited through blog and forum messages posted with permission in the selected communities. After two weeks, private messages were sent to all the patients within the communities, with an interview invitation including a reminder of the blog and forum message. Table 3 shows the background characteristics

Respondent	Gender	Age (in years)	Diagnosed with Parkinson's disease since (in years)
A	Male	42	3
B	Female	49	10
C	Female	57	2
D	Male	56	4
E	Male	39	9
F	Female	58	5
G	Male	52	18
H	Female	56	7
I	Male	53	10
J	Female	48	4
K	Female	65	8
L	Female	58	5
M	Male	60	9
N	Male	61	1
O	Female	48	9
P	Male	51	9
Q	Male	47	6

Table 3. Participants' background characteristics.

of all interviewees. Respondents' activity levels varied from only reading to active posting of various messages.

During the interviews, patients were invited to talk about how, why and how often they used the online P2D community, and what their (positive and negative) experiences were with this use. In addition, they were asked to react on the findings from the observations. There were four telephone interviews and thirteen face-to-face interviews, conducted at the respondent's home (at their request), and lasted 73 minutes on average. Interviews were tape-recorded and transcribed verbatim. Six respondents wanted to receive their own transcript and checked it for accuracy. Data saturation (i.e. no new information) was reached after the 13th interview and confirmed by the four remaining interviews (Saumure and Given 2008).

Content analysis

The observation field notes and interview transcriptions were both submitted to qualitative content analysis. A process of open coding was performed, by carefully reading all the data and by giving labels to words, sentences or paragraphs that related to each other (Graneheim and Lundman 2004). Then, categories were created, by clustering codes that shared a commonality, also known as axial-coding (Strauss and Corbin 1998). This phase facilitated insight into relevant and less-relevant codes. Finally, themes were created (i.e. selective coding, (Strauss and Corbin 1998)), by selecting the core category, relating it to other categories and determining the meaning of their interaction. This process of analysis involved a back and forth movement, just as the process of data collection and analysis (Graneheim and Lundman 2004), and was performed by the first author and checked for consistency of application of the codes to the data by the second author. All codes, categories and themes were recorded in Excel. Data was translated from Dutch to English by the first author and reverse-translated by the second author (a native English-speaker) to verify proper capture of diction, colloquialisms, etc.

Ethical considerations

Before this study was conducted, permission to perform the interviews was obtained by the Committee on Research Involving Human Subjects, Region Arnhem-Nijmegen (in Dutch: Commissie Mensgebonden Onderzoek Regio Arnhem-Nijmegen). The content on the website MijnZorgnet.nl is available for scientific research as a result of the user agreement of the website. Active solicitation of interview respondents via community postings was done with express written permission of Mijnzorgnet.nl and community managers. Participants were informed about the purpose and the procedure of the study and interviews were recorded with respondents' permission. Furthermore, the respondents were told that participation was voluntarily and that they were free to withdraw at any time. To protect the participants' privacy, pseudonyms have been used (Creswell 2003).

RESULTS

Different reasons for using P2D communities

In the P2D communities on MijnZorgnet.nl, information-seeking and information-provision processes were facilitated through blogging applications, forums, wikis and the option to save files. Through these applications patients and healthcare professionals posted various questions, answers and documents, such as newspaper articles. Topics varied widely, but included medication, treatment options, announcements of television broadcasts about a specific disease, insurance issues, and the combination of working and dealing with disease:

> *"Who is 100% unfit for work and is still working – though perhaps unpaid, voluntary or as an entrepreneur? [I] would like to share experiences."* (Posted by a patient in 'PD and labor' community, observation 12-Jan-2011).

> *"What is known about how menopause influences medication for Parkinson's disease?"* (Posted by a patient in 'PD in young patients' community, observation 11-Jan-2011).

The observations and interviews revealed that online P2D health communities were used by patients for three different sets of activities: (1) *medical activities*, which refer to activities related to the patients' disease such as gathering information about medicines or preparing the consultation with the doctor; (2) *emotional activities*, that is, performing activities to deal with the patients' state of mind, for example by expressing emotions and thoughts or gaining recognition; and (3) *lifestyle activities*, which refer to activities related to managing the patient's life with the condition, such as gathering tips and tricks for instance on tools to facilitate walking. These activities were reasons for patients to use P2D communities. See Table 4 for an overview of each set of activities.

Additional activities available to patients with the presence of physicians in online communities (compared to P2P communities) relate to the *medical* domain. That is, disease-related activities that can only be performed when healthcare professionals post information or when they are present, such as: (a) proposing scientific research to healthcare professionals (e.g. about the effect of a diet or pesticides on PD, as initiated by respondents K and O during the interviews); (b) searching for scientific research programs of physicians in which patients can participate; (c) reflecting on professional performance (i.e. by asking other patients and physicians how they would react in particular situations); and (d) getting in touch with professionals:

> *"One benefit I experienced is… I first had a neurologist in [Dutch city], where I lived back then. But now I live with my parents and consult a neurologist in [another Dutch*

city] whom I actually contacted via MijnZorgnet.nl. She reacted well to it. So that's how I got in touch with her. That's quite special.'' (Respondent P).

Type of activities	Activities performed by patients using P2D communities
Medical activities	Gathering information about disease
	Being informed about scientific research programs (in which patients can participate)
	Proposing ideas for scientific research to professionals
	Preparing consultations with doctor
	Getting in touch with professionals (treatment relationship)
	Reflecting on professional performance
Emotional activities	Gaining recognition
	Expressing emotions and thoughts
	Connecting with patient peers
	Self-reflection ('how am I doing in relation to peers')
	Helping others by providing information
Lifestyle activities	Reading tips and tricks, for example on how to combine working with having a disease or on different tools that patients could use to facilitate walking

Table 4. Patients' reasons to use patient-to-doctor communities.

Information providers within P2D communities: laymen versus experts

To sustain a system where the aforementioned activities can be performed by patients, community members must not only *search* for information; they must also *provide* information. Although the majority of reactions were given by patients, healthcare professionals also posted answers. Most respondents explicitly mentioned that they preferred information from both patients and physicians, and that they see the presence of both as the added value of MijnZorgnet.nl:

"If someone asks a question you get a response from the expert and you also get an answer from, what's that again… experiential expert. Those reactions together provide real added value compared to just one of the two. That's very clear." (Respondent I).

"In mixing the experience of the healthcare professional and the experience of the patient, synergy could emerge. Then it's more than just the scientist or more than just the patient." (Respondent P).

The quotes illustrate that patients make a clear distinction between information from healthcare professionals and information from patients. Where 'expert knowledge' is valued from healthcare professionals, 'experiential knowledge', often resulting in tips and tricks, is appreciated from fellow patients. Although most respondents explicitly mentioned that they preferred information from both patients and physicians, several indicated that they

actually do have a preference, for instance when they encountered conflicting information in the community.

> *"[Information] from the healthcare professional is more reliable than from someone who just says something. Because some [patients] talk about how they experience a certain medication, and they're not pleased with it, whilst others say that they're very happy with it. When ordinary people say that, I'd rather have an expert [healthcare professional] saying something about it. Not that he's right but I could ask for his recommendation or opinion regarding the medicine."* (Respondent A).

> *"[Patients] come pretty regularly with, drinking coffee would be good or smoking or whatever. But it would be better if a neurologist, someone who's knowledgeable, says something about it. For example there's a new medicine, or there was also some fuss with stem cell therapy or something… I do realize that it would ask a lot of a neurologist, but it would actually be very useful when somebody with authority says something about it."* (Respondent H).

Patients indicated during the interviews that they prefer the responses from healthcare professionals due to their 'expert status', formal education and training, and expertise in healthcare delivery. According to the patients, professionals, being someone with authority, give more reliable information and provide an additional 'check' on the advice and information that patients give one another.

Besides a distinction between expert and lay knowledge, three respondents distinguished 'knowledge' differently: they separated evidence-based knowledge or medicine (EBM) from knowledge that is not scientifically proven. Patients find both types of information useful:

> *"I find it most important that there is a lot of variety when I look at my own physicians and what they think that PD is about and what I learn on MijnZorgnet.nl and from other people, which may not be officially recognized everywhere, but I gain a lot from that."* (Respondent C).

This patient finds it helpful that online communities facilitate the provision of information from healthcare professionals and patients, resulting in a broader view on a disease through the inclusion of both EBM and non-EBM or other 'unrecognized' knowledge in P2D communities. According to respondent C, this broader view leads to information that, while not provided by a professional, is nonetheless relevant to the personal situation, which leads to a better understanding of the disease (process) and assessment of the need to act in certain situations (e.g. in relation to medication side effects or unexpected symptoms). De-

veloping a broader view on one's disease by using P2D communities is also recognized by respondent F, who followed a specific diet to lose weight but found out on MijnZorgnet.nl (after not feeling well) that this diet did not combine good with certain medications. In fact, respondent F read experiences indicating that it was perhaps best to reduce a specific food that was central to this diet. The neurologist had not said anything about this particular food, because, "It hasn't been proven, therefore we may not say that." (Respondent F).

The reliable expertise of healthcare professionals is valued, yet simultaneously perceived by some patients as incomplete or restrictive because it is limited to evidence-based knowledge. Respondent I indicated that patients are in a favorable position for providing non-EBM, compared to healthcare professionals in P2D communities:

"*So not everything is known or proven and researchers [and healthcare professionals] will not mention things that might be true but aren't proven yet. Though a patient can… I can freely write about that I believe that running is good for [people with PD].*" (Respondent I).

This patient had the opinion that precisely the combination of members (patients and physicians) within P2D communities is an advantage; as bringing together both types of knowledge results in better understanding of one's personal health.

Reliability of information

While it is easy for patients to provide information in P2D communities, it is important that the provided information is still valuable and that discussions on the reliability of information do not get out of hand. Some patients feel that this issue is resolved by the presence of physicians in P2D communities: a healthcare professional stands out and is able to check the information being exchanged:

"*I also think that it's for a significant part the presence of [a neurologist] who just hovers above [the discussion]. If something happens that leads to a debate, then he can just write a blog about it and there's no flaw in that argument.*" (Respondent I).

A few respondents explicitly mentioned not worrying about the reliability of the information, because they were sure it was controlled by the attending healthcare professionals in the online community and/or the website administrators:

"*I think that those who maintain MijnZorgnet also check whether there's nonsense written in the online communities. Because that's something you need to look out for. What I mentioned earlier, that people say all kinds of stuff, you should take those medications… and then a healthcare professional writes 'hey wait a minute, not every*

medication is applicable for every patient, so check with your own neurologist'. So that's something that's checked. Yeah, they make sure that there isn't any nonsense.'' (Respondent J).

''When the information is too colored or incorrect, then healthcare professionals react to it.'' (Respondent Q).

''Healthcare professionals at least provide the correct answers. If there were only patients, well I think that you would get the strangest answers and stuff on the Internet. And that's of course not what you want.'' (Respondent J).

Some patients think that healthcare professionals act as information moderators by checking and correcting postings. However, participating physicians have not been asked to agree to this 'job description'. As is further discussed below, this results in a potentially unjustified sense of security: patients are confident in the trustworthiness of the information because of the presence of healthcare professionals, although they do not necessarily act as patients expect.

DISCUSSION AND CONCLUSION

This study explored patients' experiences with online P2D health communities. Patients use these communities to perform medical, emotional and lifestyle activities, such as preparing consultations or learning about latest scientific research. In P2D communities, two parties can provide relevant information: patients and healthcare professionals. Information from healthcare professionals is simultaneously considered as authoritative and therefore more reliable, but at the same time too limited, while peer information may be less reliable, but nonetheless relevant to the individual situation. The value of P2D communities lies primarily in the combination of information from patients and professionals. The risk of P2D communities is that some patients think that all posted information is controlled by physicians, which is not always the case.

Discussion

When confronting the results of this study with literature on P2P communities, it becomes clear that both types of communities have medical, emotional and lifestyle functionalities for patients, and thereby facilitating self-management activities (Elissen et al. 2013; Redman 2007). There is, however, also a difference between the communities: the information exchange in P2D communities is broader than just sharing experiences between peers. In P2D communities, patients can also exchange knowledge with healthcare professionals. This

stimulates additional patient activities, such as proposing new scientific research to professionals or reflecting on professional performance by asking other physicians for advice. Furthermore, it facilitates an additional mode of interaction with healthcare professionals.

The knowledge exchange with healthcare professionals is valued differently compared to the knowledge exchange with peers. Patients in this study make a clear distinction between these two knowledge domains, whereby demarcation is primarily based on the idea that healthcare professionals receive formal training and education, leading to 'authoritative knowledge' or expertise in the opinion of patients, while patients have experiential knowledge. The combined knowledge of patients and healthcare professionals, which results in a mixture of EBM and (scientifically) unproven knowledge, is seen by most patients as the benefit of P2D communities. Both knowledge domains contribute in their view to the knowledge and management of their own disease. This can be explained by Kleinman's distinction between lay and professional 'explanatory models' of sickness (Kleinman 1978, 1980). Healthcare professionals perceive sickness often as a *disease* ("a malfunctioning of biological and/or psychological processes") for which they provide treatments, whereas patients perceive sickness often as an *illness* ("the psychosocial experience and meaning of perceived disease") (Kleinman 1980, p. 72), for which they seek not only "symptom relief but also personally and socially meaningful explanations and psychological treatments for illness" (Kleinman 1978, p. 88). The latter is often only provided within family contexts and by non-professional healing specialists (Kleinman 1978). The experience of illness causes people therefore to consult not only healthcare professionals but also others about their health (Leslie 1980) and P2D communities can bring these people together.

In addition to the insight that patients appreciate finding different types of information in one place, this study also shows that patients like to rely on information from different sources, as this is part of the triangulation process that also has been recognized in earlier studies (Adams et al. 2006; Henwood et al. 2003). That several respondents had the impression that information on the website was screened and that inaccurate information would be corrected or commented on by professionals, (a) has implications for the information patients consider to be 'true' and how they apply this to their own healthcare situation, and (b) reflects that patients do expect physicians to take an active role in "vetting" information. However, because there were no official agreements articulated with physicians regarding their monitor activities, it was not their responsibility to correct for misinformation. Although most respondents were aware that not all information was verified by an authority, this should be clear to all participants in accordance with e.g. the HON code of conduct (www.hon.ch/HONcode).

Limitations of the study and future research

The use of two data collection methods, long-term observations and in-depth interviews, was a useful combination for this study, as it provided a thorough understanding of patients'

experiences with and their use of P2D communities. There are, however, also four limitations regarding these methods. First, there is potential bias in the respondents, as the majority of the patients volunteered for an interview and were active on MijnZorgnet.nl (i.e. 'posters'). This could result in empirical data that are only applicable for one kind of user. However, some respondents had not posted any messages and therefore declined the interview invitation by sending a message to the first author. By emphasizing that their experiences were also important, a number of respondents decided to participate, resulting in empirical data based on a mixture of active and less active respondents.

Second, the observations and interviews were performed by one researcher, which could influence the data collection and analysis. The following safeguards were taken to limit potential preconceptions and to ensure dependability of the research findings: self-reflection, audit trail, in-depth data collection including searching for 'contrasting cases', and frequently discussing and analyzing the research findings with the second author (Creswell 2003; Schwartz-Shea and Yanow 2012).

Third, although P2D communities with different disease subjects were observed, interviews were only held with patients with PD, which made it difficult to transfer the findings of this study to other P2D communities. Future research is needed to verify the findings of this study and to provide additional insight on differences and similarities between P2D communities for other health conditions.

Fourth, this study was aimed at exploring patients' experiences with P2D communities. It would, however, also be interesting to understand professionals' experiences with and their use of P2D communities, to explore how they see their role in such communities.

Conclusion

This paper explored patients' experiences with and the consequences of using online health communities connecting patients and physicians. As P2D communities combine two parties, information can also be derived from two sources: patients and healthcare professionals. Patients prefer this combination of information because it gives a broader view on their disease. Information from an expert (i.e. physician), whom they see as having authority is considered to be reliable, yet limited, while experiential relation from patient peers – although not scientifically proven – is also valuable.

Practice implications

Establishing P2D communities can help patients in dealing with chronic health conditions. The presence of healthcare professionals in P2D communities may, however, implicitly suggest that the information within communities is reviewed for accuracy and reliability. When information is not officially being checked, this should be stated explicitly on the website and supplemented with a statement that patients should always contact their own physicians to discuss if and how the retrieved information applies to their personal circumstances.

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CHAPTER 4

Personal health communities:
a phenomenological study of a new
healthcare concept

ABSTRACT

Context: Fragmentation of care, complexity of diseases and the need to involve patients actively in their individual healthcare led to the development of the personal health community (PHC). In a PHC, patients can – regardless of the nature of their condition – invite all professionals that are involved in their healthcare process. Once gathered, the patient and healthcare team can exchange information about the patient's health and communicate through several functionalities, in a secured environment.

Objectives: Exploring the use, first experiences and potential consequences of using PHCs in healthcare.

Design: Qualitative phenomenological study.

Participants: Eighteen respondents, consisting of women experiencing infertility (N = 5), persons with Parkinson's disease (N = 6), a gynecologist, a fertility doctor, a fertility nurse, three Parkinson's specialist nurses and a neurologist.

Results: First experiences with PHCs showed that patients use their PHC differently, depending on their condition and people involved. Various (potential) advantages for future healthcare were mentioned relating to both organizational aspects of care (e.g. continuity of care) and the human side of care (e.g. personal care). Patient involvement in care was facilitated. Disadvantages were the amount of work that it took and technological issues.

Conclusions: Using PHCs leads to promising improvements in both the organization of care and care experience, according to the participants in this study. They indicate that patients with different diseases and in different circumstances can benefit from these improvements. The PHC seem to be an online tool that can be applied in a personalized way. When (technically) well facilitated, it could stimulate active involvement of patients in their own health and healthcare. It warrants further research to study its effect on concrete health outcomes.

INTRODUCTION

Current healthcare faces some serious challenges. Due to complexity of diseases, healthcare services are increasingly distributed across multiple clinicians in different specializations and institutions (Corrigan et al. 2001; Wagner et al. 2005). Healthcare has evolved into multidisciplinary teamwork of various physicians, nurses and other care providers, who often work in different departments and organizations (Naik and Singh 2010). This poses challenges not only for healthcare professionals, but also for individual patients, as it demands a more active role in the organization of their own healthcare (Richards 2011; Greene and Hibbard 2012). Policy is therefore more and more focused on transforming patients from their current (often) passive position to engaged individuals who actively participate in their own health network (Van de Bovenkamp 2010). Additionally and importantly, many patients also express the wish to be more actively involved (Tomes 2007; Kremer et al. 2011). However, current healthcare is not prepared to respond to these developments adequately for several reasons. First, healthcare is primarily organized from the healthcare provider's perspective, instead of the patient's. Secondly, the complex care pathway that an individual patient has to deal with is generally poorly organized. In most cases, no one really leads the process and adequate communication between the different healthcare providers could be improved (Nijkrake et al. 2007). Thirdly, so far, interventions to activate patients and put them in the heart of the health system are not yet well developed (Greene and Hibbard 2012; Frosch and Elwyn 2011; Hibbard et al. 2007; Van de Bovenkamp and Zuiderent-Jerak 2015).

Reflecting these developments and challenges, the online personal health community (PHC) was developed. A PHC can – in fact – be defined as the patient's own 'online hospital'. Online, he or she can gather all different healthcare professionals from different healthcare organizations, who are relevant for his or her health. With the patient in the lead, all members of the community can share information about the patient's health and communicate with each other about this information through several functionalities in the PHC, including blogs and forums. This way, the PHC could be a tool to deal with some of the aforementioned difficulties in current healthcare. The PHC resembles initiatives that have been developed in recent years, such as www.patientslikeme.com, NHS' Healthspace, personal health records (PHR) and some electronic health record (EHR) systems. Most of these initiatives provide patients a tool to have insight into their own medical data (Archer et al. 2011; Greenhalgh, Wood et al. 2008; Sheikh et al. 2011; Zulman et al. 2011; Wicks et al. 2010; Greenhalgh, Stramer et al. 2008). On the website www.patientslikeme.com, patients can discuss their medical data online with 'patients-like-them' (Wicks et al. 2010). However, the concept of the PHC also differentiates itself on multiple aspects. First, the PHC *puts the individual patient in the heart of the health system*, acknowledging the multiple and personal contexts of individuals' lives. Second, the PHC *makes the complex patient's network*

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transparent for both the patient and his or her healthcare providers. Third, to have access to the PHC, healthcare professionals *need consent* from their patient. This is ethically more justifiable than the often occurring model of implied consent, in which the record can be accessed by anyone who claims to have a relationship with the patient (Greenhalgh, Wood et al. 2008). Finally, in many of the aforementioned systems, patients missed the *opportunity to communicate with others*, and in particular healthcare professionals, about their medical data (Sheikh et al. 2011; Zulman et al. 2011). Combining medical data with the possibility to communicate with others seems required to meet self-management goals (Shachak and Jadad 2010) and is possible within PHCs.

Although many studies are conducted into the development, implementation and use of PHRs and EHRs (see for example Sheikh et al. 2011), to our knowledge, there is no information about the consequences for healthcare professionals and patients using PHCs. The aim of this study is therefore to qualitatively evaluate the use and the potential consequences of using PHCs for patients and healthcare professionals. The research question is threefold: (i) *How do patients and healthcare professionals use the PHCs in daily practice*; (ii) *what are their first experiences*; and (iii) *what are their expectations (regarding the (dis) advantages) of using PHCs for future healthcare?* A qualitative research design can ideally answer this question, because one can go in-depth to capture the complexity of data (Pope et al. 2000).

METHODS

We used a phenomenological approach to explore experiences and possible advantages and disadvantages related to the concept of PHC. Phenomenology is a qualitative methodology that aims to explore the participants' lived experience and that reveals the meanings of the experience to the respondents' care (Giorgi 2005; Toscano and Montgomery 2009; Starks and Trinidad 2007; Reeves et al. 2008). Phenomenological analyses do not discover causes (Giorgi 2005). The goal is to clarify the meaning of a certain phenomenon: in this study the PHC.

The personal health community
The PHC is provided by www.mijnzorgnet.nl, a secured Dutch website offering an online platform for healthcare professionals, informal caregivers and patients to communicate, share information and exchange knowledge within online health communities.

A PHC is an online space owned by the patient. It offers the possibility to store and share medical information. The information consists of diaries written by the patient, forums for asynchronous communication, uploaded files with medical information and third party applications (e.g. forms, tools for decision support, questionnaires). The patient can invite

people who are relevant for his/her health to become a member of the PHC, for instance a GP, medical specialist, psychologist, family members and friends. Members have access to all personal information and communication possibilities. This allows transparent communication across all members of the healthcare team, including the patient. All activities in the community are logged. This way, the patient can see who 'entered' his or her community at what time. The PHC offers the possibility for the patient to be in the lead and to contribute to his or her own healthcare. When first visiting www.mijnzorgnet.nl, patients register using their personal DigiD, which is an identification and authentication method provided by the Dutch government to ensure safe access to all (semi-) governmental institutions. After making a profile, patients can start their own PHC. Healthcare professionals need to use their national electronic identification for healthcare professionals, called UZI, to register and log onto the website. Thereafter, they can accept their patients' invitations to join their PHCs. Registration is free of charge and untraceable to the individual user.

Setting

We performed this qualitative study aimed at exploring the experiences and possible advantages and disadvantages related to the concept of PHC in two patient populations, that is, suffering from infertility and Parkinson's disease (PD). Each population and related care context will now be briefly described.

Dutch infertility care

Infertility is defined as any form of reduced fertility with a prolonged time of unwanted non-conception. Infertility care is multidisciplinary in its nature and receiving treatment in more than one hospital is not uncommon. Several medical disciplines are involved in infertility care, such as nurses, clinical embryologists, psychologists and gynecologists. Moreover, other medical conditions, such as Diabetes Mellitus, could influence fertility treatment protocols and effects, which asks for collaboration between different medical specialists. In the Netherlands, couples with impaired fertility can be referred by their GP to every gynecologist for further assessment of their fertility problem, for intra-uterine insemination (IUI) and ovulation induction (OI) as the first treatment possibilities. In vitro fertilization (IVF), including intracytoplasmatic sperm injection (ICSI), is only performed in 13 IVF-licensed hospitals in the Netherlands: eight university hospitals, four general hospitals and one private clinic (tertiary healthcare). In some hospitals without an IVF-licensed laboratory, physicians can start up and monitor IVF cycles and refer the patient to an IVF-licensed hospital for the oocyte retrieval and/or embryo transfer. Overall, treatment for infertility is often lengthy, and the emotional impact of being infertile on patients is usually large (Verhaak et al. 2007; Schmidt 2006).

