

BMJ Open

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Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-012110
Article Type:	Research
Date Submitted by the Author:	31-Mar-2016
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Primary Subject Heading:	Patient-centred medicine
Secondary Subject Heading:	Health informatics
Keywords:	patient empowerment, online communities, Parkinson-s disease < NEUROLOGY, e-health

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Do on-line communities change power dynamics in healthcare?

Using qualitative interviews and observations to examine the use of online health communities by Parkinson's patients

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Total number of words: 3,607

Key words: patient empowerment; e-health; online communities; Parkinson's disease

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Abstract

Objective: Communication technologies, such as online health communities, are increasingly considered as a tool to realize patient empowerment. However, little is known about the *actual* use of online health communities. Here, we investigated if and how patients' use of online communities supports patient empowerment.

Setting: A network of primary and secondary care providers around individual Parkinson's patients.

Participants: We conducted a qualitative study to examine our research question. We interviewed 18 patients with Parkinson's disease and followed 14 of them for an average of one year.

Primary outcome measures: We analysed the content of the interviews and the online conversations between patients and healthcare providers, using Foucault's framework for studying power processes.

Results: We observed that patient empowerment is inhibited by a number of implicit norms that exist within these communities around the number and content of postings. First, patients refrained from asking too many questions to their healthcare providers, but felt obliged to offer them regular updates. Second, patients scrutinized the content of their postings, being afraid to come across as complainers. Third, patients were cautious in making knowledge claims about their disease.

Conclusion: Changing these implicit norms within online communities and the context they exist in would seem necessary to achieve greater patient empowerment. Possibilities for changing these norms might lie in open dialogue between patient and healthcare providers about expectations, revising the curriculum of medical education, and redesigning online communities to support two-way knowledge exchange.

Strengths and limitations of this study

- This study is among the first to examine the actual use of online communities rather than just their potential or limitations;
- This study uses a more complex framework for understanding power, drawn from the social sciences;
- The sample for this qualitative study is relatively small (we have interviewed 18 patients but observed 691 postings in total), but its size allows for studying these power dynamics in-depth.

Introduction

The healthcare sector increasingly calls for patients to become more actively involved in their own care provision.¹⁻³ Better empowered patients might result in decreased costs as well as increased quality of care.^{1 4 5} Implementing new communication technology to support communication between individual patients and their healthcare providers has been introduced as a possible new way to achieve these goals.⁶⁻⁹ Existing research tends to focus on the reasons why patients and healthcare providers do or do not use communication technology.¹⁰⁻¹² This research shows that data security and decrease in workload are important issues that determine whether or not healthcare providers adopt new technology.¹⁰ For patients, privacy is important, next to the technical skills necessary for using the Internet.⁹ However, little is known about the actual use of online health communities, and the behaviour of patients and providers therein. Online tools for patients are becoming widespread, often focused on patient-to-patient support or feedback from a (unknown) expert.^{13 14} The online communities under examination here present a different transformative potential because they integrate communication, previously conducted dispersedly among one patient and her or his own healthcare providers, into a secured online forum. Knowing *how* patients and healthcare providers use these online communities (rather than *why*), allows us to demonstrate the possible relationship between online health communities and patient empowerment, and to identify possible barriers as well as facilitators. Therefore, this article questions if and how patients' use of online health communities supports patient empowerment.

To answer our research question, we examined personal online health communities used by patients with Parkinson's disease. This degenerative chronic illness provides an interesting test case to examine the use of online communities. The chronic nature of this disease¹⁵ ensures that Parkinson patients build a long-term relationship with their healthcare providers,

1
2
3 and thus have a greater need to track their illness longitudinally. This makes it potentially
4 more gratifying for such chronic patients to invest in communicating online. Moreover, most
5 patients receive multiple therapies (offered by a range of different professional disciplines),¹⁶
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7 and the online communities potentially offer a convenient way to connect the different
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12 healthcare providers.¹⁷
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16 Personal online health communities, which have been developed specifically for this group of
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18 patients, enable online communication between an individual patient and his or her healthcare
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20 providers.¹¹ Specifically, both patients and their team of healthcare providers can access the
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22 community by logging onto a secure website. This website offers multiple options for posting
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24 healthcare-related messages.^{11 17} Patients can post diary entries to update their healthcare
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26 providers, or start ‘virtual meetings’ where issues around the patient’s health can be
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28 discussed. Furthermore, there is an option to post documents within an online library, and a
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30 list of individual health problems can be stored and updated when necessary. The patient is
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32 the formal owner of the community, and he or she is the person who invites others to join.
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39 To study patient empowerment via these communities, we draw from Foucault’s framework
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41 for studying power processes.^{18 19} In contrast to more conventional definitions of power (such
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43 as the individual’s ability to steer someone else’s behaviour), we use this work from the social
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45 sciences to argue that power processes operate under the surface, through the distribution of
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47 norms that determine what normal and abnormal behaviour for patients is. These norms are
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49 communicated via representation of healthcare provision in the news, TV shows,
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51 commercials, magazines, or medical textbooks.²⁰ These implicit norms make it seem natural
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53 how, for example, patients should approach their healthcare providers. There is no one person
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55 or institution who defines such norms, as all individuals in society (unconsciously) engage in
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3 activities to (re)produce these norms. Therefore, actively changing such norms is not possible
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5 for any individual healthcare provider or patient, but instead requires (larger groups within)
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7 society to develop and adopt a new common discourse about healthcare provision. Our
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9 analysis focused on the norms that exist around the use of online healthcare communities and
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11 their effect on patient empowerment. By bringing in this social sciences perspective, this
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13 article would be an important addition to the current and lively debates around patient-centred
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15 healthcare,^{1 21} as it brings a new and important view on power processes.
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20 21 **Methods**