Dutch Parkinson's disease care

PD is a complex and debilitating disease. Patients become progressively incapacitated, not only because of the typical motor symptoms (e.g. bradykinesia, rigidity and tremor), but also because of a wide variety of non-motor symptoms (such as swallowing problems and bowel disorders). Conventional therapies, such as pharmacological treatment and stereotactic deep brain surgery (DBS), offer only partial and temporary relief, particularly in more advanced stages (Langston 2006). More and more, professionals are convinced that a multidisciplinary team approach is desirable for most PD patients (Nijkrake et al. 2007). In the Netherlands, the lead physician is a neurologist, whereas Parkinson specialist nurses and a variety of allied healthcare professionals, physical therapists, speech language pathologists and occupational therapists are regularly involved in treatment of PD patients (Nijkrake et al. 2007).

Ethical approval

Ethical approval for the study was obtained from the Ethics committee of the Radboud University Nijmegen Medical Centre.

Data collection

The experiences with PHCs were investigated in infertility- and PD care, as these two populations were the first users of PHCs on www.mijnzorgnet.nl. By including both populations, it was possible to apply the principle of 'sample diversification' to obtain results that are relevant to a broader range of settings (Gibbs et al. 2007). Both conditions share common characteristics, such as the multidisciplinary character and the impact on the patient's life. However, both have also important differences, such as mean patients' age (respectively, 20–40 years versus 60–80 years), other types of care providers and/or experiences with the Internet. The inclusion of these two conditions can contribute to the transferability of our findings.

Inclusion and exclusion criteria

The first author approached all healthcare professionals (N = 10) for an interview, who joined at least one PHC between the 1st of September and the 1st of December 2011, which were one gynecologist, one fertility doctor, one fertility specialist nurse, four Parkinson's specialist nurses, one physical therapist, one occupational therapist and one neurologist. Seven professionals agreed on participating in this study (the infertility professionals, three Parkinson's specialist nurses and one neurologist). Subsequently, a selection of these professionals (one gynecologist and three Parkinson's specialist nurses) were asked to invite their patients into this study from whom they were joining the PHC, to prevent double invitations as much as possible. Then, potential participants received information by telephone about the aim and the procedure of the qualitative study from the first author, after which they could give oral consent. The five infertile patients who had started a PHC

on the 1st of September 2011 all agreed on participating in the study. In addition, six of the ten PD patients who started a PHC in the period between the 1st of September and 1st of December 2011, gave consent to participate as well. The most frequently mentioned reason for not participating for both patients and healthcare professionals was lack of experience with the PHC. Table 5 shows the background characteristics of all interviewees. By involving patients and healthcare professionals, data triangulation was reached, which increases the validity of this study.

Interviews

The first author performed semi-structured face-to-face interviews with all participants (i.e. patients and healthcare professionals: N = 18) who agreed to participate in the study. The location of the interview depended on the participants' preference: their home (N = 11), the hospital (N = 5) or by Skype in an online face-to-face meeting (N = 2). The inter-viewer was not involved in the patients' clinical care and did not speak before with the healthcare professionals about the PHC. The interviews were conducted according to a semi-structured interview guide, which was based on literature and developed specifically for the purpose of this study. One interview guide was developed for patients and one for healthcare professionals (see Box 1). During the interviews, techniques such as open-ended and reworded questions were used to clarify meanings and to explore new issues that

	Patient	Healthcare professional
General	What is the course of your condition?	What is your profession?
	What is the type of treatment?	
	How many healthcare professionals and clinics are involved and how is your relationship with them?	
	What do you find important in the relationship with your care provider?	What do you find important in the relationship with your patients?
PHC	What was the reason to create a personal health community?	Why did you decide to participate in the personal health community of your patient?
	How long ago did you started?	How long ago did you started?
Expectations	What were your expectations? And were these expectations met? Why (not)?	What were your expectations? And were these expectations met? Why (not)?
Experiences	How much do you use your PHC?	How much do you use the PHC of your patients?
	Who is currently participating? Who did you invite or wanted to invite? Why these people?	In how many PHCs do you participate?
	Could you give some examples of information you uploaded? Could you give examples of questions you posted?	What have you actively contributed to these PHCs (e.g. answering questions, uploading information)?

	Patient	Healthcare professional
	Could you explain in what way the PHC is (dis)advantageous for you and your health?	Could you explain in what way the PHC could be (dis)advantageous for patients' health?
	How do you experience the contact with your healthcare professionals in the PHC?	How do you experience the contact with your patients in the PHC?
	Did you talk about the PHC during a consultation with your doctor in the hospital?	Did you talk about the PHC during a consultation with your patient?
Quality of care[b]	Do you think that the introduction of a PHC could improve dimensions of quality of care? - Accessibility? - Equitability? - Efficiency? - Timeliness? - Effectiveness? - Safety? And why/how?	Do you think that the introduction of a PHC could improve dimensions of quality of care? - Accessibility? - Equitability? - Efficiency? - Timeliness? - Effectiveness? - Safety? And why/how?
Patient-centeredness of care[c]	Do you think that the introduction of a PHC could improve patient-centeredness of care? Regarding - Accessibility of care - Communication - Information provision - Patient involvement - Continuity and transition of care - Respect for patient's values - Competence and knowledge - Emotional support - Care organization And why/how?	Do you think that the introduction of a PHC could improve patient-centeredness of care? Regarding - Accessibility of care - Communication - Information provision - Patient involvement - Continuity and transition of care - Respect for patient's values - Competence and knowledge - Emotional support - Care organization And why/how?
Future perspectives	What do you think that the PHC could contribute to future healthcare in relation to … - your role in your disease management - role of your care provider - patient-doctor relationship - your quality of life	What do you think that the PHC could contribute to future healthcare in relation to … - the role of your patient - the role of you as a care provider - task division between different healthcare professionals - patient-doctor relationship
	What are the conditions to meet these future perspectives?	What are the conditions to meet these future perspectives?

[b] Dimensions based on framework for quality of care of World Health Organization (2006).
[c] Dimensions based on patient-centeredness framework, respectively in infertility of van Empel et al. (2010) and in Parkinson's disease of van der Eijk et al. (2011).

Box 1. Interview guide patients and professionals.

Patients	Gender	Age (yrs.)	Primary health condition (since)	Current treatment	Healthcare professionals involved into patient's health[a]
1	Female	31	Primary infertility (2009)	2nd IVF cycle	IVF team, gynecologist (other hospital)
2	Female	28	Secondary infertility (2008)	1st IVF cycle	IVF team
3	Female	31	Primary infertility (2002)	2nd IVF cycle	IVF team, clinical social worker, internist, GP
4	Female	37	Secondary infertility (2006)	4th ICSI cycle	IVF team, GP
5	Female	32	Secondary infertility (2009)	1st ICSI cycle	IVF team, GP
6	Female	69	Parkinson's disease (2000)	Pharmacological	GP, PD neurologist, PD nurse, PT, OT
7	Male	67	Parkinson's disease (2004)	Pharmacological	PD neurologist, PD nurse, OT
8	Female	70	MSA – P (2007)	Pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, 2nd PD neurologist
9	Male	70	Parkinson's disease (2000)	DBS, pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, neurosurgeon, cardiologist, urologist
10	Male	74	Parkinson's disease (1988)	Pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, urologist
11	Female	74	Parkinson's disease (2006)	Apomorphine, pharmacological	GP, PD neurologist, PD nurse, PT, OT, ST, cardiologist, 2nd neurologist
Professionals	Gender	Age (yrs.)		Function	
12	Male	52		Gynecologist	
13	Female	52		Fertility physician	
14	Female	40		Fertility specialist nurse	
15	Female	45		Parkinson specialist nurse	
16	Female	32		Parkinson specialist nurse	
17	Male	43		Parkinson specialist nurse	
18	Male	56		Neurologist	

[a] Different healthcare professionals could be involved because of the primary health condition, but also because of co-morbidities or side effects of treatment; Yrs. = years. IVF team is the medical multidisciplinary team at a Dutch IVF clinic and comprises infertility specialized gynecologists, nurses, fertility doctors, medical assistants, clinical embryologists and lab technicians. GP = General practitioner; PD = Parkinson's disease; PT = physical therapist; OT = occupational therapist; ST = speech therapist; DBS = deep brain stimulation.

Table 5. Participants' background characteristics.

had been brought up. Furthermore, the interviewer encouraged participants to talk freely and to describe their answers in depth. The interviews lasted 30–70 min, were digitally recorded, and transcribed verbatim. Data were analyzed concurrently with the data collection. Insights obtained through analysis guided the further interviews. Data saturation within the patient population was reached, as the last two interviews with patients did not bring new information forward. Data saturation was not reached within the healthcare professional population. However, the maximum number of healthcare professionals who participated in the PHCs and agreed to take part in the study, were interviewed.

Reflexivity

The interviewer (JA) was aware that her personal experiences due to her medical education could influence the data collection and analysis. The safeguards included an independent assessor doing the verbatim transcription and the independent analysis of the transcripts by two researchers (JA and FV), resulting in researcher triangulation, which will be further outlined below.

Data analysis

Data were analyzed according the phenomenology methodology (Giorgi 2005). The aim of the data analysis was to understand the complexity of meaning of the PHC to patients and healthcare professionals. The methodology comprised of four stages: (i) Two researchers (JA and FV) independently extracted inductively meaningful units relevant to the research question (i.e. open coding). (ii) The units from the several interviews were then clustered and themes determined (Hycner 1985) (i.e. axial coding). (iii) The themes were contextualized (i.e. checked for consistency with the whole interview to maintain the context) and attributed a code. Eidetic reduction was applied, meaning that the researchers have expressed what is essential about the specific expressions used by the participant (Giorgi 2005). (iv) Primary themes and subthemes were determined, their interaction and the meaning of their interaction (Shachak 2010) (i.e. selective coding). As the analysis evolved, the two researchers discussed the emerging themes and codes. Points of discussion were reflected upon and any discrepancies were discussed until consensus was reached. The analysis gave insight into the experiences and possible advantages and disadvantages related to the concept of PHC, which will now be discussed.

RESULTS

In line with our research question we first discuss how healthcare professionals and patients (are planning to) use PHCs, focusing specifically on the latter. Secondly, based on first experiences with PHCs, we focus on the future expected advantages and disadvantages of using

PHCs for healthcare. We do this by making a distinction between PD- and infertility care and between patients and healthcare professionals and taking the participants altogether.

Composition and use of the PHC dependent on individual patient's context

> *"I have diabetes and therefore I regularly visit – amongst others – the internist. And I'm also having treatment at the reproductive medicine department. Furthermore, I have a general practitioner, who in general never knows how I'm doing. He receives a letter from a physician, but that's all he knows about me. So I really thought that maybe this [PHC] is a way to gather all these different people. Maybe this way I can get a total picture [of my health]."* (Respondent 3, patient).

Bringing together different medical disciplines and getting a complete picture of the patient's condition(s) and ongoing treatment(s) is one of the reasons patients mentioned to start a PHC. This did not only apply for patients suffering from multiple conditions (as in the quote), but also for patients with singular diseases that involved several healthcare professionals. The number of professionals invited in a patient's PHC was strongly dependent on the type of condition the patient was suffering from and the related number of professionals involved in the patient's care. All patients stated that they would only invite a professional to their PHC if trust and medical expertise were present. The number of people invited depended also on the patient's personal preference who to invite: for instance, some patients did not want to invite all their healthcare professionals and whereas some wanted to invite family members. From the interviews it appeared that this preference varied across participants. A schematic overview of the PHC/online health network of two respondents is presented in Figure 1.

Besides the variation in the number of invited participants in PHCs, there was also a variation among respondents in the way they used the different functionalities in the PHC. This depended on their personal needs. For instance, a PD patient preferred to ask medical-related questions and used primarily the forum, whereas an infertile patient wanted to see her lab results and used the 'library' function. This variation in use is shown in Table 6. Nevertheless, it is clear that most patients and professionals made use of the 'diary' and the 'forum' and to a lesser extent of the 'library' and 'patient file'. Both patients and professionals stated that these functions were less developed and could be valuable in future use.

(Future) advantages and disadvantages of using PHCs based on first experiences

Based on first- and short-term experiences, both patients and professionals mentioned a number of advantages and disadvantages of using PHCs in future. These (dis)advantages are discussed from three perspectives: (i) PD versus infertility; (ii) patients versus healthcare professionals; (iii) across all participants altogether.

PD versus infertility

Particularly PD patients and healthcare professionals expected that using the PHC could lead to better tuning, exchanging and collaboration between healthcare professionals. It is more transparent who is involved in the individual patient's care. Furthermore, they expected that professionals and patients can contact each other more easily. This could result in 'shorter communication channels'.
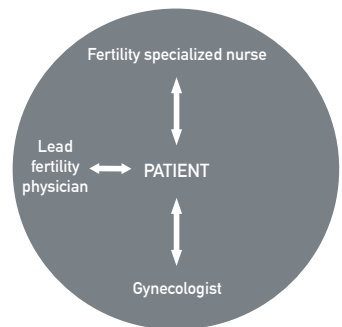
This patient was under fertility treatment at one IVF clinic. She had no other health problems. She appreciated the possibility to interact with a clinic's gynecologist, her lead fertility physician and fertility specialist nurse for emotional support and tailored information provision.

This PD patient had many healthcare professionals involved in his health: for PD, but also for other comorbidities (cardiological, urological). He preferred to have them all in his PHC for several reasons. He appreciated the possibility to ask questions to his healthcare providers. He also expected some healthcare professionals to interact with each other about, for instance, interaction between medications he got prescribed. He preferred to have his son in his PHC, because his son, working in healthcare, could advice him and keep track of everything happening in his PHC.

Figure 1. Two examples of PHC composition representing a patients' online health network.

Patients	PHC since* (weeks)	Experience with PHC			
		Diary	*Forum*	*Library*	*Patient file*
1	6	Description of course of disease (facts)	Posted 1-5 questions	(-)	(-)
2	8	Description of course of disease (facts)	Posted 1-5 questions	(-)	(-)
3	8	(-)	Posted 1-5 questions	Added test results	(-)
4	10	1 -3 daily stories	Posted 1-5 questions	(-)	Added test results; Added medication overview
5	10	(-)	Posted 1-5 questions	(-)	(-)
6	8	1 -3 daily stories	Posted 1-5 questions	Added medication overview	(-)
7	2	(-)	(-)	Added medication overview	(-)
8	4	1 -3 daily stories	(-)	Added medication overview	(-)
9	4	1 -3 daily stories	(-)	Added medication overview	(-)
10	2	(-)	(-)	(-)	(-)
11	4	Description of course of disease (facts)	Posted 1-5 questions	Added medication overview	(-)

Professionals	PHC since (weeks)	Experience with PHC			
		Diary	*Forum*	*Library*	*Patient file*
12	8	Posted reaction	Answered questions	(-)	Added test results
13	5	Posted reaction	Posted 1-5 questions; Answered questions	(-)	(-)
14	2	(-)	(-)	(-)	(-)
15	8	Posted reaction	(-)	(-)	(-)
16	8	Posted reaction	Posted 1-5 questions	(-)	(-)
17	8	Posted reaction	Posted 1-5 questions	Added medication overview	(-)
18	3	(-)	(-)	Checked medication overview for errors	(-)

*(-) Indicates that the participant did not gained any experience with the particular function of the PHC; * At time of interview.*

Table 6. Participants' use of and participation in the personal health community.

"The main interesting part [of the PHCs] is in the first place that one another can find each other more easily; the consultation format could take place more easily. Also among different medical disciplines. That someone, a client, has a question and that all persons who're involved in the treatment team could be contacted at once. That's to my opinion the most interesting part. I notice that [by using it]. Patients prefer this as well. In the past, many mistakes have been made in this particular care aspect." (Respondent 17, professional).

"To me it appears to be a win-win situation. You can consult each other easily, communication channels are shorter. In addition, it becomes more easily to get feedback about the follow-up of your patient." (Respondent 16, professional).

Parkinson's disease patients and healthcare professionals see many advantages from an organizational perspective of care, while, contrastingly, patients and professionals in fertility care mentioned merely advantages related to the care experience, including emotions and experiences from a psychosocial perspective (i.e. human factors). The latter group underlined that the PHC made healthcare more personalized. For instance, it improved the patient–physician relationship. Mostly, infertility respondents found it advantageous that patients could post a message to the medical team at any time of the day, also outside office hours, reducing stress.

"The idea that at all times you find yourself in a secure [online] environment: at the moment that you need help, you're worrying about something, you encounter problems or if you have a comment about something. That you can always express these thoughts at any time, that's great." (Respondent 13, patient).

"You can only contact the secretariat [of the hospital] between 9 and 10 a.m. or between 9 and 11 a.m. But then I lost some blood in the middle of the day. I stressed out and I could not phone the hospital, because you may only call in case of emergencies. This wasn't really an emergency but you're not feeling comfortable. I immediately placed a message in my PHC and I received a response from the doctor right away. I found that perfect." (Respondent 4, patient).

Participants from both conditions argued that the possibility of asking questions online 24 hours a day contributed to the continuity of care. Also other PHCs components led to more continuous care flows, which will be discussed in the next paragraph.

Patients versus healthcare professionals

By comparing the views of patients and healthcare professionals regarding the advantages and disadvantages of PHCs, it becomes clear that especially patients thought that healthcare professionals could stay more up to date about the situation and condition of their patient.

> "*I want to invite my general practitioner, my physical therapist, my neurologist. That they all can have a look in my PHC to see how I'm doing.*" (Respondent 10, patient).

Participation in a PHC provides healthcare professionals with the possibility to follow the situation of their patient at a distance (e.g. occurrence of complications or in case of temporary treatment elsewhere). It contributed, according to patients, to continuity of care.

Additionally, patients indicated the possibility to ask specific questions online to their own healthcare professionals about their own situation, as an advantage. This advantage could often not be met in public or general health forums, where everyone can read along and healthcare professionals answer merely in general terms. Also, through the different medical disciplines participating in the PHC, patients could easily have access to different views of conditions and treatments. According to the patients, this could result in (i) more complete information, which enables them to make an informed choice about their own healthcare and (ii) professionals could tune their views on medical advises to the views of others. This was partly agreed on among the participating professionals. In the current PHCs, not much medical data was stored yet, which seemed a prerequisite to achieve the aforementioned advantages.

> "*My fertility physician recommended to lose weight, while my internist gave me the advice to stop doing that, because of my stressful life at the moment, because I already have to monitor all these hormones and blood sugars. It would be great if both doctors could agree on the best strategy. In reality this seems often very difficult to establish.*" (Respondent 3, patient).

The possibility of asking questions to their own medical team online provided patients also with another advantage: they did not have to call or visit the hospital anymore for every question. The PHC offered the possibility to get a quick response on simple but urgent questions. This possibility gave patients much relief and (emotional) support.

In contrast to these more 'practical' advantages, primarily derived from patient interviews, healthcare professionals put more emphasis on the impact of using PHCs on current healthcare with respect to the change of 'traditional' roles of their profession but also from patients. For instance, they mentioned that they have to get used to patients 'owning' their own records. Another example is that by using PHCs, they have to take into account not only the physical condition, but to a larger extent also the mental condition. They mentioned

that they are getting to know their patient in another way, which could result in a changing relationship between patients and the medical team.

> *"The [relationship] changes enormously. If patients meet me, then they have a really special doctor in front of them and I think that the patient is also special to me. You see the patient from a different perspective, because you're continuously investing time in that person. In a 'normal' consultation it happens step wisely and you don't see your patients so often. And now [with the PHC] you could have contact almost every day and you could follow how the patient is doing from day to day. I think that the relationship with the medical team really changes."* (Respondent 13, professional).

Both patients and professionals also mentioned disadvantages of using the PHC. Patients, for instance, do not want to be confronted with their condition all the time, which the PHC might bring about. For optimal use of the PHC, it asks for routine and discipline and patients are not sure whether they could fulfill this task. One patient was anxious that different views expressed in the PHC could make him insecure.

Professionals mentioned having much work pressure and using the PHC would come on top of that. As a prerequisite for the implementation, they suggested that more time should be scheduled for using the PHC next to their tasks.

Finally, particularly PD patients and professionals uttered their concerns about the technological difficulties of the PHC. Through these difficulties (e.g. size letter type, visual organization of website) the PHC is not accessible or user friendly to everyone.

Other expectations of PHCs in future healthcare across all participants
All participants argued that – independent from the condition – a PHC could contribute to an increased patient's insight into his or her own health and healthcare.

> *"I really like the idea that a patient gets much more insight into his own illness and in the way how different disciplines handle his disease."* (Respondent 16, professional).

> *"Yes, you receive information from different perspectives and you can get a quick answer in an easy way which makes your treatment better. You get more insight into your treatment. Particularly the number of healthcare professionals (…)."* (Respondent 1, patient).

By using PHCs, patients get more involved into their own treatment and it increases the rate of active involvement of patients in their own healthcare. By asking questions and receiving (your own) medical information, the patient could be more in the lead.

"*That is also a little bit of autonomy; that you can see your own medical data.*"
(Respondent 3, patient).

Furthermore, the respondents stated that it is beneficial that all information is collected and accessible for the patient and all relevant healthcare professionals. This is, for instance, convenient when the patient forgets easily, has changed from healthcare professional(s), wants to use it as a reference work, or wants to check if nothing has been forgotten.

"*It's such an emotional rollercoaster and we both are very busy working. I was like – by the way I'm not a diary person – we have to write things down that when our [fertility] treatment is not successful, we have a sort of script of the treatment cycles before. Maybe something went wrong and so on.*" (Respondent 4, patient).

Different views were given on the characteristics of patients who could benefit the most of PHCs when added to their usual care. Some said that it could be very convenient for autonomous patients who prefer to have the lead in their own care process, whereas others stated the opposite.

"*The transition of data and thinking along is maybe something a critical and autonomous patient would do more naturally. The PHC could support this.*" (Respondent 1, patient).

"*For those patients who are less involved, it's of course easier and less confronting to ask their questions in their PHC, than in a face-to-face encounter with their doctor.*" (Respondent 4, patient).

One PD patient mentioned that PHCs are beneficial for patients who are recently diagnosed with a condition, because they have many questions to ask. Contrastingly, other PD patients put forward that the PHC should be offered in a later phase of the condition, because in the beginning there is too much to deal with already. Other characteristics that were mentioned: PHCs are suitable (i) when a greater geographical distance exists between patient and physician, (ii) when a patient has a great number of healthcare professionals, (iii) when a patient has a condition and follow-up of treatment is important (e.g. repetitive laboratory results), (iv) when patients have a health problem hard to talk about to others, (v) when patients have complex care, and (vi) when patients have co-morbidity. In short, a great variation of characteristics was repetitively mentioned. All participants agreed that computer and Internet skills are required for using the PHC adequately.

DISCUSSION

This study qualitatively evaluated the use of and first experiences with the PHC. Interviews with patients and healthcare professionals showed that patients designed their PHC differently, suiting their own individual situation. It depended on the type of condition, the number of people involved in their care and their individual needs. The (potential) advantages outnumbered the disadvantages and related to both organizational aspects of care (e.g. better transition and continuity of care), and patient care experiences (e.g. more personal care, reducing stress). The PHC features and the aforementioned advantages could possibly be a facilitator for the societal need for more personalized care (the acknowledgement of the broader context of an individual patient and not only the disease) and active participation of patients (in terms of self-management) (Olsson 2013). This could, for instance, facilitate general practitioners or other healthcare professionals in overseeing the complexity of their patients. The basis for this implication is threefold.

First, a PHC is person-specific. This is in contrast with PHRs, which are often bound to one specific disease/patient population (e.g. Diabetes, IVF patients) (Osborn et al. 2010; Tuil et al. 2007). These are not suitable anymore when looking at the above-mentioned future healthcare perspectives. As the participants in this study underlined, the personal contexts of individual patients' lives and the web of relationships and interactions they have with the medical and social environment, ask for a more generic system, such as the PHC. In the PHC 'disease experts' (e.g. physicians) and 'personal context experts' (e.g. the patient, family) can be integrated. This integration could take place in the PHC. Hence, different types of patients could benefit from the PHC by using it in an individualized way; and hereby facilitating personalized care at the same time. This does not mean that only patients with chronic diseases or co-morbidity could benefit. Every individual person has an important broader personal context that goes beyond his or her medical condition (Kleinman 1978). For instance, some of this study's women experiencing infertility did not suffer from another condition. However, because of the impact of their infertility, they appreciated the continued communication with their healthcare providers outside traditional face-to-face care.

Second, in many EHR and PHR projects no clear role and position of the patient was defined (Pluut 2010). In the PHC the patient is in the lead as he/she is the owner of the PHC and has access to and can manage (parts of) his/her medical records, anticipating more involvement in care. Based on our data, it seemed that patients felt to be more actively involved by using the PHC. In particular, this could account for patients who are not autonomous naturally. Carefully, our study suggests that the PHC could strengthen the participation in care from a variety of patients, but maybe particularly those who need some help. The professional participants in this study indicated this change of the patient's role. Though, first the technological difficulties of the PHC need to be resolved.

Third, the PHC offers the possibility of both sharing medical data and communication between patient and healthcare professionals. This combination was missing in other EHR and PHR systems (Greenhalgh, Wood et al. 2008). Many participants in this study valued this possibility enhancing patient participation in deciding personal health choices. Also, professionals thought that it could improve the collaboration between different healthcare providers, reducing fragmentation of care. However, this feature was not fully exploited in this study. Not much data was stored yet in the PHCs. Systematically integrating medical data into the patient's PHC from the providers' electronic medical records could provide a solution for this.

Future research

As aforementioned, this study is based on short-term experiences of patients and healthcare professionals with PHCs. The Medical Research Council (MRC) developed a framework for the evaluation of complex interventions. This framework includes as a first step that identifying the potential consequences of a complex health service activity (such as the PHC) (Campbell 2007) in a first pilot study can provide important information for future evaluations (Graneheim and Lundman 2004). Hence, the current study could also be considered a first pilot study. To the best of our knowledge, this is the first paper to describe such a healthcare concept including its first evaluation in which we collected insight into the directions for future research. These directions consist, for instance, of (a) elaborating the research among a broader population (i.e. more respondents and involvement of more different conditions) to investigate long-term experiences and affirmation or rejection of results; (b) investigating if the potential organizational consequences for healthcare (e.g. improvement in continuity of care) and patients' care experiences result in an improvement of quality of care (in cost-effectiveness, safety etcetera); and (c) studying the implementation of the PHC into healthcare. Despite the promising future perspectives, an adequate implementation strategy is needed acknowledging all barriers, possibly hampering its future success (Greenhalgh, Wood et al. 2008; Sheikh et al. 2011).

Limitations of the study

In our experience, the phenomenological qualitative approach was very useful for the exploration of meanings of experiences with the 'phenomenon' of the PHC. It provided in-depth insight in patients' and professionals' views. Efforts were made to ensure the trustworthiness of the qualitative data (Graneheim and Lundman 2004). To enhance credibility, we performed investigator triangulation (Polit and Beck 2004), reduced possible bias from the personal experiences of the interviewer, and selected carefully meaningful units. There are, however, three limitations related to participant selection and the number of respondents. First, for our study aims, we were dependent on selecting participants who had already gained some experience with a PHC. Given the nascent stage of the PHC,

there is a possibility that these participants were typical 'early adopters' and might thus not be fully representative for the general population. However, as participants consisted of both patients and professionals from two types of conditions, we tried to minimize this bias. Second, some patients only just started using their PHC and did not have the time yet to explore all its possibilities. Their current view could thus change over time. Nevertheless, we found it also very valuable to explore participants' expectations based on these early experiences to get a grasp of what a PHC could contribute to future care. Third, qualitative research is often criticized for its sample size. The number of interview participants in this study may seem small, but this is not necessarily a shortcoming. As our study achieved data saturation within the patient group, the patient sample was sufficient in size and more interview participants would not have altered the results. The only shortcoming with respect to the sample size is the small number of different healthcare professionals. Another potential limitation is that a few interviews were performed using Skype, which means that interviewer and participant were not in the same room. However, both sound and video were used during these interviews. Hence, both verbal and non-verbal communication could be 'recorded', which is one of the most essential elements of interviewing.

CONCLUSION

Using PHCs in healthcare could lead to promising improvements in both the organization of care and care experience, according to the patients and healthcare professionals involved in this study. They indicated that patients with different conditions (i.e. PD and infertility) and in different individual patient-related circumstances (e.g. different number of healthcare professionals involved, level of autonomy, stage of disease) could benefit from these improvements. The PHC seems to be an online tool that can be applied in a personalized way. When (technically) well facilitated, it could stimulate active involvement of patients in their own health and healthcare. It warrants further research to study its effect on concrete health outcomes.

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HOSPITAL DEPARTMENTS INITIATIVE

CHAPTER 5

Co-production in healthcare:
rhetoric and practice

ABSTRACT

Co-production in healthcare is receiving increasing attention; however, insight into the process of co-production is scarce. This article explores why hospitals involve patients and staff in co-production activities and hospitals' experiences with co-production in practice. A qualitative study with semi-structured interviews (N = 27), observations (70 hours) and document analysis was conducted in five Dutch hospitals, which involved patients and staff in order to improve services. The results show that hospitals have different motives to involve patients and staff and have adapted existing methods to involve patients. Interestingly, areas of improvement proposed by patients were often already known. However, the process of co-production did contribute to quality improvement in other ways. The process of co-production stimulated hospitals' thinking about how to realize quality improvements. Quality improvements were facilitated by this process as seeing patients and hearing their experiences created a sense of urgency among staff to act on the improvement issues raised. Moreover, the experiences served to legitimatize improvements to higher management bodies.

Points for practitioners

Different participation methods can bring patients' experiences with healthcare services to the fore, which can be used for quality improvement. Our study shows that adapting existing methods to local hospital resources is likely to be beneficial for co-production processes within a given context. However, adapting and tailoring also poses risks. Tailoring activities, such as using criteria to select patients, influence what is considered to be legitimate patient input. In addition, as the co-production process is important, the method should consist of an organized trajectory in which patients and staff are involved and personal experiences are presented. Therefore, project teams need to critically reflect on the consequences of adaptations and tailoring actions, and their desirability, when carrying out quality improvement projects.

INTRODUCTION

In the public administration literature, introducing user-generated knowledge in public service delivery by involving individual citizens and groups is known as 'co-production' (Verschuere et al. 2012). The 'co' refers to an action that occurs together, jointly or mutually between professional providers of public services and clients or consumers (Farr 2012). In healthcare, the concept of co-production (although more often phrased in terms of patient participation or patient and public involvement) is receiving increasing attention, as the involvement of both patients and healthcare staff in the design and production of their services is seen as an important means to improve the quality of care (Bate and Robert 2007).

Co-production in healthcare means that patients contribute to the provision of health services as partners of professional providers. This can take place on the macro level (i.e. between government and patient organizations), the meso level (i.e. between the healthcare institution's board of directors and their client council), and on a clinical micro-system level (i.e. between healthcare professionals and patients on a specific ward). In this article, we focus on the latter: the clinical micro-system level. The co-production literature generally focuses on people's motives to co-produce and on key variables that could make co-production effective (see e.g. Van Eijk and Steen 2014; Verschuere et al. 2012). Less attention is paid to why organizations and professional providers (i.e. regular producers) want to co-produce with clients, and to the process of co-production in practice on the micro level. In addition, little is known about the added value of co-production processes to quality improvement on this level (Verschuere et al. 2012). Studying the clinical micro-system level could result in an improved understanding of how co-production works in practice.

To obtain more knowledge on co-production at the clinical micro-system level, this article focuses on hospitals involving patients and healthcare professionals in order to improve the quality of care on Dutch hospital wards. The research question guiding this article is: *Why are hospitals interested in co-production activities and what are the experiences with co-production in practice?* To answer this question we conducted a qualitative study in five Dutch hospitals that involved patients and staff to improve their quality of care. The results of this study provide a better understanding of how co-production works in practice and is of practical value as it provides insight into the way patients and staff can be involved in the co-production of hospital care.

This article begins with a brief overview of the co-production literature and the use of this concept in healthcare. This is followed by a description of the research design. In the results section, we clarify hospitals' reasons for involving patients and staff in co-production, and describe the co-production process. In addition, we discuss some results of using co-production in healthcare improvement and argue that it is especially the co-production process that matters. In the discussion and conclusion we reflect on the main findings of this article.

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CO-PRODUCTION

Co-production is not easily defined. It refers to "the idea of involving people outside gov-ernment organizations in producing public services as well as using or otherwise benefiting from them" (Alford 2002, p. 32) and implies a partnership between professional providers of public services and clients (Farr 2012). The concept gives citizens an active role, as public service agents (i.e. 'regular producers') and citizens are jointly involved in public service production and undertake more or less simultaneous efforts to produce goods or services (Percy 1984). The 'co' in co-production refers thus to an action that is designed mutually by regular producers and patients, but not necessarily through direct interactions of their efforts (Pesthoff 2006). Since co-production should influence public services, it should go beyond collecting input from users. From the 1970s and early 1980s onwards, interest in co-production has grown. The expectation was that using the unique experiential knowledge of citizens would lead to higher service quality, more efficient services and cost reductions (Bovaird and Loeffler 2013; Brudney and England 1983). However, involving citizens in co-production processes also has a more ideological component: it is meant to democratize decision-making. In this view, citizens have the right to be involved in decisions concerning their lives and should be given opportunities to influence public decision-making (Van de Bovenkamp 2010).

Also in healthcare, co-production can count on increased attention. Until the 1980s, the traditional model of healthcare service production was characterized by professionals who were exclusively charged with the responsibility to design and provide high-quality services to patients (Boivin 2012). Patients were mostly seen as passive recipients of care whose "trust was placed with professionals to operate according to their professional eth-ics" (Farr 2012, p. 60). However, over the years, developments such as increasing medical needs, limited capacity of public service provision, rising healthcare costs, and a growing demand for high-quality and personalized care have changed ideas about patients' roles (Boivin, 2012). Today, active patient involvement is increasingly pursued by, among others, stimulating patients to share their experiences with using health services and products, in order to improve the quality of care (Adams 2011; Bate and Robert 2007). This more active role of patients has transformed public service production; patients are asked to participate actively and act as consumer producers, next to and in interaction with health-care professionals and other decision-makers in healthcare such as policy makers (Bate and Robert 2006; Pesthoff 2006). Healthcare is therefore an interesting sector in which to study co-production.

The above shows that co-production comprises a myriad of activities. Therefore, it is important to unravel the concept further. The distinction between co-producing public services on the macro, meso and micro levels is one way of differentiating between co-production activities. Another way is to differentiate between the various activities under-

taken by co-producers, resulting in additional 'co' concepts: co-commissioning, co-design, co-delivery and co-assessment of public services (see e.g. Bovaird and Loeffler 2013; Farr 2012). We follow Bovaird and Loeffler (2013) by arguing that co-production is the general umbrella term to describe the various activities employed by both professional providers and clients. This article specifically studies instances of co-design in healthcare: the process of designing a product or service. This involves not only designing the functionality, safety and reliability of the product or service, but also the whole interaction with it and how it feels or is experienced by users (Bate and Robert 2006). By also focusing on the latter, not only healthcare services but also patients' experiences with treatment and care could be improved (Bate and Robert 2006).

THE DUTCH CONTEXT

This article focuses on co-production of hospital care in the Netherlands. Here, a system of regulated competition was officially introduced in 2006 (Van de Ven and Schut 2008), which led to three different markets: a procurement market, an insurer market and a delivery market. For this article, the last one is important. In the healthcare delivery market, providers compete for patients who have a free choice of provider, restricted only by general practitioners who act as gatekeepers, and by insurers, that can guide (but not force) patients to hospitals they have contracted. The assumption behind the regulated market is that with the help of competition not only efficiency but also healthcare quality will increase (Ministry of Health, Welfare and Sport 2006), as quality could function as an important selection criterion for patients (and health insurers). As a result, it has become increasingly important for healthcare providers, including hospitals, to provide patient-centered care and to attune care to patient preferences (Van de Bovenkamp et al. 2013). Thus, co-production processes have become a subject of interest on the level of healthcare organizations and specific wards within those organizations.

The Dutch government has a longer history in playing an active role in stimulating co-production in healthcare. For example, healthcare institutions are obligated by law to have a client council and complaints commissions. In addition, government finances patient organizations and creates opportunities for them to be involved in decision-making. They have been attributed a third role next to healthcare insurers and healthcare providers. Furthermore, aside from system and regulatory changes, government also stimulates co-production within healthcare institutions in other ways such as financing projects on co-production. So, in the area of co-production, the Netherlands already has a tradition of bringing patients' voices to the fore.

METHODS

This article is based on research in five Dutch hospitals that involved patients and staff to improve the quality of their services. Four of these hospitals participated in a one-year national government-funded project, in which consultants, researchers and professional staff of a patient organization offered training courses and advice on the use and implementation of patient participation methods. The authors' role was to study the co-production processes, to learn more about how they develop in practice and to draw lessons from these practices. The fifth hospital was not included in the national project, but showed interest in co-designing their services and participated in the training sessions. This study's hospital selection was based on (1) variety in experience with co-production, and (2) type of hospital: general hospitals (N = 2), general hospitals providing highly specialized care (N = 2), and a university medical center (N = 1); rural versus urban hospitals (two and three, respectively); and large, medium, and small hospitals (one, two and two, respectively). Of the five hospitals, one hematology and four oncology departments participated, all using, albeit in different ways, patient experiences to improve the quality of their services.

We used a qualitative multi-method research design to explore how hospitals involved patients and staff to improve healthcare services. In-depth semi-structured interviews were conducted with members of the five hospital project teams, who were responsible for the content and progress of the projects. The project teams (formally) consisted of a manager, quality employee, doctor, (specialized) nurse, and a patient representative, for example a member of the hospital's client council (reflecting the co-production idea within the project teams). In practice, however, only one project team maintained this set-up during project meetings; in other hospitals the doctor, patient representative and/or quality officer were often not present. In total, 27 interviews were conducted: 13 at the start, eight during the projects and six at the end. Most respondents were invited for multiple interviews and during four interviews various respondents were present, resulting in 25 project team members being interviewed. During the interviews, respondents were invited to talk about their experiences with the project, the purpose of the project, the (reasons for the) selected participation method, and their expectations regarding future developments within the project. Twenty-three interviews were conducted face-to-face at the hospitals and lasted approximately one hour. Four interviews were conducted by telephone and lasted 30 minutes on average. Except for one telephone interview, all interviews were recorded, with permission, and transcribed verbatim.

Besides interviews, observations (70 hours) were also conducted during project team meetings and at times of patient and/or staff involvement (for instance during focus groups, patient/staff events and co-design groups). Through these observations, insight was gained into how patients and staff were involved in shaping public services. With permission, some observations were recorded and transcribed verbatim. During the observations, informal

interviews were conducted with the team members. During all observations, extensive field notes were taken.

To gain a more in-depth, triangulated view of the empirical data, we analyzed relevant documents, including hospitals' 'actions plans' (which contained notions e.g. of the target group and project purpose), minutes of meetings of project teams, letters of invitation to patients, and letters containing information about the project aimed at healthcare professionals. The documents provided insight into the way patients and staff were involved in improving the quality of hospital care and the motives of the project team members to involve patients and staff.

All empirical data were gathered, shared and analyzed by the authors FV, HvdB and KG, resulting in researcher triangulation. The multiple coders selected significant sections of the analyzed documents, field notes and interview transcripts and created codes close to the original words of the empirical data. These codes were then further clustered into themes, and discussed by the authors until consensus was reached. In addition, during the discussions, the different themes were compared by looking at their interactions, resulting in primary and secondary themes, which are described in the results section. Data analysis and data collection alternated with each other and the results were fed back to the hospitals in the middle and at the end of the national project, adding validity to the research findings (Tong et al. 2007).

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RESULTS

In this section, we first focus on hospitals' reasons for involving patients and staff. In addition, we describe how patients and staff were involved in co-production processes. Furthermore, we briefly discuss improvement issues raised by patients and staff and the improvement activities. Finally, we elaborate on the added value of using co-production in healthcare.

Drivers of co-production in Dutch hospitals

Our study shows that reasons for hospitals co-producing stem from three different logics. First, a 'quality of care logic' can be identified which consists of the expressed wish to explore how patients experience the care provision on the ward and to improve the quality of care on the basis of these experiences.

> *"What I like about this is to get more detailed information [compared to surveys] about what people really think about the care they receive, that we provide, and what their ideas are about that [. . .]. Of course we do, or try to do a lot of things which we feel that patients find good or fun or pleasurable. But is that really the case?"* (Doctor, hospital E).

Besides improving the quality of care, reasons for involving staff and patients also originate from an 'organization logic': motives related to organizational aspects within the hospital. For example, one hospital ward manager wanted to hear patients' experiences regarding the scattered location of the oncology services throughout the hospital, assuming that oncology patients did not like being mixed with other patients on other wards. This could provide him with a strong argument within the hospital for a separate oncology unit, which he tried to establish. Another example of a reason stemming from the organization logic was that involving patients for quality improvement matched a hospital's customer-oriented vision.

Lastly, a 'market logic' can be distinguished:

> By carrying out this [co-production] project, the hospital can present itself in the region and thereby strengthen its market position. (Project plan hospital A, 2012: 12).

The market logic includes reasons (brought forward by managers and physicians) such as better public relations, meeting the conditions of healthcare insurers and accreditation bodies to address patient participation, and keeping up with national healthcare trends such as more transparency and patient involvement, to gain, in the end, a better market position.

The variety of reasons shows that, for some, co-production is an instrument to reach other goals besides quality improvement. Reasons stemming from organization and market logics run the risk of using patients' experiences instrumentally, which might limit the room for patients' input.

Modes of co-production: adaptation of methods to local contexts

At the start of the national project, a number of patient participation methods were presented to the hospitals. They included: in-depth interviews, focus groups, reflection/feedback meetings, shadowing, patients as educators, and experience-based co-design (EBCD). The latter method is especially interesting in terms of co-production, since patients and staff are involved throughout the quality improvement process, including deciding on key issues for improvement and the implementation phase. This intensive method is very specific and consists of six prescribed phases; see Table 7.

Phase	Activities	
1	Interviews with staff	Staff are asked to describe their experiences regarding working with particular services.
	Participant observation on the ward	To understand the patient pathway from the perspectives of both patients and healthcare professionals.
	Filmed patient interviews	Patients are asked to describe their experiences of receiving care.
2	Staff event	Reviewing improvement themes based on staff interviews and observations, and identifying priorities for service improvements.
3	Patient event	Showing an edited film of important themes/'touch points' from the patient interviews. Prioritizing touch points with an emotional mapping exercise: indicating the emotional impact of touch points along the pathway.
4	Joint patient-staff event	Showing the patient film for the first time to staff. Presenting improvement priorities of both patients and staff and identifying joint priorities.
5	Co-design working groups	Patients and staff design and implement service improvements together.
6	Celebrating event	Patients and staff review the co-design working groups' activities and celebrate established improvements.

Table 7. EBCD method (Bate and Robert 2007; Tsianakas et al. 2012)

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After receiving information about the different methods, four hospitals chose to apply EBCD, as they already had some experience with the other participation methods. In addition, they thought EBCD would have an added value compared to other methods, as ''the patient becomes a partner and sits around the table'' (Project leader, hospital A), resulting in a bigger impact of patients' feedback. The fifth hospital (hospital E) was less experienced in involving patients, and had chosen to use focus groups and 'client experience cards' to develop service improvements within their oncology department. It took a step-by-step approach to the project, also with respect to the question of whether and how patients should be involved throughout the process:

"Well, about that [involving patients at the implementation phase] we [project group] will take it step-by-step. Obviously, we'll look at this ourselves first, but we also said we want to involve the patient during prioritization and implementation as well. But we don't know exactly how we'll do that. It also depends on what issues come up. If they say, we want better coffee, which I can imagine very well, then I don't know if we should involve the patient in implementing that. If they say, we want the waiting room to be decorated differently; well in that case you can involve a patient very well of course." (Doctor, hospital E).

Although four project teams set out to apply the official EBCD methodology, early on they adapted the method in different ways; see Table 8. For instance, hospital C chose to skip the co-design workgroups in which patients and staff work together to design and implement service improvements that they decided on together, as (1) they concluded that it would require too much from participants, and (2) they were not immediately convinced of the added value of this phase. Moreover, hospitals B and C used focus groups to gather patient experiences instead of filmed interviews with individual patients, which the EBCD method officially prescribes. Also, hospitals A and B skipped the interviews with professionals altogether. Stated reasons for adapting the EBCD method were mainly to pursue translation to the local hospital context. This mostly implied a limitation of the required time and financial investment needed.

> *"In recent years in hematological oncology care, and that's certainly not unique for our hospital, much more needs to be done within a short time, and all the beautiful golden edges slowly get nibbled away [...]. So you know, it's reality: production. There's simply no money for extra stuff. So you need a stripped to the bone [participation method] version, but with results."* (Project leader, hospital B).

Although the hospitals adjusted the EBCD method in different ways, all hospitals brought patients' experiences to the fore and used these experiences to shape and improve the quality of their services. Therefore, we can analyze them as 'co-production' processes. We will go into this process more in the following sections.

Involving staff in co-production: overcoming barriers

Although the project team members who were interviewed were generally enthusiastic about the project, they had to overcome certain barriers regarding the involvement of staff. Challenges were experienced, for instance, in convincing staff to join the project, as some physicians feared being criticized by patients on their care delivery. To overcome this barrier, much effort was put into talking with healthcare professionals and emphasizing the projects' goal. Organizational barriers also played a role in the involvement of staff. Due to healthcare provision activities, involvement in other hospital projects, sudden labor shortage, hospital reorganizations, and the limited duration of the project (i.e. one year), some project members experienced not having enough time to carry out the project properly:

> *"I just find it very, very, very exhausting. That's mainly what it is. I've consultations with patients in the morning. In the afternoon I often have meetings about all kinds of things related to oncology care, about my patients, but also a multidisciplinary consultation. So it's something that's added and that's not possible with things like this [the co-design project]."* (Nurse specialist, hospital A).

Hospital	Patient involvement method(s)
A	* Filmed patient interviews * Patient event, with improvement themes prioritized after discussion * Staff event: watching the patient film and discussing improvement priorities based on the film * Joint patient–staff event: watching the film together and discussing selected improvement priorities in co-design working groups
B	* Involving a patient 'sounding board' to discuss the project * Focus group with patients * Patient event: discussing the focus group results and prioritizing improvement areas using emotional mapping * Staff event: discussing and prioritizing improvement issues based on their own experiences and externals' observations on the ward * Joint patient–staff event: discussing results from the patient and staff events, identifying joint priorities, and discussing improvement suggestions in co-design workgroups * Co-design workgroups * Celebrating event * Forming a patient 'sounding board' to monitor improvements made
C	* Involving a patient representative in the project team * Staff survey: staff are asked to describe areas of improvement * Filmed focus group with patients * Staff event: watching the patient film and discussing key priorities for service improvement * Patient event: watching the patient film and discussing the improvements selected in the staff event * Joint patient–staff event: discussing improvement solutions * Improvements rest with individual professionals
D	* Filmed patient interviews * Interviews with staff * Participant observation on the ward * Patient event * Staff event * Joint patient–staff event, including discussing improvement suggestions in co-design workgroups * Co-design workgroups
E	* Involving a patient representative in the project team * Three focus groups with patients * Patient experience cards * Feedback to patients who participated in the focus groups at several stages of the project * Feedback to professionals on the ward * Forming a patient 'sounding board' to monitor improvements made

Table 8. Applied patient involvement methods within the hospitals under study.

In particular, respondents using some form of EBCD perceived it to be a time-intensive method that is not 'simply' carried out next to regular working activities. This often led to a step-by-step approach without paying attention to activities that had to be carried out in the future.

Not all respondents experienced the lack of 'official' time for the project and a step-by-step approach as a problem per se. According to some, the key to success is to find

motivated people who are willing to work on this subject in their spare time. Although hospital E seems to have done well in this regard, financial policies and societal trends could hamper this in the future:

> *"[Quality improvement projects] are part of your job I feel, but I don't have time for it in that sense. My fee is based on the number of patients I treat. Every ten minutes that I don't see a patient, I don't get any money. That's okay, but those are the facts. I think, that frustrates me sometimes, that if you're portrayed so negatively in the media as a profession [e.g. regarding high incomes], and all the positive things we, but also many others, do don't get attention. I think if you increasingly tighten the thumb screws then eventually the enthusiasm to do these kinds of things will increasingly become less."* (Doctor, hospital E).

We already saw that national policies, such as market-based reforms in healthcare, can be reasons for hospitals to implement co-production. However, this quote illustrates that other policies and national trends can also hamper co-production, as it could influence the ability and willingness of staff to work on co-production in a negative way.

Involving patients in co-production: tailoring patient input

Although project members paid attention to the involvement of professional staff, which was seen as a crucial success factor, most attention was given to patient involvement. To turn co-production processes into a success, project members felt they had to take certain measures concerning the involvement of the 'right' patients. A first critical stage of this quest was the selection of patients for the focus groups and interviews. Although some respondents were happy that client council members participated in the project teams, they thought it was especially important to talk to patients who actually received care on a certain ward and not someone who was representing them:

> *"And he [doctor in project team] thinks I'm not really a good patient of course, because I'm not an oncology patient, fortunately […]. I don't know anything about his ward and about coming there during the day and what it's like when you leave again. So in that sense I can say what I feel is important, but then he says: yes well but you're not my patient."* (Client council member, hospital E).

However, not all patients receiving care on such a ward were perceived to be the 'right' patients either. Respondents talked about inviting patients who have a critical point of view, are mentally and physically in good enough condition to participate, and able to tell their story. In addition, 'complainers', 'satisfied people' and 'troublesome people' (e.g. 'no show'

patients) were also selected. At the same time, the selected patients should serve as a representative sample of the hospital ward population:

> *The project leader says that she's of the opinion that the sounding board, and thus the focus group, should, at least, be accompanied by a 70+ patient, a young patient, a patient from Turkey or Morocco, ideally both, and two "regular" patients. She also suggests inviting more patients, in case there are dropouts. The other project members agree with these suggestions.* (Observation project team meeting hospital B).

Lists of patient names were checked by the project members, and patients were selectively chosen and invited to participate; thus, choices were made about who counts as a good patient to represent the target group of the hospital ward, whose story should be heard and used for improvement processes and whose should not. As a result, patients' input was tailored according to the criteria of the project teams, as far as they were able to include certain patient groups.

Also, after patients' experiences were gathered choices were made by the project teams regarding which parts of the patients' stories should be put forward as input for quality improvement. This is a crucial aspect in the process since the choices made largely determine which issues will be on the improvement agenda. Moreover, these choices can have an important impact on the co-production process.

> *A compilation film was made of the patient focus group, which was shown to patients. Although patients expressed both positive and negative experiences during the focus group, the compilation showed almost only negative experiences, as the editors thought that this information was most helpful for realizing improvements. After seeing the film, patients were a little upset, as they didn't mean to be so negative about the hospital.* (Observation patient event hospital C).

Patients' input: much that is already known

Patients' input showed that patients are generally satisfied with staff on the ward and the healthcare treatments they receive, but that there is still room for improvement. Noteworthy is that improvement areas identified by patients were quite similar across hospitals. Apart from some specific experiences with medical treatments, they mostly concerned 'softer' aspects of quality of care, such as the decoration of waiting rooms, waiting times, communication, and coordination with general practitioners. The improvement issues that were identified were thus not only related to individual professions or the hospital ward, but also to the hospital organization and other healthcare providers. These improvement areas have been reported in other participation practices as well (Van de Bovenkamp et al. 2008) and were mostly not new or surprising for the team members:

The client council member arrives late for the meeting. The project manager updates her briefly on the discussion they're having about the results of the focus group; the major points for improvement are waiting times and information. The client council member responds: "so the usual stuff". (Observation project team meeting hospital E).

This time, however, some of the improvement issues were acted upon. For instance, in hospital E, psychosocial care is now proactively offered during consultations with doctors and nurses, as focus groups disclosed that patients often did not know about this type of care. The following is an improvement made in hospital B:

The patient focus group disclosed that not all patients received information about visiting the dentist when undergoing cancer therapy. Physicians and patients priori-tized this as an improvement issue, and co-design workgroups followed. During the co-design phase it was explicated what patients should know about this subject, which resulted in an information leaflet made by patients and staff together. This leaflet is added to the information map patients receive when treated at the hospital. (Observation celebrating event hospital B).

Although this improvement was made by both patients and staff, patients were not always involved in the improvement and implementation process. According to the respondents, inclusion of patients depended on the improvement theme. In practice it meant that patients were not involved when it was felt that they had too little knowledge about the subject (e.g. about information patients should receive); when it concerned physicians' behavior (e.g. during diagnostic conversations); when it was thought that involvement was too much to ask from patients; and when it seemed more effective to only check afterwards whether patients positively evaluated the changes made. Also, when healthcare professionals thought they already had enough input from patients on how to make improvements, patients were not involved. These can all be legitimate reasons, especially when keeping the time invest-ment of both staff and patients in mind. However, it is important to note that the project teams decided whether patients needed to be involved in this phase.

Added value of co-design: the importance of the co-production process

Although patients' input was not very new or surprising, the co-design process did result in improvements which had not been made before. Our results indicate that it is not so much what patients say that is important; it is the process and the way they are given the opportunity to have their say. First, letting their 'own' patients talk about their experiences in a common 'action' setting affects professional staff, as patient stories make visible what the impact of (already known) problems really is on patients. The active role of patients and the

way they express their experiences creates a sense of urgency to act on the improvement issues raised.

> I [the researcher] tell the project team that similar points are brought forward by patients in the different hospitals such as waiting times and information provision, and note that the process seems to be important. The doctor nods: yes you know but you don't apply that to yourself. You've to get engaged and you need this process for that.
> (Observation project team meeting hospital E).

Second, going through the process is important for organizational reasons, for instance to get (financial) support for improvements from higher management bodies such as the hospital's medical staff and Board of Directors. Patients' input can then be used as an instrument to gain legitimacy and set improvements in motion.

Next to information on why the co-production process is important, our results provide insight into aspects of this process that according to our respondents can facilitate its success. Keeping the project 'small', in terms of not wanting to improve everything at once and focusing on one hospital ward, was, for instance, seen as an important factor. Also, doctors' commitment to the project and the involvement of their own patients were perceived as important process aspects. Moreover, it is possible that being part of a national project with training, advice and certain deadlines played a facilitating role as well.

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DISCUSSION

Whereas other researchers have focused on the motives of users to co-produce (e.g. Van Eijk and Steen 2014), this study sheds light on the motives of 'regular producers' (i.e. hospitals) to involve users (i.e. patients and staff) in quality improvement instead. In the scarce available literature on this topic, goals such as higher quality services, cost reductions and democratization of decision-making have been described (Brudney and England 1983; Pesthoff 2012). In addition, more 'instrumental' reasons for involving citizens, for instance, to steer public policy in a certain direction or to position citizens as a countervailing power to other policy actors, have been found (Van de Bovenkamp and Trappenburg 2011). This study shows that similar reasons for involving patients in co-production exist on the micro level. These motives were partly the result of the macro-level structure of the Dutch healthcare system. National policies and trends can thus positively influence co-production processes at the micro level. However, we have shown that it could also hamper co-production processes, for instance when financing structures (such as fee-for-service systems) do not directly reward projects such as these. Public choice theory can provide a partial explanation for this result, as this theory assumes that people will co-produce

when benefits outweigh costs (Verschuere et al. 2012). However, our results also show the importance of other values and goals, such as the professional norm to provide good quality care, that can stimulate co-production. Since incentives produced by the context in which co-production processes take shape clearly play a role, it is important to study the wider context of co-production further.

National policies and trends are not only important when looking at hospitals' motivation to co-produce with patients, they also influence the adaptation and tailoring activities of co-production processes. Adaptation of the participation methods used is an important aspect of this; hospitals adapt participation methods mainly to limit the time required and financial investments needed, to limit the demands on patients, and because they do not always see the added value of involvement throughout the process. This adaptation need not be a problem and can even be considered a positive one. Findings presented in this article and in other studies that strictly followed EBCD (e.g. King's Fund 2011) indicate that similar improvement points were identified by patients and acted upon. This makes it likely that the method chosen to distil patient experiences and the adaptation of existing methods in itself does not matter that much. Adaption is even likely to be beneficial for success within a specific context.

However, adapting and tailoring can have an impact on the co-production process and should not be done uncritically. Tailoring activities such as using various criteria to select patients can influence what is considered to be legitimate patient input. Moreover, the literature on citizen participation has shown that certain groups of citizens, the white highly educated middle and upper classes, are more likely to participate than others (Bovens and Wille 2011; Verba and Nie 1972). This could lead to decisions, in our case quality improvements, that are beneficial for some but not necessarily for others (Van de Bovenkamp et al. 2013). Therefore, project teams need to critically reflect on the consequences of adaptations and tailoring actions and their desirability, in order to find an appropriate balance between adding value for specific users and adding value for the whole patient community (Alford 2009).

Based on our findings we conclude that the fact that healthcare improvements are realized, using different methods and hearing familiar points for improvement, is primarily the result of the process of co-production: an organized trajectory in which patients and staff are involved and personal experiences are brought forward (Tsianakas et al. 2012). Apparently, hospitals need to follow this process in order to bring improvement issues to the fore and more importantly to act on them. Several explanations for this can be put forward. First, the explanation could lie in the set-up of the co-production projects: a setting is created where patients and staff can actively work on improvements together and time is made to implement improvements. A national project with certain deadlines plays a facilitating role in this respect. The importance of time is confirmed by Verschuere et al. (2012), who also argue that acknowledging the investments of co-producers is essential

for effective co-production. We can add that this also applies to regular producers. Second, as our respondents pointed out, the process of involving patients is important to gain (financial) support from higher management bodies such as the hospital's Board of Directors. Patients' input functions then as an instrument to set improvements in motion. Lastly, it could also be that the improvement issues are known in a general sense, but healthcare professionals do not realize what the implications are for patients or think that it is not relevant for their ward. Hearing it from their own patients could highlight to them that they are no different. That this might be the case is indicated by the fact that staff mainly wanted to involve their 'own' patients. Seeing and hearing their patients talk about their experiences can function as an eye-opener (De Wit et al. 2008), improve the understanding of patients' needs (Alford 2009) and give discussions on improvements a point of reference: it is about real people who publicly state what the indirect consequences are of private actions (Nelis et al. 2004). According to Emmanuel Levinas, the sheer presence of patients would be enough to appeal to the responsibility of healthcare professionals, to make sure that they act accordingly (Duyndam 2007). We argue that lessons such as these derived from citizen and patient participation literature can complement the public administration literature on co-production (Farr 2012) since it provides insight into why the process is important to facilitate improvements.

Studying co-production processes such as the ones described in this article leads to the important question of what co-production actually is. Adaptation and tailoring of co-production methods will always take place to a certain extent. However, it is important to further explore the limits of adapting and tailoring co-production methods and patients' input, since at a certain point the question can be raised whether we can still speak of co-production. As stated at the beginning of this article, co-production is not easy to define; it refers to 'an idea' of involving people (Alford 2002) and has been described as a multi-faceted concept (Brudney and England 1983; Verschuere et al. 2012). It is generally felt that this involvement should go beyond collecting input and should have an impact on the service provided, which happened in all of our case studies. Nonetheless, our study shows that it is important to continue unraveling the concept further. Next to distinguishing between co-production on different levels and between activities (e.g. Bovaird and Loeffler 2013; Farr 2012), we think that unraveling attempts should focus on the co-production process, to provide input for the discussion on the boundaries of the concept.

RESEARCH EVALUATION

This article contributes to the body of knowledge on co-production by studying organizations' motivations to initiate co-production activities and by empirically describing the process of co-production on the micro level. The use of three qualitative data collection

methods was useful in this respect. It made it possible to triangulate the data, resulting in a more complete and validated view on co-production processes. The gathering of data in five different hospital wards specializing in different diseases (hematology and oncology), who varied in their previous experiences with involving patients and in the involvement of patients during the project, also lead to a deeper understanding of the functioning of co-production in hospital wards. It made it possible to critically reflect on contrasting cases to validate the conclusions, and it contributes to the transferability of the findings to other hospital wards. However, insight into other diseases and care settings (such as nursing homes) is needed to be able to transfer the results to healthcare organizations in general and warrants further research.

CONCLUSION

This study focused on hospitals' motivations to initiate co-production activities and on manifestations of co-production at the micro level. The findings show that hospitals have motivations related to market, organization, and quality of care to initiate co-production activities. In addition, co-production processes stimulate hospitals' thinking about how to realize quality improvements. Quality improvements were facilitated by this process as seeing patients and hearing their experiences created a sense of urgency among staff to act on the improvement issues raised. The experiences served to legitimate improvements to higher management bodies. While the participation method chosen does not seem to matter much, there are several aspects that facilitate co-production processes, including participation in a national project and involvement of doctors' 'own' patients.

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CHAPTER 6

Involving patients and staff in deliberative healthcare quality improvement projects: the impact of design choices on deliberation practices

ABSTRACT

The healthcare sector increasingly stimulates deliberative discussions between patients and professionals with the aim of improving quality of care. Deliberation refers to the exchange of viewpoints to stimulate reflection on preferences and reach well-informed decisions. Various methods are employed to stimulate deliberative discussions. However, research has indicated that, in practice, these methods are often adapted to local contexts. As the implications of such adaptations are largely unknown, this paper focuses on the impact of design choices on deliberation opportunities and quality improvements. We conducted a qualitative study based on interviews, document analysis and observations (between 2012-2014) in four Dutch hospitals that wanted to improve quality of care by involving patients and staff in deliberative practices. Our findings confirm the difference between ideal deliberative methods and practical implementation, and show that the design choices made have three types of implications: 1) they limit the depth of deliberation taking place, 2) they influence the role of affect within deliberation, 3) they influence whose voices are heard in the process. They thus steer which improvement themes and solutions are selected (e.g. only patients' or staff's points of improvement) and raise the question whether improvements are actually reached. Organizers who want deliberative processes to enhance healthcare quality could best make design choices that keep deliberation aspects intact as much as possible. In addition, reflection on the implications of choices is necessary.

INTRODUCTION

Deliberative democracy is a "political approach focused on improving the quality of democracy". (Held 2006, p. 232). The idea is that the quality of democratic decision-making can be enhanced by changing the form and nature of citizen participation. Instead of only voicing individual preferences and aggregating private citizen views to form decisions (as is the case with voting), citizens are encouraged to first share ideas and thoughts in discussions and debates, so they can form carefully considered preferences, on which basis they can make fully informed decisions. Deliberative citizen participation is thus very (pro)active, with the exchange of viewpoints and public reason its central elements. It enables citizens to reflect on their own values and opinions, which ultimately leads to better (informed/shared) decisions (Abelson, Forest et al. 2003; Farr 2012; Held 2006).

The field of healthcare increasingly promotes deliberation through the exchange of viewpoints between citizens/patients and professionals with the idea that the practice will result in new or better ideas, opinions and decisions (Abelson, Forest et al. 2003; Iedema et al. 2010) and because patients' experiential knowledge provide another perspective on healthcare practices that complements that of the professionals. Sharing, discussing and challenging viewpoints between citizens/patients and healthcare professionals can lead to well-informed, good quality decisions that, in turn, enhance quality of care. Methods used in healthcare to encourage deliberation include citizen juries (Street et al 2014), deliberative focus groups (Abelson, Eyles et al. 2003) and experience-based co-design (Bate and Robert 2007; Iedema et al. 2010).

The impact of deliberation methods in healthcare and their success in terms of quality improvement depends on how they are designed and implemented. Insight into the design and implementation of deliberation methods is therefore crucial (Street et al. 2014). Research into deliberative involvement practices in healthcare has already pointed us to the importance of adapting deliberation methods to local contexts (Street et al. 2014; Vennik et al. 2016). These adaptations can be necessary for participation to succeed in a specific context (Vennik et al. 2016). However, at the same time, they can have substantial consequences for deliberation opportunities. For example, recruitment choices can result in unvaried participant groups since certain groups are easier to involve than others. This can limit citizens/patients' opportunities to exchange perspectives and the quality improvement potential of deliberation (Street et al. 2014). Because design choices shape deliberation possibilities and thus the quality of resulting decisions, Street et al. (2014) argue that further research into the consequences of these choices is important.

The aim of this paper is to provide more insight into the impact of design and implementation choices for practices promoting deliberation in healthcare, by analyzing methods that encourage deliberation in four Dutch hospitals. The research question guiding this paper is: *What choices are made in the design and implementation of methods that stimulate*

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deliberation in healthcare and what is their impact on deliberation opportunities and healthcare quality improvements? Answering this question is important as the insights gained will enable better reflection on decisions made during deliberative participation, e.g. by project facilitators and researchers studying deliberative methods.

The paper begins with a brief overview of deliberative democracy literature and the use of deliberative notions in healthcare. This is followed by a description of the research design. In the results section, we discuss design and implementation choices and illustrate the impact of these choices. In the discussion and conclusion we reflect further on design and implementation choices, focusing on the consequences for quality improvements.

DELIBERATIVE DECISION-MAKING PROCESSES

Deliberative democrats assume that people's preferences and judgments are not given or fixed (Held 2006). Through a process of information sharing and hearing opposing viewpoints, individuals' understanding (and related judgments and preferences) can be reinforced or transformed. Farr (2012, p. 33) describes this as follows: "*It is in the process of public reason and deliberation that people come to understand a range of issues from different perspectives that enables them to reflect on their concerns and alter their values and opinions in the process of coming to mutual understanding over common concerns.*" The deliberative democracy literature contains various opinions on whether deliberation processes eventually lead to unanimity (i.e. consensus) in decision-making. 'Impartialists' argue that consensus can be reached by force of the better argument (Held 2006, p. 239). They assume that deliberation can be free from any power relations (Farr 2012) and that citizens will not just follow their self-interest. However, critics of this rational view point out that, in practice, deliberation occurs under non-ideal conditions, such as incompatible values, status inequalities, and incomplete understanding, which make it hard for individuals with varying interests to reach a consensus, as deliberation will not just turn self-interested actors into altruistic people (Abelson, Forest et al. 2003; Held 2006). Some authors point out that citizens can also have solid reasons for sticking to their argument. In addition, critics contest the exclusion of affect (i.e. passions, emotions and sentiments) from rational deliberative dialogue (Krause 2008). They argue that affect is an inherent part of deliberation, it cannot be switched off. Affect is necessary to make decisions, as it helps humans to decide on a course of action. It functions as a motivation, providing a sense of what matters (Krause 2008). It also helps understanding other perspectives, resulting in better judgments. Searching for *the* better argument should therefore not be seen as the only practice meant by deliberation. Diverse complex affective practices, such as storytelling or showing emotions to share perspectives (Farr 2012; Krause 2008) should be admitted as belonging to the deliberative processes as they enhance the sensitivity of sentiment (Krause 2008). Some claim that affective com-

municative styles are also necessary for including diverse participants in deliberation as focusing strictly on cognitive reasoning (to the extent this is possible) would, for example, only include educated citizens (Sanders 1997).

DELIBERATION PRACTICES IN HEALTHCARE

In healthcare, deliberative notions can count on increasing attention. Healthcare is a setting where non-ideal deliberative conditions are a given: information asymmetry and power differences characterize the doctor-patient relationship, patients are not always able to participate due to the burden of disease, and the emotionally loaded topics of life and death lead to complicated discussions. These aspects have an impact on deliberation opportunities as, for example, they influence patients' ability to voice opinions and listen to and reflect on those of others. The importance of a better understanding of deliberation in these circumstances has long been highlighted in the literature (Gutmann and Thompson 1996).

Healthcare uses various methods solely designed to foster deliberation, such as citizen juries and focus groups (Smith and Wales 2000), mainly to promote discussion on ethical questions (Street et al. 2014). Participation is not restricted to patients in these cases. Often citizens or patient representatives are involved, e.g. because of the social (and not necessarily patient-specific) nature of ethical topics. There are also participation methods for quality improvement, which explicitly include deliberative elements. A promising example used increasingly in many countries is experience-based co-design (EBCD) (Bate and Robert 2007; Donetto et al. 2014; Larkin et al. 2015; Farr 2012). It engages patients and staff with various communicative styles, including film and emotional mapping, to achieve quality improvements. Most interesting is that EBCD puts emotions center stage as input for deliberation on quality improvement. The method contains six prescribed steps (see Table 9, left column), several of which are explicitly designed to foster deliberation. For example, phases 2 and 3 can be considered settings that stimulate "enclave deliberation" (Karpowitz et al. 2009, p. 579), as they create a safe environment, in one's own group, where participants can develop their own ideas and preferences first, and articulate their voice (Abma and Baur 2014). Phases 4 and 5 stimulate deliberation between groups of healthcare professionals and patients, encouraging them to discuss their experiences, perspectives and preferences together. This should lead to a joint prioritization of improvement issues in phase 4, and to shared improvement solutions in phase 5.

EBCD specifically includes emotions and storytelling as communicative styles and thus does not solely rely on rational dialogue. Emotions are put center stage to stimulate a better understanding of perspectives and, consequently, reflectivity. In addition, emotions challenge the dominance of medical discourse, form a catalyst for further action (to change services) and are actively promoted to achieve quality improvements (Farr 2012). Because

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of the emphasis on deliberation and emotional communicative styles, EBCD is an excellent case study to gain a better understanding of the use of methods encouraging deliberation in practice.

Despite its detailed prescription, EBCD is often adapted to local contexts in practice (Larkin et al. 2015; Vennik et al. 2016). Various phases, or steps within phases are omitted or replaced. Street et al. (2014) argue that such design choices in deliberative fora are often necessary due to contextual factors (e.g. financial constraints). Moreover, their review of the use of citizen juries in health policy decision-making identified choices related to citizen recruitment strategies, duration of deliberative processes, the way information is retrieved (e.g. asking experts or providing research results), and the way decisions are made (e.g. reaching consensus or voting). Based on their findings, Street et al (2014) argue that adaptations and thus a more pragmatic use of methods would stimulate the development of new ideas, and it could even be counterproductive to adhere strictly to a certain 'ideal' methodology or design. However, design variations can have negative implications for (results of) deliberative processes (Mullen 1999). For example, variations in recruitment procedures can influence target group representation (Street et al. 2014) and tailor participants' input (Vennik et al. 2016). The aim of this paper is to gain an understanding of the impact of such design choices.

METHODS

Our case studies involve four Dutch hospitals using EBCD for the first time. As the hospitals quickly adapted the method to their local context, they are excellent cases to answer our research question.

The case studies concerned one hematology (sickle-cell anemia) and three oncology departments. These patient groups commonly have various disease symptoms that can have a severe impact on their daily lives. They differ in their ethnicity. Oncology patients are very divers; this disease could happen to anyone. Patients with sickle-cell anemia have an inherited blood disorder that mainly affects specific migrant groups in the Netherlands. Migrant groups are generally difficult to include in participation practices, which importantly should be tailored to these communities and social settings (De Freitas et al. 2014).

We used a qualitative multi-method research design to study the cases between 2012-2014. First, in each department we conducted in-depth semi-structured interviews with project team members, who were responsible for carrying out the EBCD method on the ward. The composition of these project teams varied in each hospital but often consisted of a doctor, specialized nurse(s), a manager, quality officer(s), and in one hospital a patient representative (a member of the hospital's client council). In total, we conducted 21 interviews (11 at the start, four during the project and six at the end in order to gain insight

into every stage of the method). Some respondents gave multiple interviews, resulting in 19 interviewed project team members. All interviews were recorded, with permission, and transcribed verbatim, except for one (this data is captured through notes taken during the interview and worked out immediately after). The purpose of the interviews was to explore the impact of design and implementation choices for practices stimulating deliberation in healthcare. During the interviews, respondents were invited to talk about how they applied EBCD on their hospital ward, how and why they made design choices, and they were asked to illustrate results of the participation process. We also asked them to reflect on events that stimulated dialogue and shared learning (i.e. deliberation practices).

Second, we conducted 48 hours of observations during formally planned deliberation moments (e.g. patient and staff events) and project team meetings. These observations provided insight into project teams' choices regarding the design of the quality improvement initiatives and into the results of these choices for concrete meetings with patients and staff. During the observations, we conducted informal interviews with project team members. We took extensive field notes and, with permission, recorded and transcribed verbatim some observations.

Third, we analyzed documents related to the project, either produced by the project teams or involved participants. Examples are project action plans (which described the adaptations to the EBCD method) and progress (summary) reports. The documents gave detailed insight into how each department carried out their EBCD project and thus also into the various design choices made in each department.

The authors gathered and shared all empirical data. We performed a qualitative analysis first by selecting and labeling significant sections of interview transcripts, field notes and analyzed documents, and second by clustering labels that shared a commonality (Creswell 2003). This resulted in the categories 'adapting EBCD', 'selection of improvement areas', and 'selection of improvement solutions'. As a final step, these categories were compared and contrasted with each other by discussing their interactions. Frequent meetings ensured we gained a thorough understanding of the data. We alternated data analysis and collection and to enhance validity, fed the study results back to the hospitals twice (Tong et al. 2007).

FINDINGS

This section describes the design and implementation choices that affect deliberation, focusing on the process of selecting areas for improvement and their solutions.

Adapting EBCD

All four departments included in this study wanted to use EBCD to improve the quality of their hospital care. They chose it because it facilitated dialogue between patients and

staff on quality improvement. The project teams perceived the deliberation aspect as a 'promising new facet'; something that existing patient involvement methods such as mirror conversations and focus groups (that only engaged patients in discussions) did not facilitate. This new aspect could stimulate the exchange of perspectives, experiences and preferences between staff and patients, and eventually lead to better, more attuned improvements.

Despite their enthusiasm for EBCD, the project teams quickly adapted it to their local context. Mainly this meant trying to limit the time and financial investments needed. Table 9 lists the steps each project team took to achieve quality improvements and compares them with the 'official' EBCD method, showing that the project teams adapted the method considerably. In the following, we illustrate the possible consequences of such adaptations and other design and implementation choices for deliberation processes.

EBCD Phases		Hospital A	Hospital B	Hospital C	Hospital D
Phase 1 - Information gathering					
			Patient 'sounding board' discusses the project.	A patient representative is on the project team.	
Interviews with staff	Staff members are asked to describe their experiences of working with particular services.			Staff survey held to elicit points of improvement.	√
Participant observation on the ward	Observations are intended to gain an understanding of the patient pathway from both staff and patient perspectives.		Two externals observed the ward from the patients' perspective.		√
Filmed patient interviews	Patients are asked to describe their experiences with care provision on the ward, during a filmed interview.	√	Focus group held with patients instead of filmed patient interviews.	Filmed focus group with patients instead of filmed interviews.	√
Phase 2 – Identify improvement priorities among staff					
Staff event	Staff event is held to review improvement themes based on staff interviews and observations and, by discussing different perspectives, to identify priorities for service improvements.	Staff watched the patient film and discussed improvement priorities based on the film.	Staff prioritized their improvement issues based on own experiences and observations the externals held on the ward.	Staff watched the patient film and discussed improvement priorities based on the film.	√

Phase 3 – Identify improvement priorities among patients				
Patient event	Patient event is held to show an edited film of important themes/'points of improvement' from the patient interviews. Afterwards, the points are prioritized in an emotional mapping exercise: a way to indicate the emotional impact of the points along the pathway.	After watching the film, patients discussed the improvement themes and set the priorities.	Patients discussed the focus group results and set priorities for improvements using emotional mapping.	After watching the film, patients discussed improvement solutions for themes selected in the staff event.	√
Phase 4 – Identify and decide on joint improvement priorities				
Joint patient-staff event	At this joint event staff see the patient film for the first time. After the film, patients and staff present and discuss their own improvement priorities to identify joint priorities.	Patients and staff saw fragments of the film together, discussed selected improvement priorities and initiated solutions.	Patients and staff discussed results from the previous events, identified joint priorities, and discussed improvement suggestions to the co-design workgroups.	Patients and staff discussed improvement solutions. Improvements rested with individual professionals.	Project team added co-design workgroups to discuss improvement suggestions. The project team also pre-selected the improvement themes.
Phase 5 – Identify and decide on joint improvement solutions				
Co-design workgroups	Small workgroups of patients and staff to discuss possible solutions to design and implement service improvements.	√		√
Phase 6 – Celebrate improvements made				
Celebration event	At this event patients and staff review the activities of the co-design working groups and celebrate established improvements.	√		√
			Formed a patient 'sounding board' to monitor improvements made.	

√= Hospital conducted the activity following the EBCD method. If left open, the hospital did not conduct this activity.

Table 9. Summary of EBCD phases and related local adaptations made by the four hospitals.

Information gathering (phase 1)

At the start of the projects, patients had to be invited to participate. Each project team performed a careful selection process based on two criteria. First, they wanted to include all types of patients from the hospital ward to include different perspectives. Second, they wanted to include only patients who would not be overburdened by participation, whose mental and physical health status permitted it, as they were concerned about the patients' state of mind. The first motive corresponds with the notion that successful deliberation only occurs if all relevant viewpoints are included and/or discussed (Held 2006). The second motive is the result of non-ideal conditions in healthcare and makes deviation from the first necessary; the perspectives of severely ill patients are, for instance, excluded because of this criterion. Despite the efforts made to gather a wide variety of perspectives, project teams remained dependent on the patients' willingness and ability to participate:

> "(…) I made a little document [on patient selection]. I want differentiation in age, not only complainers but also happy people, you know a whole list... I could articulate that very well, but (…) especially with sickle cell, half the patients don't speak Dutch and aren't very well educated, and of course you want to include them too. But, when you speak to them on the phone, they're too tired, or simply don't have time, or they're really ill so they won't come." (Project leader, hospital D).

After recruitment, patients were asked to voice their experience of the care they had received. Following the EBCD method, three hospitals captured all experiences on film. The editing of this 30-minute film is important for the deliberation process, since stories must be selected to form the input for discussion in the next phase. One project team explained that their selection was based on shared experiences; only improvement issues mentioned in each interview were included. This meant that other subjects, important to some patients but not all, were not in the film and thus excluded from the quality improvement process. Other decisions also had an impact on the issues represented in the film. For instance, this project team also decided to select only those filmed fragments that illustrated 'inspiring' patient stories:

> "We showed a one-hour film, but we had maybe 18 hours of material, it took a lot of work to cut it down to that. According to the interviewer, there were some difficult interviews, because, well, they were very tedious. And you know, he felt that the film should continue to inspire. (…) We cut a lot. This should be in, this not." (Project leader, hospital A).

By selecting 'inspiring' stories, the project team decided intuitively whose patient stories should be heard and whose should not. This gave storytelling and emotions very prominent places in illustrating the patients' perspectives.

Patients were not always happy with the result of the selection process. For instance, in hospital C, the project team decided to include mostly negative aspects of care in their film, as they thought that only this kind of information could lead to improvements. After seeing the film, patients were shocked since they had not meant to be so negative about the hospital. Selection processes could thus arouse certain emotions in participants watching the film.

Clearly, making a compilation of experiences is a complex process, albeit very important because the selected items form the input for further priority-setting discussions (see below).

Identifying improvement priorities among staff and patients (phases 2 and 3)

According to the EBCD method, staff experiences with healthcare services must also be gathered. Therefore the project teams invited all staff members of the involved departments (from doctors to receptionists) to participate in the project. However, they varied in when and how they involved them (see Table 9). Such variation would not necessarily have a negative influence on deliberation processes as long as the staff's preferences and opinions of service improvements were exchanged and discussed with patients during the improvement process. Hospitals A and C did not manage to achieve this. Both hospitals changed the staff event into a meeting at which staff watched the film and afterwards were asked to voice their opinions and identify key improvement areas based on the film. Staff were impressed by the stories and experienced eye-openers. However, as they could only choose from patient-identified improvement areas selected for the film by the project team, their own ideas, preferences and perspectives were not included. This approach resulted in one-sided deliberation highlighting only the patients' views.

Similar to the staff event, EBCD prescribes a patient event at which patients decide on key improvement priorities together, choosing from the priorities shown in the film. Emotional mapping is the recommended way to make the selection. This exercise involves writing down all film (or focus group) items on separate sheets and patients place sticky notes describing their feelings at the top of the sheet (if positive) or at the bottom (if negative). Items with most negative emotional notes are key improvement areas. Here, decision-making is based on the impact of emotions and the number of shared negative experiences (and in the case of equal numbers, on a vote). Hospitals B and D followed this method. Hospital C showed the film to discuss improvement actions but did not ask patients to set key priorities. Instead, the project team used the key priorities staff identified after watching the film. Due to the patients' limited influence, certain improvement points patients identified as important did not make it on to the improvement agenda:

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In the film, patients complained about the competence and attitude of apprentices. They explained that apprentices could have a very negative impact on the care they experienced. One patient suggested that apprentices should not be involved in oncology care: "Yes apprentices, sure they need training. But I don't think they should be working with cancer patients. You're all nerves and then you get someone who knows nothing." However, staff did not select this as a key improvement priority, because they considered it a hospital-wide problem, broader than the quality of their department. As staff made the selection, patients had no influence on the final decision. (Researcher's observation in hospital C).

Clearly, there might be good reasons why issues raised by patients do not make it on to the improvement agenda. However, the idea behind deliberative processes is to achieve a common understanding through the exchange of different views. This did not happen in this case because of the adaptation of the EBCD method.

Identifying and deciding on joint improvement priorities (phase 4)

To reach a final selection of improvement areas, the EBCD method includes a joint patient-staff event at which patients and staff meet to communicate their key improvement themes and discuss *joint* improvement priorities. At this event in hospital A, the project leader explained that since both patients and staff had indicated the same improvement areas after watching the film, any further discussion and selection was unnecessary. So, there was no deliberation between professionals and patients, as staff had not communicated their own views to patients during the quality improvement project. The department's final selection of improvement themes was 'diagnostic conversation', 'family involvement' and 'available disease information'. A closer look at our results shows, however, that 'available disease information' was only included in the film and was not set as a priority by patients and staff after watching the film. The project team selected this theme from the patient film but framed it as a joint priority, which illustrates their steering capacity. In another case, deliberation between professionals and patients was not skipped altogether but was steered by the project team, as they pre-selected key improvement topics. Participants had, however, different views of their ability to solve or control the quality improvement themes, and were able to change this prioritization during deliberation.

When an effort was made to foster deliberation between professionals and patients, it often proved useful. The project teams indicated that the deliberation processes helped in acknowledging (the impact of) improvement problems and especially staff gained insight into views they had not been aware of before. For example, despite treating young sickle-cell patients daily, one doctor realized only through the exchange of emotional experiences in the project that the pain of these patients has a great impact on their families.

However, deliberation proved also to be hard to do in practice. An emphasis on emotion in deliberation practices can, for instance, quickly accentuate only the patients' experiences. In addition, discussions between staff and patients can be difficult to arrange. For example, in one hospital patients and staff were first divided into small groups at the joint patient-staff event. Each group had to reach consensus on two (out of ten) important improvement areas, selected in previous events. This was not always easy, as the following extract illustrates. In the extract, two healthcare professionals and three patients (of whom two were immigrants) tried to find consensus on the second key improvement theme. They had just selected the first: better information exchange between the hospital ward and general practitioners; a theme brought up by patients.

H (healthcare professional) 1: *And what's your experience of the staff-client interaction? Because, if it were up to me, I'd see it as one of the two most important things, but we are supposed to select the topics with the five of us.*

P (patient) 1: *What do you mean exactly?*

H1: *Well, I mean, to what extent would you say that the staff-client interaction should be one of the two most important improvement points?*

P1: *Yes, they talk about wooden chairs in the waiting room, that isn't important for me. I want that the doctor is 100%. I'll survive that wooden chair. That is something I don't find important.*

P3: *Chair will be in the last, last… place. Though, it's important. Last place I give to shape of the chair.*

H1: *Okay, but what about staff-client interaction?*

P3: *Yes, I mean, that general practitioners are aware, that's one of the most important. Because if my surgeon doesn't pay attention to this during a control visit, my situation and my pain, I go to GP, GP can send me to doctor right away instead of… I visited whole Amsterdam. Visited GP, visited orthomanual, I really had to walk through Amsterdam with much pain and effort, with a cane. Had to ask people to help me, because I couldn't go any further. GP is not informed…*

H1: *Yes, but the GP is clear to me. It's also about what the second theme could be.*

P3: *The second theme, oh yes.*

H1: *Yes, we have to select two points and I was thinking about staff-client interaction, but then it's important to know about your experiences with staff-client interaction.*

P3: *What is staff-client interaction? Could you…*

H1: *How the staff speak to you, the reception you get, treated with respect…*

P1: *Well, there's nothing to criticize about that at all, I think. At least with the doctor I'm seeing. I don't know if others see different doctors, but I see doctor [name] for thirteen years now, never a hassle or…*

H2: But when you visit the outpatients department, the people who work at this department, at the desk for example?

P3: Very friendly, but sometimes they forget to put things into the system.

P1: [name] is her name I believe, when you arrive she says 'just walk on by' and makes a little chitchat. No, I think it's excellent. Yes, that's my opinion; I'm not sure how others think about that.

P2: Staff-client interaction, I find… the welcoming is very good.

P1: Yes, I agree.

H1: But that means that staff-client interaction…

H2: Is not second on the list.

P1: No.

H1: Well, that's clear.

The above illustrates how difficult it is to conduct (deliberative) discussions when patients do not understand the subject of discussion. In the extract it leads, for example, to debates on other topics than 'staff-client interaction'. Not understanding the subject of discussion could be the result of educational or language barriers and/or cultural differences. These barriers not only influence the understanding of concepts, but also the patients' ability to voice or clarify their experiences regarding certain improvement themes. A hematology project team member indicated, for instance, that some patients with sickle-cell disease were not used to talking about their disease in public, especially in the presence of doctors and peers. Their reticence might have limited the exchange of views, which is necessary for deliberation to take place. Not understanding a particular subject could easily be solved by an explanation. However, the way staff explained 'staff-client interaction' to patients was not how it was discussed earlier during the staff event. Staff discussed this theme in terms of 'healthcare professionals' attitudes towards patients' and 'staff's ability to see the whole patient and his/her loved ones, instead of a person with a certain disease'. As these explanations were not communicated to patients, particular aspects such as the staff's ability to see the whole patient were not discussed (in-depth) and therefore did not make it on to the improvement agenda. Trying to involve patients by providing simple/partial explanations could thus influence the selection of improvement issues. This could also occur when staff do not fully understand the various aspects of the discussion subject. When healthcare professionals do not explain well to patients why they find specific improvement themes such as staff-client interaction important, and patients do not ask for explanations, it limits the deliberation and steers the selection of improvement issues. Hearing other points of view is important for reflection on one's own opinions and preferences.

Steering improvement solution decisions (phase 5)

With the EBCD approach, better-attuned improvements are most likely achieved if patients and staff deliberate on *improvement solutions*. EBCD facilitates this through co-design work-groups; meetings in which patients and staff discuss, identify and design improvement solutions together. This happened (partly) in hospitals B and D. Patients, when present during these workgroups (which was not always possible due to diseases or scheduling problems), can fulfill two roles in deliberative discussions on improvement solutions. First, patients can act as guiding forces if improvement areas require specialized knowledge: patients agree with/provide the direction of the solution (e.g. set a protocol) and stress the urgency of the improvement, but cannot fine-tune the solution as medical expertise is necessary (i.e. content of the protocol). Second, they can be the inventors of solutions, if besides providing a solution direction they also develop it further. For example, in hospital D, patients initiated 'the support friend' for peer contact meetings and also developed its ground rules. In hospital B, patients initiated the development of an information leaflet for dental visits and made it together with staff.

Not all teams facilitated co-design workgroups. Hospitals A and C used the joint patient-staff event to gather patients' ideas on improvement solutions. They felt that co-design workgroups would require too much from participants or thought improvements could be reached without patient involvement. They delegated the task to staff, when they thought that patients' experiences on certain subjects were sufficiently clear. The consequence of leaving improvement solutions up to staff is that they become responsible for and in charge of improvement decisions. This way staff could easily and unintentionally set the results of deliberation processes aside. This is best illustrated by an example from hospital B. Here, deliberative discussions revealed that patients like to get information on waiting time delays, as this helps them make decisions on whether they have time to go to the toilet or wait in a more pleasant area such as the hospital restaurant. Their improvement solution suggestion was a marquee component indicating delay times. This provides clear information at a glance, also for non-Dutch speaking immigrants who represent a large target patient group of the hospital. During a project team meeting, a doctor (not participating in this co-design group) suggested replacing the marquee component with a television screen as this could not only display waiting time delays but also other information on the hospital at the same time – the distracting information that patients wanted to avoid. The project leader told the doctor about the patients' preferences, but the project team eventually selected television screens as the improvement solution, because it was easier to change waiting times on this system. However, 19 months later, the screens were still not implemented, because the board of directors had not given them priority due to a merger with another hospital. Which information will be displayed is therefore unclear. This example illustrates that patients' opinions can easily be put aside when staff perceive patients' solutions as

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impractical, when patients' reasons for particular solutions are not well understood, and/or when the board of directors makes different prioritizations.

DISCUSSION AND CONCLUSION

In this article, we explored hospitals use of a participation method for quality improvement that fosters deliberation, i.e. EBCD. Many studies provide insight into the use of EBCD in practice and the need to make choices to fit the local context (see e.g. Larkin et al. 2015; Vennik et al. 2016; Wolstenholme et al. 2010). However, these choices have important implications that need to be reflected upon. The aim of the study was to learn more about the choices made in the design and implementation of the method and to understand the impact of these choices on deliberation opportunities and quality improvements in healthcare.

Our results show that the project teams made various choices on the design and implementation of the EBCD method. Some choices were inherent to the EBCD methodology (e.g. selecting improvement points to include in the film); others were not (e.g. denying staff the possibility to communicate their improvement themes). It is important to realize that design choices and a pragmatic use of methods are often necessary for the development of new ideas and for participation processes to succeed in a given context (Street et al. 2014; Vennik et al. 2016). However, as our findings illustrate, design choices do have consequences. They influence deliberation opportunities and the selection of possible improvements. In addition, they influence project teams' ability to steer quality improvement processes. We will explore these consequences further below. Besides design choices, in practice deliberation is also influenced by time constraints and other non-ideal conditions such as the burden of disease and patients' competences. Project teams placed, for example, lots of effort into including a broad range of patient views, which deliberative democracy literature encourages (Held 2006). Over time, however they were limited by the patients' ability and willingness to participate. Also, the participants' ability to conduct discussions and reflect on other points of view was sometimes limited in practice, which resulted, for example, in patients overshadowing the staff perspectives. Partly, these non-ideal situations are a given. However they are also caused or intensified in part by the choices made in the design of the method.

The results of our study show that design choices have three types of implications. First, many choices made for practical reasons (e.g. time constraints or not wanting to overburden patients) limited the depth of the deliberation taking place. This happened in terms of deliberation both intra (within) groups and inter (between patients and staff) groups. For instance, in one hospital, staff were not given the opportunity to formulate and communicate their improvement themes to each other or to patients in the quality

improvement process. In another case only staff prioritized improvements based on the patient film. In these examples, there was no exchange of different actor perspectives. As hearing and discussing other points of view is necessary to reflect on one's own opinions (Held 2006; Krause 2008), participants could not always review or change their preferences. Consequently, these design choices led to one-sided and not joint deliberation and prioritization processes. Leaving decisions to only one party (staff) in the context of healthcare quality improvement runs the risk of not fully meeting patients' needs (Boivin 2012). Similarly, difficulties can arise for professionals embedding improvement solutions, if only patients promote a certain change. One example showed that jointly selected improvement themes based on limited deliberation did not always lead to consensus on prioritization, as the participants' had different perceptions of their ability to solve or control a quality improvement theme. This means that not only design choices but also other (contextual) aspects influence deliberation and prioritization processes.

Second, choices made to emphasize the impact of experiences (e.g. by only including negative experiences or inspiring stories in the film) influenced the role of affect within deliberation. As described earlier, the use of affect in deliberative practices is much debated in the literature (Held 2006; Krause 2008). According to impartialists' standards, the quality of deliberation in EBCD is flawed in nature since true deliberation should rest on dialogue that is free of emotion. EBCD deliberately promotes the use of personal feelings and narratives in deliberative debates as this exposes experiences and perspectives (Bate and Robert 2007). An understanding of these perspectives is necessary to be able to identify and implement improvements in experiences of care (Adams et al. 2015). Also, affective communicative styles could help include more diverse views in deliberation practices. They could result in a better understanding of other perspectives, help in deciding on a course of action, and also be an incentive to take action (Krause 2008; Sanders 1997). Affect is thus important to deliberative practices. However, it can also pose challenges, especially if design choices emphasize certain kinds of emotion. For example, including only 'negative' or 'inspiring' experiences in the film directed how the improvement themes would be perceived. Such choices could lead physicians and patients to question the validity of the film (Adams et al. 2015). Also, because of the strong impact of some emotions, accentuating patients' stories especially, an affective communication style risks overlooking the professionals' views. These examples show that emotions not only stimulate but can also hinder deliberative improvement practices. It is important to be aware of such challenges when making design choices.

Third, choices made by project teams had an impact on whose voices were heard in the process. The participation literature has long recognized that not all citizens or patients are able and/or willing to participate (Van de Bovenkamp 2010). Proponents of deliberative democracy acknowledge this as well (Held 2006). This (in)ability to participate is often discussed from a *participant's* point of view. Our results indicate, however, that *design choices*

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influence participation opportunities as well and determine whose voices are heard in the deliberation process. Project teams' choices that are made to limit the burden on patients, to emphasize the impact of experiences, and for practical reasons, steered participation opportunities by *including* or *excluding* participants' stories and attributing a certain weight to these stories. In making these design choices, project teams also influenced the selection of quality improvement themes. This was most clearly shown in the compilation of the film. The choice of one of the hospitals to only include unanimously shared improvement themes in the film left a large portion of the improvements selection to the project team: they decided that the total number of similar patients' experiences was key in decision-making and not, for instance, the impact on healthcare quality. The described consequences indicate that the power of a project team should not be underestimated and that power differences not only occur between participants (patients and staff) (Held 2006), but also between participants and project teams. Project teams' choices influenced target group representation and tailored the participants' input, thereby limiting the exchange of different perspectives in discussions.

To conclude, our findings confirm the gap indicated in the literature between ideal deliberative methods and the practical implementation in which many design choices are made (Street et al. 2014). As stated before, design and implementation choices are insurmountable and even necessary in deliberative practices (Street et al. 2014). Also, especially in healthcare, choices have to be made which will result in deliberation taking place under non-ideal circumstances. In this paper we wanted to contribute to this body of literature by highlighting such choices and reflecting on the consequences these might have for deliberation possibilities and healthcare quality improvements. We have shown that in practice design choices made limit the depth of deliberation taking place, influence the role of affect within deliberation, and influence whose voices are heard in the process. Consequently, the choices influence which quality improvement themes and solutions are selected: certain improvement themes are not taken up and improvement solutions could have been shaped differently. Whether the improvements have met participants' expectations and contributed to improved quality of care is therefore open to debate. It is the very question deliberation could have answered as it tries to capture in-depth and informed perspectives on complex matters to reach informed and good quality decisions (Held 2006). Organizers of deliberative processes that want to stimulate deliberation to enhance the quality of care should therefore make design choices that keep deliberation aspects intact as much as possible. Within the EBCD method, this is for example possible by adapting the first phase, a format also known as 'accelerated' EBCD (Locock et al. 2014). Participation methods for quality improvement that foster deliberation, such as EBCD, have the potential to provide more in-depth knowledge on experiences of patients and staff with healthcare services compared to, for example, quantitative surveys (Bate and Robert 2007). However, the above results illustrate that it is still important for organizers and researchers involved in improvement

practices to reflect on the data gathered through these methods, because design and implementation choices have consequences for which experiences and perspectives come to the fore and which are silenced. Future research should focus more on integrating such reflection processes within deliberation practices that aim to improve the quality of care.

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DISCUSSION & CONCLUSION

CHAPTER 7

The interacting patient in quality improvement initiatives

BRAM'S PARTICIPATION POSSIBILITIES

"Every healthcare institution should be open for the experience of the patient. Not only to prevent errors, but also in cases where a mistake is made. The patient is a vital link in the evaluation of the care process. It is also important that patients become more aware of their role in this respect." (Edith Schippers, Dutch Minister of Health, Welfare and Sport. Parliamentary letter, June 12, 2014).

The Introduction of this PhD research started off with Bram, a 42-year-old palliative patient who participated in healthcare quality improvement initiatives by carrying out online health activities and by sharing his personal care experiences with the hospital department where he was treated. His willingness to participate fit perfectly within the policy impetus of the Netherlands and other Western countries to emphasize and increase patient activities in the healthcare quality domain, also reflected in the above quote from the Dutch Minister of Health. Quality improvement is no longer perceived to be just the work of healthcare professionals alone (Boivin 2012; De Vos 2014).

The Introduction detailed the various assumptions that exist regarding the possibilities for patients like Bram to become active in healthcare quality improvement. It showed that distinctions between participation levels (i.e. macro, meso, micro), forms (e.g. consulting, partnership) and methods (e.g. interviews, focus groups, EBCD) provide more clarity about the possible roles and activities patients can perform, yet do not show how active patient-ship is actually given form in complex healthcare practices. From a constructivist point of view it can be argued that active patientship is not a fixed social phenomenon that occurs naturally, but that it is continuously constructed by patient interaction with other human and non-human actors, such as technologies, within specific contexts. Since there was insufficient knowledge on how these interaction processes flourish in quality improvement practices that try to enhance patient activities, and on what the consequences of these interactions are for becoming active, this PhD research focused on answering the following research question:

How is active patientship constructed in quality improvement practices and to what effect?

This question was answered by means of a qualitative study (Bowling 2002; Creswell 2003) into patient participation processes in two quality improvement initiatives at the micro level of Dutch healthcare. A focus on participation processes made it possible to capture various forms and shapes of active patientship in quality improvement initiatives over time and it provided knowledge on how they were formed by patient interaction with the context. The initiatives related to the development and use of a new health IT (i.e. a website with online health communities) and the active involvement of patients in hospital service improve-

ments through a participation method that was new to hospitals. The reasons for selecting these initiatives were that they presented new ways to involve patients in healthcare quality improvement and they provided insight into the latest expectations concerning active patientship.

In this concluding chapter, the results of this study will be discussed in further detail. First, an analysis will be given of how patient interactions with other human and non-human actors construct active patientship in practice. Subsequently, by zooming in on six different tensions, the consequences of the construction practices will be illustrated. In addition, the theoretical, methodological and practical implications of the research findings will be elaborated. This concluding chapter will also offer suggestions for further research.

THE CONSTRUCTION OF ACTIVE PATIENTSHIP IN QUALITY IMPROVEMENT INITIATIVES

In both quality improvement initiatives, patients were expected to be(come) more integrally involved in care-related activities in partnership with healthcare professionals, family members and/or (patient) peers, thereby co-designing their own healthcare and the healthcare of others (see Chapters 2 to 6). Various aspects, discussed below, influenced the extent to which patients succeeded in fulfilling these expected co-design roles.

Active patientship in quality improvement initiatives starts with the patient's willingness to become active and the healthcare professional's readiness to provide room for this active involvement. The patients in this PhD research were willing to participate, although, as will be discussed below, they did not want to be preoccupied with their illness(es) every day. The readiness of healthcare professionals proved to be positively influenced by governmental policy such as a market-based healthcare system (Chapter 5) and national trends such as the need for more patient-centeredness and the call for less fragmentation of healthcare services (Chapters 2 to 4), because in the first place, these were all reasons to (voluntarily) initiate the quality improvement initiatives in which patients were expected to participate. These trends can in fact be perceived as soft steering objects (Bang 2004): the national attention for these trends *steers* actors in such a way that eventually they *want* to participate in quality improvement initiatives. Discourses of active patientship shape quality improvement initiatives by including patient involvement as simultaneously optional and obligatory (Singleton 2005): they feed the moral imperative that patient involvement is something that ''good professionals'' will want to strive for. Despite governmental policy and trends, some healthcare professionals did however still need some encouragement to enlarge their readiness. This became, for example, visible in Chapter 5, which showed that some staff members needed to be convinced to join the hospital departments' initiative because they feared being criticized by patients on their care delivery. Without one very im-

portant aspect of the construction of active patientship, i.e. the willingness of both patients and professionals, it is unlikely that the expected co-design roles will unfold. However, it is not the only aspect that matters.

Besides willingness, the professional's ability to facilitate active patientship and the patient's ability to be(come) active also matter. The former will be discussed first. The professional's ability to facilitate active patientship in quality improvement initiatives refers primarily to the time available to the professional to carry out the initiatives. Chapters 4 and 5 both illustrate that professionals perceive themselves to be under a lot of work pressure and see co-designing healthcare with patients and participating in online health communities as additional pressure. Although within the initiatives studied, sufficient motivation compensated for this lack of 'official' time, professionals indicated that financial policies (such as fee-for-service systems) and societal trends (such as negative representation of doctors in the media) could be an obstruction in the future, consequently affecting the professional's readiness. Policy practitioners should be aware of the influence of policies and national trends since they not only stimulate (see above) but may also hinder, i.e. they may 'construct' or 'deconstruct', active patientship.

However, the most complex construction activities relate to the ability of patients to be(come) active. Possibilities for patients to be(come) active turned out to be highly dependent on the design of the quality improvement initiatives; in both case studies these were mainly in the hands of a few healthcare providers and/or managers, who were the initiators of the initiatives. They appropriated the leadership of the design and made various decisions regarding the "lay-out". In the health IT initiative, for example, these decisions concerned the selection and design of various website functionalities; in the hospital departments' initiative decisions included choices about patient recruitment procedures, priority selection processes, and decision-making procedures. Some of these decisions immediately excluded patients from participating in the quality improvement initiatives (e.g. recruitment procedures or the difficulty level of technology), thereby getting in the way of patients fulfilling an active role (see Chapters 2 and 6). Other decisions influenced the nature and degree of patient activeness (see Chapters 2, 3 and 6).

The nature and degree of patient activeness was, among other things, influenced by choices that led to participation designs requiring patients to have various competences and skills, including technical computer skills (e.g. the ability to use different features within online health communities), information skills (i.e. to search, find, critically analyze and process various sources) and the ability to reflect (e.g. to evaluate one's own opinion after hearing and discussing other points of view, or to translate information to their own healthcare context), see Chapters 2 and 6. These essential skills, inscribed within the initiatives by the initiators, and therefore context specific, included and excluded patients from participation. In addition, they influenced the specific types of activities that (included) patients could perform within the initiatives, depending on their level of skills and competences. The nature

and degree of patient activeness was furthermore influenced by initiators' adaptations to existing participation methods (see Chapters 5 and 6). These adaptations steered the participation forms as well as the moment and duration for patients to participate. For example, within the hospital departments initiative, one hospital's project team adapted the selected participation method EBCD in such a way that patients could only emphasize the importance of certain improvements, since design choices changed the joint prioritization, selection and realization of improvements into a solo activity performed by staff. As a result of this choice, patients were, for instance, unable to emphasize which improvement themes they found most important. By making design choices and adapting participation methods, the initiators of the quality improvement initiatives thus predominantly controlled the interpretation of active patientship (Armstrong et al. 2013; Fudge et al. 2008); they decided if, when and how patients could become active. In other words, they steered the roles patients were expected to fulfill, the possibility for patients to fulfill these roles and, consequently, the results of participatory practices.

This is an interesting finding, because although design choices and method adaptations could derive from best intentions (e.g. to lessen the burden on patients, see Chapter 5), such control in fact goes against some of the arguments for active patientship presented in the Introduction chapter, such as improved democratic decision-making (Van de Bovenkamp 2010) and a re-distribution of power within the doctor-patient relationship, so that not only doctors govern and decide (Harrison and Mort 1998). In fact, an initiator's ability to steer patient activities and, with that, the results of participatory practices, could even undermine the argument of improved healthcare quality, as it raises the question of whether the refreshing (experiential) patient perspectives on healthcare services were actually included. The employed control of healthcare professionals is thus on strained terms with the various motivations for active patientship.

Active patientship within the quality improvement initiatives was, however, not solely constructed by governmental policy, national trends and initiator choices. It was also shaped by how technologies were designed and how patients reacted to and interacted with these technologies. This is carefully phrased here because there often seems to be an assumption that technologies steer individual behavior (as is for example shown by Wyatt 2008), however the technology in question (i.e. website, film) itself never purely determinant because it reflects choices made by designers (Akrich 1992; Oudshoorn et al. 2004) and is also influenced by practices of use and non-use (Wyatt 2003). An example showing that patients' interactions with technologies construct active patientship, is the finding that due to some technicalities (e.g. the complicated log in process), some patients deliberatively continued the exchange of information outside the website (see Chapter 2). Although the goal of becoming active is then arguably achieved, by performing it in another place or online space (e.g. by meeting face-to-face or using regular e-mail contact) it is a different type of active patientship than envisioned by the designers. It made the exchange of experiences

and information less visible for other patients; it therefore limited the expected collective role of co-designing healthcare of others.

The existence of different types of active patientship also became apparent when designers changed the layout of the website because patients used a technological feature differently than intended (see Chapter 2). Also in this example patients gave significance to their active role, however, this role did not correspond with developers' visions. It illustrates that if patients are given the responsibility to participate, their activities can result in different (unintended) consequences.

The above shows that being/becoming active as a patient is a very complex process. It is steered through the interactions of patients with various other actors (i.e. managers, professionals, peers) in a specific context, and these interactions can be mediated (i.e. transformed or steered) through governmental policy, national trends and technologies such as websites (Wathen et al. 2008). This finding suggests that active patientship only reaches its full growth after various performative actions, behaviors and competences; through this construction active patientship becomes a reality. Consequently, active patients alone will not lead to healthcare quality improvements; it requires hard (kneading) work from various actors within the context. In the following paragraph the consequences of the construction of active patientship will be discussed.

CONSEQUENCES OF CONSTRUCTION PRACTICES: ELICITING TENSIONS

The aim of this PhD research was to not only describe how active patientship is being constructed, but also to explore the consequences of these construction processes. The processes created various tensions and based on this research, six tensions can be identified. The tensions are between: quality improvements and alterations; expert knowledge and experiential knowledge; de-professionalization and re-professionalization; enabling and constraining participation; individualism and collectivism; and being a patient and being a person. Each of these tensions, and their practical implications, will now be described.

Quality improvements and alterations

Within the studied initiatives, active patientship was encouraged for the achievement of healthcare quality improvements. Whether improvements were actually realized, depends on how quality is defined. Despite numerous efforts, no general agreed upon definition of quality exists in the literature (De Vos 2014). Therefore, the focus is on how it was defined within the initiatives. Quality improvements in the health IT initiative meant increased opportunities for patients to actively participate in their own healthcare, better collaboration between healthcare professionals and between healthcare professionals and patients, and

a more patient-centered healthcare system. In the hospital departments' initiative, it meant that hospitals improved their care delivery on the basis of patient experience.

By following these definitions, the results of this PhD research show that quality improvements were realized in both case studies: patients could actively participate in their own healthcare by carrying out various medical, emotional and lifestyle activities on the website (see Chapter 3) and in the hospital departments initiative, for example, patients' experiences led to the development of an information leaflet about dental care during treatment for cancer (see Chapter 6). In the health IT initiative, improved collaboration and patient-centeredness had not been experienced yet but was very much expected in the future (see Chapter 4). However, the way active patientship was constructed, limited the quality improvements. For instance, in the health IT initiative quality improvements were only reserved for a select group of patients because design choices excluded or limited patients lacking adequate skills and competences in their use of the website (see Chapter 2). Moreover, the question could even be raised whether improvements were actually achieved or whether changes were just alterations. For example, design choices by project teams in the hospital departments' initiative (such as excluding patients from prioritizing improvement themes) sometimes limited patients in voicing their experiences and opinions and raised questions about the representation of patients' experiences in quality improvements (see Chapter 6).

As discussed above, the construction of active patientship, for example, through design choices could therefore be at odds with improved healthcare quality. To determine whether improvements have been achieved and for whom (quality improvements can also differ per person), it is important to involve patients not only during the quality improvement initiative, but also in the evaluation of the quality improvement process. Such an evaluation provides the opportunity to check with participants whether and how they perceive implemented changes, and to adjust them accordingly. Celebrating successes at the end of an improvement process, as is incorporated in the EBCD methodology (Bate and Robert 2007), could be a way of carrying out this activity. Such an event not only provides the possibility to discuss the process, it also demonstrates the value of the project and gives participants insight into what they have accomplished.

Expert and experiential knowledge

A second identified tension is the one between expert and experiential knowledge. By encouraging a more active role for patients in healthcare quality initiatives, the existence of a difference between patients' (lay) knowledge and professionals' (expert) knowledge became very prominent. For example, the health IT initiative showed that patients often specifically preferred the expert knowledge of professionals because of its reliable status (see Chapter 3). As this type of knowledge is often limited to evidence-based medicine, patients unintentionally maintained a bio-medical perspective of disease (i.e. a perspective

in which emphasis is mainly placed on the physical aspects of disease), though they reported a need for a broader biopsychosocial perspective on disease (i.e. a perspective which takes also the social perception of illness and quality of life into account), see Chapter 3 (Kleinman 1980; Bensing 2000). Because of the need for this biopsychosocial perspective, patients did value the availability of experiential knowledge from peers on the website as well, since this provided a broader view on their illness. Within the hospital departments' initiative, healthcare professionals valued patients' experiential knowledge because it functioned as an eye opener: it showed what the impact of (already known) problems really was on patients. Healthcare professionals used this knowledge to complement their own to realize quality improvements. The above shows that the sum of patients' and professionals' knowledge can be perceived as an advantage; however, its assemblage also caused tensions. This became apparent in the health IT initiative, for example, where both types of knowledge were present on the website and some patients incorrectly assumed that professionals had checked all written information (see Chapter 3). Patients could consequently perceive lay knowledge as reliable expert knowledge, with consequences for the value they assigned to this information. Within the hospital departments' initiative, for example, a tension became apparent when some healthcare professionals were reluctant to participate in the quality improvement initiatives because they were afraid that inviting patients to elucidate their lay experiences would only result in criticism of their healthcare provision (see Chapter 5).

The assemblage of expert and experiential knowledge therefore can lead to tensions, especially when the value of each type of knowledge is unclear. In such cases, providing more clarity on the value is important as the tensions may influence the ability of patients to perform activities and/or the impact of those activities, with consequences for the prospects of achieving quality improvements. Regular engagement in dialogue with all participants by initiators of the quality improvement initiative is a way to explore the possible tensions between expert and experiential knowledge. If tensions are perceived, initiators can help to clarify the value of each type of knowledge, for example by stimulating dialogue between participants.

De-professionalization and re-professionalization

A third tension that arises due to the way active patientship is constructed is a tension between de-professionalization and re-professionalization of healthcare professionals. This tension is best explained by further elaboration on the existence of two domains in health-care: a biomedical domain and a biopsychosocial domain (Kleinman 1980, Bensing 2000). Through the various activities (expected) from patients (e.g. searching for health information, keeping an online health record and diary, voicing experiences with health services, selecting healthcare improvement themes), patients became more involved in the biomedical domain of healthcare and gained more influence on health services (see Chapters 2 to 6), while healthcare professionals became more involved in the biopsychosocial domain of care (see

e.g. Chapter 4, where physicians not only have to take the physical but also the emotional aspects of care into account), and had to share responsibilities that previously belonged to them. Therefore, the active role of patients brought the two domains closer together, however, it also changed the profession of doctor. On the one hand, this change stimulated professionals' perceptions of de-professionalization because lay perspectives enter the medical domain and sharing responsibilities effects professional autonomy. On the other hand, it stimulated professionals' perceptions of re-professionalization because it opened up the possibility to reach better decisions that also pay attention to the social context in which patients have to act. This PhD research showed that sometimes 'work' by different actors was needed for professionals to perceive it as re-professionalization (i.e. possibility to attune care to the wishes and demands of patients) instead of de-professionalization (lay perspectives entering the medical domain) (see Chapter 5).

The above illustrates that the professionalization processes of physicians are not in the hands of the healthcare professionals alone. Healthcare professionals must realize that when they try to change patients' roles in healthcare, patients can, in turn, change professionals' roles as well. In this way, not only patients' roles but also healthcare professionals' roles become constructed by interactions in practice. This finding is confirmed by the work of Dwarswaard (2011), who nicely illustrates the relationship between changes in medical professional ethics and a changing healthcare context.

Enabling and constraining participation

A fourth tension triggered by the construction of active patientship, is the tension between enabling and constraining patient participation. The quality improvement initiatives were aimed at enabling patients to become active in healthcare. However, at the same time the results of this PhD research illustrate that the initiatives were shaped by governmental policies, national trends and social actors whose steering and selection activities had consequences for *who* was allowed and able to participate (see Chapters 2, 3, 5 and 6). Through their construction activities, for some patients participation became constrained.

As described above, active patientship is shaped in interaction with other human and non-human actors in situ. This suggests that there is no (fixed) patient participation ceiling. The possibilities for patient participation differ per patient and are dependent on a) the required participation competences, b) the presence or absence of these competences with which the expected activities can be performed, and c) the facilitation (or even education) of these competences by actors and technologies within the context. Examples of actors are doctors who provide room for patients to tell their experiential stories. Examples of technologies are websites that support patients seeking health information or films that bring the patient experience dramaturgically well into the limelight. These and other aspects determine whether patients are enabled or constrained to participate effectively. Initiating

quality improvement initiatives aimed at enabling patients to participate is therefore essential but not conclusive for patients to become active in healthcare.

Individualism and collectivism

A fifth tension identified in this research is that between individualism and collectivism. This refers to the fact that patients were expected to become more involved in their own health and healthcare treatment, but simultaneously in the healthcare of others as well. This required a dual task of the design of the quality improvement initiatives. The design had to appeal to both the individual and the individual as part of a collective. The hospital departments' initiative showed that interviews with individual patients followed by a patient event where all patients come together and discuss improvement themes, as the EBCD method prescribes, is a way to facilitate both patients' individual involvement and the integration of individuals into a collective (see Chapter 5). In the health IT initiative, especially patients participating for the collective benefit of others seemed more difficult to realize. The example of continuing the exchange of information and tips with peers outside the website because of convenience illustrates this (see Chapter 2).

If the quality improvement setting is insufficiently appealing for collective action, patients' individual activities may also be insufficiently rewarded, in the sense that responses to patients' questions or stories remain absent, which may discourage future contributions. As this limits the quality improvement potential for patients, it is important to be aware of the possible dual task that needs to be realized by a specific design when developing quality improvement initiatives. This also means that when choices or method adaptations are being made, this dual task must be taken into account as well.

Patient and person

A last identified tension triggered by the construction of active patientship is the tension between being a patient and being a person. As described above, the patients in this PhD research indicated that they liked carrying out (the expected) activities to improve their own healthcare or that of others, but they did not want to be preoccupied with their illness(es) all the time (see Chapters 3 and 4). Therefore, patients sometimes just (actively) wanted to choose to not be active in healthcare quality improvement for a moment, and 'just' be a 'person'. This corresponds with findings from Henwood et al. (2003), Trappenburg (2008) and Van de Bovenkamp (2010) that not all patients (always) want to participate, which will be discussed in more detail below.

This tension between being a patient and being a person has implications for the design of quality improvement initiatives. It means that the look and feel of the initiatives is very important. When the look and feel appeals to people's feelings of citizens participating in society, it might stimulate more activities in contrast to initiatives that appeal to people's feelings of being a patient. When developing quality improvement initiatives, asking

participants how they would like to be addressed and making an effort to incorporate this into the design, is highly recommended.

To sum up, the construction of active patientship has consequences not only for patients (i.e. the opportunity to become active and the sense of being a person), but also for the achievement of quality improvements, for the value attributed to expert and lay knowledge, for professionals' roles and for design requirements. Although the words *active patientship* only refer to patients, these consequences show that active patientship actually has a broader meaning, as it involves many different aspects of healthcare (e.g. health IT, professionals' roles, etc.). *Active patient system* might therefore be a more suitable term to use when referring to a more active role of patients in healthcare quality improvement.

STUDY IMPLICATIONS

Theoretical implications

This PhD research reveals that patients possess some degree of autonomy over their actions, but that these actions are also steered by patient interaction with other human actors such as healthcare professionals and with non-human actors such as policy and technologies. Together they shape active patientship in practice. This finding has several theoretical implications.

The first implication is that active patientship is par excellence situation-specific: it depends on the human and non-human actors concerned who are present and interact. It is important to be aware of the fact that these human and non-human actors do not always have to be physically present during participation processes, as their influence sometimes crosses levels (i.e. micro, meso, macro) of the healthcare system. This situation-specificity also suggests that the boundaries of patient participation are drawn during mundane interactions of patients with other human actors and, for example, technologies. Boundaries are thus not only created by the (limited) possibilities of patients to manage their ability and willingness to participate, but also by efforts in the context of stimulating and facilitating active patientship. As described above, this means that there is no (fixed) patient participation ceiling: the possibilities of active patientship are created in interaction. It also means that the limits of patients' power (Van de Bovenkamp 2010), as discussed in the Introduction, vary per patient and for each patient in each situation.

Another implication of the construction of active patientship is that there are more distinctions to be made than between 'active' and 'passive' patients. This research has shown that a variety of activeness exists in between these extremes. It also showed that patients could carry out a different kind of active patientship than envisioned by designers. By making design choices or adapting technologies, designers of quality improvement initiatives are

able to steer the forms of active patientship they would like to stimulate. Designers can thus purposefully make use of 'mediators' such as technologies (Wyatt et al. 2008) to increase or limit patients' voices and activities. The power of designers to effect change shows that they can have a significant influence on the realization of active patientship. However, it should be noted that patients' reactions to and interactions with technologies also steer patients' activities, which suggests that designers' steering activities through mediators such as technologies can also have different results than intended.

Methodological implications

This research focused on a specific aspect of active patientship, that is, active patientship in quality improvement initiatives at the micro level of healthcare. 'Zooming in' on quality improvement initiatives at this specific level of healthcare has helped understanding and re-presenting practice (Nicolini 2009). Through this methodological focus it was possible to gain in-depth knowledge on how active patientship is constructed within this specific context.

The finding that within different 'places' of participation processes, i.e. online health communities and hospital departments, active patientship is constructed by different human and non-human actors, suggests that these construction practices also take place in other micro level healthcare contexts where patients are expected to become active. This suggests that this result is also generalizable to other situations (Mortelmans 2007), such as nursing homes. The fact that client councils at meso level and patient organizations at macro level, despite their legally embedded activities, are not always able to fulfill their roles (Van de Bovenkamp 2010; Zuidgeest et al. 2011), suggests that, also at levels other than the micro level of the healthcare system, active patientship is interactively constructed. When considering again the previously discussed theoretical implication that different types of activeness exist due to construction practices, it might be more fruitful to legally embed participation processes at these levels, instead of specific patients' activities. Future research could explore in-depth how construction activities unfold in other places and at other levels to develop a broader understanding of active patientship.

In addition to 'zooming in' on these specific places and levels to explore how construction activities unfold, future research must also 'zooming out' of practice (Nicolini 2009). This suggestion is based on Chapter 5, which touches upon aspects relating to a broader healthcare context that might influence the construction of active patientship in the future. An example is the current fee-for-service system in the Netherlands. Healthcare professionals indicated that this financial policy had not influenced their readiness to participate in the studied quality improvement initiatives, but that it might hinder it in the future when this system is not changed into a different system (such as pay-for-performance where the emphasis is not on time but on performance results). By re-positioning the focus of the research and including different levels and places, it is possible to include these potential

influential aspects and to explore all aspects that influence the construction of active patientship, as well as its evolving nature.

In considering methodological implications, it is also necessary to reflect on the role of the researcher. As a researcher, I had to continuously balance between distance and proximity. In the field, I was often expected to collect data from an appropriate distance by being a 'fly on the wall': i.e. observing in the background, but not actively participating as a researcher. For example, during focus group meetings with patients or staff in a hospital department, the project team intentionally positioned me outside the circle of respondents for me to literally observe from a distance. However, at the same time, field parties frequently expected me to give up my distance in order to provide feedback and facilitate reflection. In the health IT initiative I was, for instance, asked to reflect on my research findings by presenting my results in an evaluation report and presentation. In the hospital departments, the project teams consulted me for tips on intended design choices. Also, during project team meetings, questions were asked like 'did we forget anything?'. These requests asked for proximity and empathy with the initiatives. This made the 'fly on the wall' role difficult to enact, if not undesirable to hold on to. These examples show that like active patientship, the role of a researcher is co-constructed by different actors in practice (Schwartz-Shea and Yanow 2012). Moreover, it is likely that in my role as a researcher I have influenced the construction of active patientship. During this PhD research I have continuously searched for an appropriate balance between proximity and keeping a distance. I have recorded these moments in a diary-like fashion, which helped me to reflect on my own position and on how my persona may have affected the research setting (Mortelmans 2007). In doing so, I realized, for example, that by informing project teams about the results accomplished within other participating hospitals, I could have induced feelings of 'lagging behind' or being 'on schedule'. These feelings might have influenced project teams design choices that limited time but also influenced patients' participation possibilities. In addition to reflection notes, I also made use of various methodological instruments including peer-review and triangulation, to critically assess the research findings (Mortelmans 2007).

General practical implications

Quality improvement initiatives that facilitate patients' activities such as the development of health portals (Otte-Trojel 2015), "share-your-experience" websites (Adams 2011), and "ask 3 questions" campaigns[5] (NPCF 2015), are often developed with the idealized view that they directly support patients in taking on an active role. However, this PhD research has shown that this structural-emphasis perspective (De Vries 1995), i.e. the perspective

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5   Ask 3 questions campaign refers to the questions 'What are my possibilities?', 'What are the advantages and disadvantages of these possibilities?' and 'What does it mean in my situation?', that patients need to ask according to the federation of medical specialists and of patients in order to receive proper information.

that structures, such as technologies[6] and rules, are dominant and can solely steer human activities, does not confirm how active patientship works out in practice. Active patientship is constructed in situ through various interactions between patients and other actors, which can be mediated through technologies, governmental policy and national trends. Consequently, active patientship does not unfold through, for example, the existence of a website that aims to stimulate patient involvement in healthcare quality improvement; it involves work. Based on this PhD research, a number of general recommendations related to this work can be provided for initiators of quality improvement initiatives, policy makers and CEO's of healthcare institutions to help facilitate patients like Bram, who may be willing and able, to be(come) active in healthcare quality improvement.

For *initiators* (e.g. healthcare professionals and managers) of healthcare quality initiatives aimed at involving patients, it is important to be aware of how their work can influence the possibilities for patients to be(come) active. This PhD research has shown that the design choices and method adaptations of initiators have implications for who is able to participate and how. Consequently, initiators can also influence the results of participation processes. Reflection on initiators' choices is therefore needed. Reflection moments could, for example, be scheduled during progress meetings of project teams. However, in order to fully understand and anticipate the consequences of choices it is also important to involve patients within the design process, especially in relation to the development of health IT.

In addition, initiators should be aware of the fact that various types of active patientship can exist. These will not always resemble the types of activeness they envision. For example, patients can perform activities (e.g. asking questions) that initiators anticipate but in unintended places. Involving patients in the design of quality improvement process is one way to become aware of these different types of activeness, and, when necessary, to steer them in deliberate ways.

For the work of *policy makers* it is interesting to know that national policy reforms, such as the introduction of a market-based healthcare system, positively influence the healthcare professional's readiness to facilitate active patientship at the micro level of healthcare (see Chapter 5). At present, this policy can therefore be regarded as effective. However, the research findings also suggest that its effectiveness could be limited in the future due, among other things, to how other policies, such as healthcare financing structures are arranged. Policy makers should therefore pay close attention to the coherence of different policy proposals, because in the absence of complementation they might obstruct active patientship.

For policy makers it is also important to know that besides patients who are not able and willing to participate in healthcare quality improvement, there are patients who are willing and able, but who do not want to be preoccupied with their illness(es) all the time.

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6   When structures only concern technology, this way of thinking is also known as 'technological determinism' (Akrich 1992; Oudshoorn and Pinch 2003).

They also want to feel like 'just' a 'person'. Currently it is unclear how much room healthcare policy provides to patients to opt-out or decide on the moments in which they do or do not want to be active; after all, active patientship is encouraged not only to improve healthcare quality but also to achieve other policy goals, such as lessening the burden on healthcare systems by letting patients do more themselves. In future, policy and scientific research could pay more attention to this issue as well as to the question how active patientship relates not only to these policy goals but also to people's identity (i.e. perception of being a patient or a person) and quality of life.

A last recommendation is related to the work of the *CEOs of healthcare institutions*. Patient experiences are a source of knowledge for CEOs. They provide information (in a different way than indicators, for example) on the specificity of care practices, which is of increasing importance for the legitimacy and effectiveness of management (Putters 2009). Within this PhD research, CEOs of the participating hospitals provided room for patients to elucidate their knowledge and to participate by supporting the quality improvement initiatives, for example, through the facilitation of meetings and the reimbursement of film editors. However, they also limited the results of patient participation processes, for instance, by making other (hospital wide) prioritizations (see Chapter 6). It is part and parcel of the work of CEOs to weigh different interests and to set priorities (Putters 2009) and it is evident that not all the patient's wishes can be fulfilled. It is therefore important that CEOs know at the beginning of such quality improvement projects what the purpose of patient participation processes is, and that they communicate this purpose to all participants. This way, the expectations of all involved members, including patients, regarding active patientship and possible quality improvements, can be better managed.

CONCLUDING REMARKS

The quality improvement potential of 'active patients' as discussed in the introduction is not an inherent capacity of patients; it requires hard work between patients and other actors in situ, especially from healthcare professionals and initiators of quality improvement initiatives. It is through their (inter)actions, which can be mediated through technologies, governmental policy and national trends, that active patientship becomes into being and quality improvements can be achieved. This makes the specific healthcare context in which patients are expected to participate very important. It also means that active patientship and thus the various roles that patients can perform in quality improvement initiatives are situation-specific. This shows that it is important to not talk in generic terms about active patientship.

Looking to the future, it is likely that healthcare delivery remains 'shared work' (Mol 2008) and that health technologies continue to develop. To stimulate and facilitate active

patientship in such a context, it is crucial to pay attention to above described interactions. In addition, it is important to be aware of the fact that the stimulation and facilitation of active patientship not only has consequences for patients but also for other aspects of the healthcare system. For example, it changes the roles of healthcare professionals and demands specific design requirements from health IT. This suggests that 'active patient system' might be a more suitable concept to use when referring to a more active role of patients in healthcare quality improvement.

If initiatives that stimulate a more active role for patients are designed to improve the quality of patients' own treatment and healthcare or that of others, and the healthcare context in which a patient is expected to participate does not easily facilitate active patientship or a patient is not willing or able to participate, this needs not necessarily be a problem when participation is expected to be a one-off. However, this is different if participation is structurally assumed, especially when patients have to keep themselves or others informed through online health communities and have to inform their doctors by keeping a personal health record. In such cases, not being able or willing to participate can have a negative effect on the quality of care that (other) patients receive. This, in turn, leads to quality differences between patients who can fulfill an active role and patients who cannot or will not. As this research, as well as prior research (e.g. Van de Bovenkamp 2010; Trappenburg 2008), has illustrated that not every patient is willing or able to participate (all the time), albeit through reasons that relate to patients themselves or their context, there should remain opportunities for patients to opt-out from participation (or for them to say in Trappenburg's (2008) words 'enough is enough'). Solutions need to be developed to ensure that in such cases patients can still receive an adequate level of care.

Considering active patientship as a collective endeavor of various human and non-human actors is an important step towards developing a better understanding of active patientship in practice. It means that in order to facilitate patients to become active, focus should not be only on patients like Bram who may be willing and able to participate, but also on the human actors (e.g. healthcare professionals) and non-human actors (e.g. health IT) present in a patients' specific healthcare context.

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SUMMARY

The promotion of active patient participation in healthcare quality improvement projects is an important policy goal in the Netherlands and other Western countries. Healthcare quality improvement is no longer perceived to be an exclusive professional activity; patients, who may be able and willing to participate, are also expected to assume an active role in this respect. For example, they are expected to be actively involved in the improvement of their own healthcare by searching for relevant health information on the Internet and in the healthcare of others by sharing their thoughts with healthcare professionals on how to achieve health service improvement solutions. This book explores how the active role(s) of patients are shaped in these quality improvement initiatives and what this means for the activities expected from patients.

Chapter 1 describes the attention for a more active role of patients in healthcare quality improvement. It shows that in the debates on active patientship, different assumptions exist as to the types of roles patients can fulfill and what their activities can bring about. On the one hand, the added value of patient involvement is emphasized with arguments such as how the patient's unique experiential knowledge could provide a fresh and complementary perspective on the professional's point of view, and how patient activities can function as an incentive for professionals to improve their services. On the other hand, however, there are also critical opinions that pinpoint issues such as the instrumental use of active patientship by healthcare organizations and the burden that being/becoming active can pose on patients.

Current overviews in literature aimed at providing more clarity on the possibilities of active patientship in healthcare quality improvement – such as a distinction between different participation levels, forms and methods – give insight into the multifaceted nature of active patientship. Chapter 1 shows, however, that in-depth studies of patient participation processes are needed to really understand how active patientship is shaped in the messiness of everyday practice and what this means for the roles and activities expected from patients. This PhD research is focused on these participation processes and specifically on those processes that take place at the clinical micro level of healthcare: the level at which individual patients interact with their own healthcare professionals. This level is, among other things, interesting for studying participation processes because it is at this level in particular that new (technological and participatory) initiatives are being developed to actively involve individual patients in healthcare improvement practices.

Studying participation processes provides insight into how active patientship is shaped in complex healthcare practices. With this knowledge, we learn more about the possible active roles patients are able and expected to fulfill. The participation processes are studied from a constructivist point of view, which means that active patientship is not considered

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to be a fixed social phenomenon but that it is continuously constructed through patient interaction with other human actors (e.g. healthcare professionals or managers) and non-human actors (e.g. technologies or healthcare policy) within specific contexts. In this first chapter, the central research question of this thesis is formulated as follows: *How is active patientship constructed within healthcare quality improvement initiatives and to what effect?*

To answer the research question, participation processes are studied within two Dutch quality improvement initiatives, using a qualitative research design. The first initiative concerns patients' (expected) use of a new health information technology, i.e. a website with online health communities. The second case concerns the active involvement of patients in hospital service improvement through a – for the hospital – new participation method.

Chapter 2 starts by unraveling how active patientship is constructed in quality improvement initiatives by studying the design and development of a patient-oriented website (www.mijnzorgnet.nl). Technologies, such as websites, that attempt to foster patient activities are particularly interesting for studying the construction of active patientship as they carry inscriptions of developers and designers about the users. By studying these technologies, it is possible to highlight these inscriptions. In this way, the specific ideas and notions that developers have of future users, and the activities these users need to perform, can be examined and clarified. In other words, it reveals the expectations they have for the future active patient/user. Observations of the website, interviews with the employees of the organization who developed the website and observations at this organization were used to capture and explore designers' inscribing practices and the consequences of these inscribing practices for the expected competences and activities of patients using the website. This chapter shows that designers inscribed two 'co-design roles' that active patients were expected to perform on the website (i.e. co-designing their own healthcare and co-designing the healthcare of peers), which required at least eight different competencies.

Besides exploring the design aspect, this chapter examines how patients utilize the website. Based on the data collection methods described above and interviews with patients who were members of the website, this chapter shows that website developers' design choices have consequences for the inclusion and exclusion of users and for the extent to which included users are able to use (all) available functionalities. This influenced the possibilities of patients to fulfill the expected co-design roles. Variations in website use show that different types of active patientship exist which suggests that more distinctions can be made than between active and passive patients. Finally, this chapter illustrates that not only designers but also patient interaction with technology influences the design of the website, and thus steer the roles patients can fulfill.

Chapter 3 focuses on a specific online space on the website where patients are expected to become active. This chapter examines online health communities (in particular patient-

to-doctor communities), where care professionals and patients who generally do not know one another (and thus do not have a formal treatment relationship) meet to exchange information. Such exchanges take place through different features, such as a blog, forum or a wiki, and are stimulated to increase the opportunities for patients to actively participate in their own healthcare. In this chapter, the use and experiences with online health communities are examined.

Based on observations of online health communities on the website and semi-structured interviews with patients (users), this chapter shows that the website facilitates patients to carry out different (and sometimes new) health-related activities. For example, patients can easily share suggestions for future scientific research with healthcare professionals. The explored activities are divided into three categories: medical activities, emotional activities and activities that relate to patient lifestyle. Due to the presence of both evidence-based knowledge of healthcare professionals and experiential knowledge of peers within the online communities, the patients experience that they are able to carry out these different types of activities. Patients therefore perceive the assemblage of these different types of knowledge as an advantage of the online health communities. However, this assemblage also causes tensions. The presence of healthcare professionals within the online health communities may, for instance, inadvertently insinuate that the quality of information used for the activities, is controlled. If however, information is not officially being checked, this can have undesired implications for the health-related activities that patients cultivate based on this information. This chapter also shows that patients are willing to carry out activities that improve healthcare quality for themselves and others, but that they do not want to be preoccupied with their illness(es) all the time. They also want to be 'just a person'.

Chapter 4 zooms in on another online space on the website, where physicians and patients generally *do* know one another, namely the personal health community (PHC). This is a community where a patient – regardless of the state of his health – can invite care providers and other relevant actors to participate in the exchange of his/her care information. Additionally, the various participants can communicate with one another using diverse features such as an online diary and a forum. Initiating the communities is inspired by the prevailing trends to make healthcare more patient-centered and less fragmented. This chapter explores the value patients and professionals place on such new quality improvement initiatives in care and illustrates the impact of the design and use of such technologies on the roles of patients and professionals in healthcare.

Based on interviews with patients and healthcare professionals, this chapter shows that patients use their PHC differently, depending on the state of their health and people involved. Patients and healthcare professionals mentioned various (potential) advantages of the PHC for future healthcare, in terms of both organizational aspects of care (e.g. continuity of care) and the human side of care (e.g. personal care). There were some disadvantages,

such as the amount of work involved for healthcare professionals and technological issues. The results also show that patient activities in PHCs stimulate a change in 'traditional' roles of both patients and healthcare professionals. This ensures, for example, that healthcare professionals are expected to support not only the physical but also the emotional aspects of being ill.

Chapter 5 shifts the focus to hospital departments that want to improve the quality of their services with the help of patients (e.g. by asking them to tell their experiential stories). To facilitate this process, they use a participation method that is new for the hospitals. This chapter explores why hospitals are interested in patient involvement and studies how hospital project teams designed the patient participation processes aimed at improving the quality of care.

Based on interviews with project team members, analysis of documents drawn up by participants during the project, and observations of project team meetings and meetings with patients, amongst others, this chapter illustrates that hospitals' motives to involve patients not only derive from the desire to improve healthcare quality, but also from other objectives, such as achieving a better market position. This shows that governmental policy, such as the introduction of a market-based healthcare system, is able to stimulate active patientship. Chapter 5 provides further insight into how project teams designed the patient involvement processes to achieve quality improvements. The results show the various choices made concerning the design of the participation process and adaptations made to existing participation methods. These choices and adaptations derive, among other things, from the ambition to limit the time and financial resources needed, to limit the burden on patients, and to adjust the method to the specific hospital context. The next chapter shows that these choices do, however, have consequences. Finally, Chapter 5 illustrates that patients' experiences created a sense of urgency among healthcare professionals to act on the (often already known) improvement issues raised, and that participating in a national project and the involvement of a doctor's 'own' patients also helps in this respect.

Chapter 6 elaborates further on Chapter 5. It focuses specifically on four hospitals that want to use the new participation method 'experience-based co-design' (EBCD) to reach quality improvements based on patients' experiences, but who quickly adapt this method from the start of the initiatives. Characteristic of EBCD is, amongst others, that patients are not only involved in the identification and prioritization of improvement issues, but also in the process of initiating and implementing improvement solutions. According to EBCD, patients and hospital staff should jointly carry out these activities during meetings that facilitate deliberation. Deliberation here means the exchange of thoughts, viewpoints and emotions to stimulate reflection on preferences and to reach well-informed decisions, in this case with regard to quality improvements. This chapter zooms in on the consequences

of choices made in the design and implementation of EBCD for deliberation opportunities and healthcare quality improvements.

Research has shown that for participation practices to succeed within a specific context, adaptations to existing participation methods are often necessary. However, based on semi-structured interviews with project team members, observations of, among other things, formally planned deliberation moments and project team meetings, and analysis of documents related to the initiatives (such as minutes of meetings), it can be concluded that these choices do have consequences. Specifically three types of implications are indicated in this chapter. Firstly, many choices made for practical reasons (e.g. time constraints or not wanting to overburden patients) limit the depth of the deliberation taking place. This has consequences for the quality improvement priorities selected and for the kind of improvement solutions resulting from this. Secondly, choices can create a very prominent place within deliberation for emotions. Emotions can be useful as they can create a sense of urgency among healthcare professionals to act on the improvement issues raised. However, they can also hinder deliberation because they may influence which (emotionally disclosed) improvement topics receive attention. Emotions can particularly accentuate patients' stories, which create the risk of overlooking the professionals' views. Thirdly, choices made by the project team have an impact on who is allowed to participate and whose voices are heard in the process. This also has consequences for the selection of quality improvement topics.

Steering by project teams by means of making choices raises the question of whether improvement solutions meet the expectations and wishes of participants and of whether quality improvements are actually achieved. In practice, in addition to design choices, deliberation is also influenced by time constraints and other non-ideal conditions such as the burden of disease and competences of patients.

Chapter 7 provides a reflection on how active patientship within quality improvement initiatives is constructed and to what effect. It shows that quality improvement initiatives contain the expectations that patients become more involved in both their own health-related activities in partnership with healthcare professionals, family members and peers, and in the health-related activities of others. Different aspects influence whether patients can fulfill these active roles.

First, it depends on a patient's willingness to participate. This willingness existed, however, patients indicated that they do not want to be preoccupied with their illness(es) all the time, and therefore do not want to constantly participate in quality improvement initiatives that emphasize their sense of being a patient. In addition, it depends on the readiness of healthcare professionals and managers to facilitate active patientship. It turns out that governmental policy (e.g. the introduction of a regulated market system) and national trends (e.g. patient-centeredness) have a positive influence on that readiness. These often form the motivation for initiating quality improvement initiatives that stimulate a more active role

for patients. Furthermore, the fulfillment of a more active role for patients depends on the ability of healthcare professionals to facilitate active patientship. Due to a high workload, healthcare professionals often work on quality improvement initiatives in their spare time but indicated that financial policies and societal trends might hinder this in the future. Finally, it depends on the patient's ability to participate. This ability depends predominantly on the design of quality improvement initiatives, which is often in the hands of initiators of the initiatives. The results show that these initiators make a lot of design choices that have an impact on the inclusion and exclusion of patients in the initiative and on the extent to which included patients are able to participate. They also adapt existing participation methods, which has consequences on when and for how long patients can participate. The design of the quality improvement initiatives and the fulfillment of a more active role are, however, also steered by patients, who can, for example, carry out activities in different ways.

Therefore, fulfilling the expected roles depends not only on the willingness, capabilities and activities of patients, it also depends on the interactions with and activities of other actors (mainly healthcare professionals and designers of quality improvement initiatives) in a patient specific healthcare context. It is through their (inter)actions, which can be mediated through technologies, governmental policy and national trends, that active patientship is created and quality improvements achieved.

In addition to a description of how active patientship is constructed, this last chapter discusses the consequences that construction processes can bring about: for example, they bring about different tensions. Based on the results of this PhD research, six tensions can be identified. The tensions are between: reaching quality improvements and alterations; expert knowledge and experiential knowledge; de-professionalization and re-professionalization of the role of the professional; enabling and constraining participation; individual and collective action; and being a patient and being a person. Together, these tensions illustrate that although the words 'active patientship' refer only to patients, a more active role for patients has implications for many different aspects of healthcare (including the design of health technologies and the roles of professionals) so it might be more suitable to use the concept of 'active patient system'.

Finally, this chapter closes with some study implications. Theoretically, it can be argued that the quality improvement potential of 'active patients' is not an inherent capacity of patients; it requires hard work from patients and other actors in a patient healthcare context. This makes the specific healthcare context in which patients are expected to participate very important. It also means that active patientship and thus the various roles that patients can perform in quality improvement initiatives are situation-specific. These are subject to continuous change and manifest themselves in various types. A resulting recommendation is that it is important to not talk in generic terms about active patientship in daily practice. Another recommendation is to involve patients in the development and design of quality improvement initiatives, in order to gain insight into the various types of active patientship

that arise and to adjust these when necessary to fit the types the developers have in mind. Developers should also think carefully about the types of active patientship they want to achieve, and to align this with selected and designed participation methods and technologies.

S

SAMENVATTING

Het stimuleren van een actieve rol van patiënten bij kwaliteitsverbeteringinitiatieven in de gezondheidszorg is een belangrijk beleidsdoel in Nederland en andere Westerse landen. Kwaliteitsverbetering wordt niet langer als een exclusieve activiteit van zorgverleners gezien. Van patiënten wordt hierbij ook een actieve rol verwacht, indien zij dit willen en kunnen. Er wordt bijvoorbeeld verwacht dat zij actiever betrokken raken bij het verbeteren van hun eigen kwaliteit van zorg door relevante informatie op internet op te zoeken. Maar ook wordt verwacht dat zij bijdragen aan een verbetering van de zorg van anderen. Bijvoorbeeld door ervaringsverhalen met zorgverleners te delen die gebruikt kunnen worden om de kwaliteit van de dienstverlening in zorginstellingen te verbeteren. Dit proefschrift exploreert hoe de actieve rol van patiënten tot stand komt binnen kwaliteitsverbeteringinitiatieven en wat dit betekent voor de activiteiten die van patiënten verwacht worden.

Hoofdstuk 1 beschrijft de aandacht voor een actievere rol van patiënten bij kwaliteitsverbetering in de zorg. Het laat zien dat in het debat over actief patiëntschap verschillende assumpties bestaan over welke rol(len) patiënten bij kwaliteitsverbetering kunnen vervullen en wat de bijbehorende activiteiten opleveren. Enerzijds wordt in dit debat de toegevoegde waarde benadrukt. De unieke ervaringskennis van patiënten kan een verfrissend en complementair perspectief bieden op dat van zorgverleners en activiteiten van patiënten kunnen als een incentive dienen voor professionals om hun service te verbeteren. Anderzijds zijn er ook kritische geluiden zoals het instrumenteel gebruik van actief patiëntschap door zorginstellingen en de last die het patiënten kan bezorgen.

Huidige indelingen in wetenschappelijke literatuur die gemaakt zijn om meer duidelijkheid te scheppen over de mogelijkheden van actief patiëntschap bij kwaliteitsverbetering in de zorg – zoals een onderscheid tussen verschillende niveaus, vormen en methoden van participatie – bieden inzicht in het meervoudige karakter van patiëntenparticipatie. Hoofdstuk 1 laat zien dat echter diepgaander onderzoek naar participatieprocessen nodig is om inzicht te krijgen in hoe actief patiëntschap vorm krijgt in de dagelijkse zorgpraktijk en wat dit betekent voor de rollen en activiteiten die patiënten geacht worden te vervullen. Dit proefschrift richt zich op deze participatieprocessen en specifiek op processen die plaatsvinden op het klinische (micro)niveau van zorgverlening. Dit is het niveau waar individuele patiënten met hun eigen zorgverleners interacteren. Dit niveau is onder meer interessant om participatieprocessen te onderzoeken omdat hier veel nieuwe (technologische en participatieve) initiatieven ontwikkeld worden die een actievere rol van patiënten bij kwaliteitsverbetering stimuleren.

Het onderzoeken van participatieprocessen geeft inzicht in hoe actief patiëntschap vorm krijgt in complexe zorgpraktijken. Met deze kennis leren we meer over de mogelijke actieve rollen die patiënten kunnen – en geacht worden te – vervullen. De participatiepro-

cessen worden in dit proefschrift vanuit een constructivistisch perspectief onderzocht. Dit betekent dat actief patiëntschap niet als een 'gegeven' wordt beschouwd, maar als iets dat gevormd wordt door interacties tussen patiënten met andere actoren (zoals zorgverleners en managers) en actanten (zoals technologie en gezondheidszorgbeleid) in een bepaalde context. De onderzoeksvraag die in dit proefschrift centraal staat, is in Hoofdstuk 1 als volgt geformuleerd: *Hoe wordt actief patiëntschap binnen kwaliteitsverbeteringinitiatieven geconstrueerd en wat zijn daar de gevolgen van?*

De onderzoeksvraag wordt aan de hand van kwalitatief onderzoek onderzocht, waarbij twee Nederlandse case studies centraal staan. De eerste case betreft de ontwikkeling van een nieuwe website gericht op het vergroten van de mogelijkheden van patiënten om te participeren binnen hun eigen gezondheidszorg. De tweede case betreft vijf ziekenhuizen die de kwaliteit van hun zorg willen verbeteren aan de hand van ervaringen van patiënten en met behulp van een voor de ziekenhuizen nieuwe participatiemethode.

Hoofdstuk 2 begint met het ontrafelen van hoe actief patiëntschap geconstrueerd wordt in kwaliteitsverbeteringinitiatieven, door het ontwerp en de ontwikkeling van een patiëntgerichte website te onderzoeken (www.mijnzorgnet.nl). Technologieën, zoals websites, die de activiteiten van patiënten proberen te stimuleren, zijn interessant om te onderzoeken voor de constructie van actief patiëntschap omdat zij inscripties van ontwikkelaars en ontwerpers in zich dragen over de gebruikers. Door de technologieën te onderzoeken, is het mogelijk om deze inscripties inzichtelijk te maken en daarmee de specifieke ideeën van ontwerpers over de gebruikers naar voren te krijgen. Met andere woorden, het laat de verwachtingen zien die ontwerpers hebben ten aanzien van de (toekomstige) actieve rol van patiënten/gebruikers. In het hoofdstuk laat ik op basis van observaties van de website, interviews met websiteontwikkelaars en observaties bij de organisatie die de website ontwikkelde zien dat er twee rollen van patiënten verwacht worden. Enerzijds worden patiënten geacht de eigen zorg te 'co-designen' door meer betrokken te zijn bij eigen zorg gerelateerde activiteiten, anderzijds wordt verwacht dat zij de zorg van anderen co-designen, door ook betrokken te zijn bij zorg gerelateerde activiteiten van anderen. Voor het uitvoeren van deze rollen via de website waren ten minste acht verschillende competenties nodig.

Naast onderzoek naar het ontwerp van de website is in dit hoofdstuk ook het gebruik van de website onderzocht. Op basis van de hierboven besproken dataverzamelingsmethoden en interviews met patiënten die deelnamen aan de website, laat ik zien dat keuzes in het ontwerp van de website (gemaakt door designers) gevolgen hebben voor de inclusie en exclusie van gebruikers en voor de mate waarin geïncludeerde gebruikers erin slagen om van alle functionaliteiten gebruik te maken. Dit beïnvloedde de mogelijkheden van patiënten om de verwachte co-design rollen te vervullen. Variaties in het gebruik van de website laten zien dat er veel verschillende varianten van actief patiëntschap bestaan, waardoor er meer gradaties te benoemen zijn dan alleen het veel gemaakte onderscheid tussen actieve

en passieve patiënten. Tot slot laat ik in dit hoofdstuk zien dat de website niet alleen door designers werd vormgegeven maar ook door de interactie van patiënten met techniek. Zowel ontwerpers van de website als patiënten in interactie met techniek sturen daarmee de rollen die patiënten kunnen vervullen.

Hoofdstuk 3 richt zich op een specifiek onderdeel van de website waar patiënten een actieve rol dienen te vervullen, namelijk online zorgcommunities. Dit zijn communities waarin zorgverleners en patiënten die elkaar (over het algemeen) niet kennen (en geen behandelrelatie hebben) participeren door informatie en kennis uit te wisselen met behulp van verschillende functionaliteiten zoals blog, forum en wiki. In dit hoofdstuk wordt het gebruik en de ervaringen van patiënten met online zorgcommunities onderzocht.

Op basis van observaties van online zorgcommunities op de website en semige-structureerde interviews met patiënten (gebruikers), laat ik in dit hoofdstuk zien dat de website patiënten faciliteert in het uitvoeren van verschillende type (en deels nieuwe) zorgactiviteiten. Zo kunnen patiënten bijvoorbeeld eenvoudig suggesties voor wetenschap-pelijk onderzoek aan zorgverleners aandragen. Alle geëxploreerde activiteiten zijn onder-gebracht in drie categorieën: medische activiteiten, emotionele activiteiten en activiteiten die betrekking hebben op de levensstijl van patiënten. Patiënten ervaren dat zij deze verschillende activiteiten kunnen uitvoeren doordat in de communities zowel op weten-schappelijk onderzoek gebaseerde kennis van zorgverleners aanwezig is als ervaringskennis van lotgenoten. Het samenkomen van deze verschillende typen kennis wordt dan ook door patiënten als een voordeel van deze online zorgcommunities gezien. Echter levert deze samenkomst tegelijkertijd ook spanningen op. Zo doet de aanwezigheid van zorgverleners op de website onopzettelijk bij patiënten vermoeden dat alle informatie gecontroleerd wordt en daardoor inhoudelijk klopt. Wanneer informatie niet gecontroleerd wordt, kan dat ongewenste gevolgen hebben voor de zorg gerelateerde activiteiten die patiënten ontplooien, die gebaseerd zijn op eventueel onjuiste informatie. Dit hoofdstuk laat tevens zien dat patiënten graag activiteiten voor hunzelf en anderen ontplooien die de kwaliteit van zorg kunnen verbeteren, maar dat zij soms ook 'gewoon mens' willen zijn en niet altijd met hun ziekte bezig willen zijn.

Hoofdstuk 4 zoomt in op een andere omgeving op de website waar artsen en patiënten elkaar wel kennen, namelijk de persoonlijke zorgcommunity (PZC). Dit is een community waarin de patiënt – onafhankelijk van zijn of haar aandoening – zijn eigen zorgverleners en eventueel andere relevante actoren kan uitnodigen en waarin informatie over de gezondheid van de patiënt uitgewisseld kan worden. Daarnaast kunnen de verschillende deelnemers met elkaar communiceren met behulp van diverse functionaliteiten zoals via een dagboek en forum. De communities zijn geïnitieerd op basis van heersende trends zoals het patiëntgerichter en minder gefragmenteerd maken van de zorg. In dit hoofdstuk wordt

gekeken naar hoe patiënten en zorgverleners deze nieuwe technologische ontwikkeling waarderen en wat de consequenties zijn van het ontwerp en gebruik van de PZC's voor de huidige rollen van patiënten en zorgprofessionals.

Aan de hand van interviews met zowel patiënten als zorgverleners wordt in dit hoofdstuk zichtbaar dat iedere patiënt zijn of haar PZC anders gebruikt en dat dit gebruik afhankelijk is van de aandoening(en) die de patiënt heeft en van de actoren die in het zorgproces van de patiënt betrokken zijn. Patiënten en zorgverleners benoemden ver-schillende (toekomstige) voordelen die PZC's kunnen hebben voor de gezondheidszorg die met name gerelateerd zijn aan de organisatie van zorg (bijvoorbeeld waarborgen van continuïteit) en de menselijke kant van zorgverlening (bijvoorbeeld het bevorderen van persoonlijke zorg). Technologische moeilijkheden en de extra arbeid die het genereert voor zorgverleners worden onder andere als nadelen van de PZC's beschouwd. De resultaten laten verder zien dat een actieve rol van patiënten in PZC's een verandering in 'traditionele' rollen teweegbrengt voor zowel patiënten als zorgverleners. Het zorgt er bijvoorbeeld voor dat zorgverleners niet alleen het fysieke aspect maar ook de emotionele kanten van ziek-zijn worden geacht te ondersteunen.

In **Hoofdstuk 5** verschuift de aandacht naar ziekenhuisafdelingen die met behulp van activiteiten van patiënten (onder andere het expliciet maken van hun ervaringskennis) de kwaliteit van de dienstverlening willen verbeteren. Om dit proces te faciliteren gebruiken ziekenhuizen een voor hen nieuwe participatiemethode. Dit hoofdstuk onderzoekt waarom ziekenhuizen geïnteresseerd zijn in het betrekken van patiënten bij kwaliteitsverbeteringen en hoe projectteams, verantwoordelijk voor de uitvoering van de kwaliteitsverbeteringiniti-atieven, de participatieprocessen vormgeven.

Op basis van interviews met projectteamleden, analyse van documenten die tijdens het kwaliteitsverbeteringproject gegenereerd zijn door de participanten en observaties van onder andere projectteam vergaderingen en bijeenkomsten met patiënten, laat dit hoofdstuk zien dat de motieven om patiënten te betrekken niet alleen zijn ingegeven vanuit de wens om de kwaliteit van zorg te verbeteren, maar ook voortkomen uit andere doelen zoals het verwerven van een goede marktpositie. Dit laat zien dat overheidsbeleid zoals de invoering van een gereguleerd marktsysteem ook actief patiëntschap kan stimuleren. Verder wordt in dit hoofdstuk inzicht gegeven in hoe het proces van het betrekken van patiënten bij kwaliteitsverbetering wordt vormgegeven door de projectteams. De resultaten laten zien dat er veel keuzes gemaakt worden in het ontwerpproces en dat vooraf uitgekozen participatiemethoden achteraf veelvuldig worden aangepast. Deze keuzes en aanpassingen komen onder andere voort uit de wens om zowel tijd als geld te besparen, om patiënten zo min mogelijk te belasten en om de methodiek te laten aansluiten bij de context van het ziekenhuis. De gevolgen van de keuzes en aanpassingen worden in het volgende hoofdstuk uiteengezet. Hoofdstuk 5 laat tot slot zien dat ervaringen van patiënten de urgentie onder

zorgverleners om iets aan (reeds bekende) verbeterpunten te doen kan vergroten en dat participeren in een nationaal project en het betrekken van 'eigen' patiënten van zorgverleners daarbij ook stimulerend kan werken.

Hoofdstuk 6 gaat, zoals aangegeven, verder in op de bevindingen uit Hoofdstuk 5. Het richt zich specifiek op vier ziekenhuizen die de nieuwe methode 'experience-based co-design' (EBCD) willen gebruiken om kwaliteitsverbeteringen aan de hand van patiënten ervaringen te realiseren, maar deze methode vanaf de start al snel aanpassen. Kenmerkend aan EBCD is onder meer dat patiënten niet alleen betrokken worden bij het identificeren en prioriteren van verbeterpunten, maar ook bij het initiëren en implementeren van verbeteroplossingen. Deze activiteiten dienen volgens de methode gezamenlijk door patiënten en medewerkers van het ziekenhuis uitgevoerd te worden middels bijeenkomsten die deliberatie tussen patiënten en medewerkers stimuleren. Deliberatie verwijst naar de uitwisseling van gedachten, perspectieven en emoties om zo tot weloverwogen voorkeuren en geïnformeerde keuzes te komen, in dit geval ten aanzien van kwaliteitsverbeteringen. Reflectie op eigen waarden en meningen is daarbij belangrijk. In het hoofdstuk wordt onderzocht wat de consequenties zijn van keuzes in het ontwerp en de implementatie van EBCD voor deliberatie mogelijkheden en kwaliteitsverbeteringen.

Onderzoek heeft laten zien dat het maken van goede keuzes ten aanzien van het ontwerp van participatiemethoden vaak noodzakelijk is om participatieprocessen in een bepaalde context te doen slagen. Op basis van semigestructureerde interviews met projectteamleden, observaties van onder andere formeel geplande deliberatiemomenten en projectteam vergaderingen, en de analyse van aan het kwaliteitsverbeteringinitiatief verbonden documenten (zoals vergadernotulen), kan echter gesteld worden dat het maken van keuzes ook consequenties heeft. Specifiek kunnen er drie implicaties genoemd worden. Ten eerste beperken keuzes, die gemaakt worden op basis van praktische overwegingen (zoals beschikbare tijd en het niet te veel willen belasten van patiënten), de mogelijkheden om te delibereren. Dit heeft gevolgen voor welke verbeterprioriteiten er gekozen worden, alsmede tot welke verbeteroplossingen dit leidt. Ten tweede kunnen gemaakte keuzes voor een zeer prominente rol van emoties binnen de participatieprocessen zorgen. Emoties kunnen heel nuttig zijn, bijvoorbeeld omdat ze de urgentie om kwaliteitsverbeteringen aan te pakken onder zorgverleners kan vergroten. Echter kunnen ze ook deliberatie beperken, doordat ze kunnen sturen welke (emotioneel aan het licht gebrachte) verbeterpunten aandacht krijgen. Emoties kunnen voornamelijk de verhalen van patiënten accentueren waardoor al snel het risico ontstaat dat de perspectieven van zorgverleners het onderspit delven. Ten derde hebben keuzes ten aanzien van het ontwerp van participatieprocessen invloed op wie er mag participeren en wiens stem gehoord wordt tijdens het participatieproces. Ook dit heeft vervolgens gevolgen voor de selectie van verbeterpunten.

De sturing van het projectteam door het maken van keuzes roept de vraag op of de verbeteroplossingen aan de verwachtingen en wensen van de participanten voldoen en of er daadwerkelijk kwaliteitsverbeteringen worden gerealiseerd. Naast gemaakte keuzes door het projectteam wordt deliberatie in de praktijk ook beïnvloed door tijdsdruk en andere omstandigheden zoals ziektelast en competenties van patiënten.

Hoofdstuk 7 geeft een reflectie op hoe actief patiëntschap binnen kwaliteitsverbeteringinitiatieven geconstrueerd wordt en wat daar de gevolgen van zijn. Het laat zien dat de kwaliteitsverbeteringinitiatieven de verwachtingen in zich dragen dat patiënten zowel meer betrokken raken bij eigen zorg gerelateerde activiteiten in partnerschap met zorgverleners, familieleden en lotgenoten, als bij de zorgactiviteiten van anderen. Verschillende aspecten beïnvloeden of patiënten aan deze actieve rollen kunnen voldoen.

Allereerst hangt het af van de bereidheid van patiënten om te participeren. Deze bereidheid bleek aanwezig, echter gaven patiënten aan dat zij niet altijd met hun ziekte bezig willen zijn en dus niet altijd willen participeren in initiatieven die het patiënt zijn benadrukken. Daarnaast hangt het af van de bereidwilligheid van zorgverleners en managers om actief patiëntschap te faciliteren. Het blijkt dat overheidsbeleid (zoals de introductie van gereguleerde marktwerking) en nationale trends (zoals patiëntgerichtheid) een positieve invloed op deze bereidheid hebben. Zij vormen vaak de motivatie om kwaliteitsverbeteringinitiatieven te initiëren waarbij patiënten een actieve rol toebedeeld krijgen. Tevens hangt de vervulling van een actieve rol van patiënten af van het vermogen van zorgverleners om actief patiëntschap te faciliteren. Zorgverleners voeren kwaliteitsverbeteringinitiatieven vaak in hun vrije tijd uit vanwege de hoge werkdruk en gaven aan dat financieel beleid en nationale trends deze bereidheid in de toekomst wellicht in de kiem kan smoren. Tot slot is het afhankelijk van het vermogen van patiënten om te participeren. Dit vermogen hangt voornamelijk af van de vormgeving van kwaliteitsverbeteringinitiatieven, dat meestal in de handen ligt van de initiatiefnemers. Het blijkt dat zij veel keuzes maken ten aanzien van het design, welke gevolgen hebben voor de inclusie en exclusie van patiënten in het initiatief en voor de mate waarin geïncludeerde patiënten activiteiten kunnen uitvoeren. Tevens blijkt dat zij bestaande participatiemethoden aanpassen, wat gevolgen heeft voor het moment en de duur waarop patiënten kunnen participeren. De vormgeving van de kwaliteitsverbeteringinitiatieven en de invulling van een actievere rol wordt echter ook door patiënten zelf gestuurd, bijvoorbeeld door niet of andere manier gebruik te maken van technologische faciliteiten.

Het kunnen uitvoeren van de verwachte actieve rollen hangt dus niet alleen af van de bereidheid, vaardigheden en activiteiten van patiënten, maar ook van de interactie met en activiteiten van andere actoren (voornamelijk zorgverleners en vormgevers van kwaliteitsverbeteringinitiatieven) in de specifieke zorgcontext. Het is door hun (inter)acties, die beïnvloed kunnen worden door technologieën (zoals websites), overheidsbeleid en

nationale trends dat actief patiëntschap geconstrueerd wordt en kwaliteitsverbeteringen bereikt kunnen worden.

Naast een beschrijving van hoe actief patiëntschap geconstrueerd wordt laat Hoofdstuk 7 zien dat deze constructieprocessen verschillende spanningen met zich mee brengen. Op basis van de resultaten uit het proefschrift zijn er zes spanningen geïdentificeerd. Een spanning tussen: het bereiken van kwaliteitsverbeteringen en het realiseren van veranderingen; expertkennis en ervaringskennis; professionalisering en de-professionalisering van de rol van zorgverleners; faciliteren en beperken van patiëntenparticipatie; het belang van het individu en het collectief; en tussen je patiënt en mens voelen. Tezamen laat een beschrijving van deze spanningen zien dat hoewel de term actief patiëntschap alleen naar patiënten verwijst, het ook gevolgen heeft voor veel andere onderdelen van de gezondheidszorg (zoals het ontwerp van zorgtechnologie en rollen van professionals), waardoor er mogelijk beter van een 'actief patiëntsysteem' gesproken kan worden.

Tenslotte sluit de conclusie af met de implicaties van dit onderzoek. Theoretisch wordt geconcludeerd dat het kwaliteitsverbetering potentieel van patiënten geen inherente capaciteit van patiënten is, maar dat het veel werk vereist van patiënten en andere actoren in de zorgcontext van de patiënt. Dit maakt de specifieke context waarin een patiënt geacht wordt te participeren heel belangrijk. Het betekent ook dat actief patiëntschap en de mogelijke rollen die patiënten kunnen uitvoeren binnen kwaliteitsverbeteringinitiatieven gesitueerd zijn. Het is continue aan verandering onderhevig en kent verschillende verschijningsvormen. Een aanbeveling voor de praktijk die hier uit voortvloeit is dat het belangrijk is om niet in algemene termen over actief patiëntschap te discussiëren. Een andere aanbeveling is om patiënten te betrekken bij de ontwikkeling en het ontwerp van kwaliteitsverbeteringinitiatieven zodat inzicht verkregen kan worden in welke varianten van actief patiëntschap ontstaan en deze indien nodig bijgestuurd kunnen worden in de vorm die je als ontwikkelaar voor ogen hebt. Ontwikkelaars moeten dan ook bewust nadenken over welke varianten van actief patiëntschap zij willen nastreven en daar participatiemethodes en technologieën op afstemmen.

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DANKWOORD

Vanaf deze plek wil ik graag iedereen bedanken voor hun bijdrage aan de totstandkoming van dit proefschrift. De totstandkoming kent overeenkomsten met de manier waarop actief patiëntschap in de praktijk vorm krijgt. Het is een resultaat van een proces waaraan verschillende actoren (collega's, respondenten, familie en vrienden) en actanten (bemoedigende kaartjes, e-mails en appjes) hebben bijgedragen. Mijn dank is groot.

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PHD PORTFOLIO

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PhD period: 2010 – 2016
Promotor: Prof.dr. Kim Putters
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Courses

Teaching study skills to students (Didactiek)	2011
Tutor skills for problem-based education (PGO)	2011
Ready in four years	2011
English speaking skills for academic EUR staff	2011
Qualitative research skills (KWALON)	2011
Netherlands Institute of Government (NIG), course Network Governance	2011
NIG skills course operationalization	2011
NIG skills course formulating research questions	2012
NIG case study research	2012
NIG skills course content analysis	2012
NIG skills course presenting your research	2012
NIG skills course getting it published	2012
NIG general methodology	2012
NIG course philosophy of science	2012
Academic writing in English	2012

Teaching activities

Supervising and co-evaluating bachelor thesis	2010 – 2014
Workgroups Philosophy of Science (BA)	2010 – 2014
Workgroups Philosophy of Science (Pre-master)	2014
Workgroups Introduction to Research Methods and Techniques (BA)	2013
Workgroups Qualitative Research Methods Healthcare (BA)	2012 – 2014
Lecture 'Analyzing in qualitative research'	2014
Course: Qualitative Research Methods Healthcare	

Presentations at conferences

EHMA (European Health Management Association) annual conference, Bern	2012
IRSPM (International Research Society for Public Management), Prague	2013
Transatlantic Policy Consortium, The Hague	2013
The 4th international workshop on Infrastructures for Healthcare: Action	2013

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Research, Interventions and Participatory Design, Tromsø

QUASER (Quality and Safety in European Union Hospitals) and DUQuE (Deepening our Understanding of Quality Improvement in Europe) congress, Rotterdam	2013
Symposium Patient as Partner in Quality Improvement, Utrecht	2013
iBMG Innovation budget 2010, Rotterdam	2013
EACH (European Association for Communication in Healthcare), Amsterdam	2014
EHMA annual conference, Birmingham	2014

Contributions to reports

Faber, M., Aarts, A., Van der Eijk, M., Vennik, F., Den Breejen, E., Putters, K., Kremer, J., Bloem, B. 2012. *Eindrapportage MijnZorgnet*. Nijmegen: UMC St Radboud.

Vennik, F., Van de Bovenkamp, H., Raats, I., De Wit, F., Visserman, E., Grit, K. 2013. *Handleiding kwaliteitsverbetering ziekenhuiszorg, vanuit de ervaring van patiënten*. Rotterdam: iBMG.

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Femke D. Vennik was born in Rijswijk (ZH) in the Netherlands on June 27th 1988. After graduating from secondary school in 2006 (pre-university secondary education, Sint-Maartenscollege), she studied Health Sciences at the Erasmus University Rotterdam. She graduated in 2010 with a master in Healthcare Management. During her studies, she developed a great interest in patient participation, which was reflected in her bachelor thesis. Starting work as a doctoral student at the Institute of Health Policy & Management of the Erasmus University Rotterdam in 2010 enabled her to pursue this interest further. Her research explores how different human and non-human actors mutually construct active patientship in practice, and examines the results of these construction activities. Besides conducting research, Femke taught Philosophy of Science and Qualitative Research Methods to Health Sciences bachelor students. In 2015, Femke entered the entrepreneurial world and started her own company: "Femke's Foodies". The aim of this retail company is to provide and develop food products beneficial to those with dietary requirements. She also participates in the supervisory board of the non-profit foundation "Liberis": an Applied Behavior Analysis (ABA) Centre for children between 2 and 12 years old who have autism, developmental issues and/or intellectual disabilities.

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