22 *Participants*

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25 Semi-structured interviews and observations were conducted between October 2012 and
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27 February 2014, involving 18 patients with Parkinson's disease (see Table 1 for some
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29 demographic information). All patients participated in a trial at four hospitals in the
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31 Netherlands where Parkinson nurses supported them in setting up a personalized online
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33 community (total number of patients included in the trial was 179). We used a purposive
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35 sampling technique by asking these Parkinson nurses to identify patients that actively used
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37 their online communities. We specifically asked for such patients, because their active use
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39 signified the intended use of the communities. Limiting our sample to these patients allows us
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41 to see how such intended use affects the possibilities for patient empowerment. No other
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43 inclusion or exclusion criteria were applied, and we stopped including more patients when
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45 data saturation was achieved. The ethics committee of the two participating hospitals
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47 (Radboudumc in Nijmegen and Martini Ziekenhuis in Groningen) approved our research
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49 protocol. All patients gave signed informed consent for both the interviews and observations.
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52 In this article, we use aliases to protect the patients' privacy.
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Interviews

We used semi-structured interviews to encourage patients to reflect on their use of the online health communities. The patient interviews were conducted face-to-face in the patients' homes, and they lasted on average 60 minutes and were performed by the first author (LV). LV, a woman, was a PhD candidate in her early twenties at the time, with previous experience interviewing elderly people. The interviews with conducted between the patient and interviewer, although in some cases, patients' partners were also present in the home (often in another room). An interview guide was used that involved questions about how patients experienced the use of their online community, the relationship with their healthcare providers, and their role in the care provision. The research team's interest in power, however, was not explicitly discussed during the interview, nor was it mentioned in the introduction to the interview to prevent any bias in the interviewees' responses.

Observations

Next to collecting data, the interviews with patients were also used to inform them about the authors' intent to observe the communication within the online health communities. Ultimately, 14 patients gave LV access to their online health communities. The 4 patients that we could not observe either declined (n=2), or were no longer reachable after the first interview (n=2). The period of observation for the remaining 14 patients varied between 1 – 1.5 year. In total, 691 postings were made during this period in the online communities of these 14 patients, either by the patients themselves or by their healthcare providers. In our observations of these postings, we analysed the placement, content and timing of postings, who authored the postings, and the content and timing of responses.

Analysis

The tape-recorded interviews were transcribed verbatim and screenshots were taken from the webpages of the online communities. Qualitative analysis was performed using ATLAS.ti.²² Using qualitative analysis methods has allowed us to gain an in-depth understanding of power processes, a complex concept difficult to adequately capture in standardized questions in a survey.²³ Framework of analysis was Foucault's definition of power.¹⁸ In contrast to more conventional definitions of power (as the individual's ability to steer someone else's behaviour), Foucault poses that power processes operate under the surface, through processes of normalization, which determine how we see the social world and what normal and abnormal behaviour is. This definition of power has received limited attention in medical journals,^{24 25} but is widely used in healthcare research in the social sciences.^{26 27} Foucault's definition of power is useful for understanding patient empowerment, because it positions changing power processes not just as a development between an individual patient and healthcare provider, but as a larger structural and societal shift. Therefore, when we examine power processes within the use of online communities, we analyse where such norms are communicated "that determine what can be said by whom and when",²⁸ using a discourse analysis approach.²⁹ This approach requires noting when respondents used phrases such as "I should", "I have to" or otherwise talked about the 'appropriateness' of the content or timing of their postings. Furthermore, we analysed how suggestions or ideas were articulated and who uses which phrasing. For example, the use of "I suggest" or "I would like to ask" shows different norms about the legitimacy of one's ideas than using phrasing such as "I feel" or "my impression is". A first coding on the basis of these themes was done by the first author, the relevant quotes that came out of this analysis were subsequently presented to IB, YB, and AvR for further in-depth analysis. The transcribed interviews and our analysis of them were

1
2
3 not returned for comment to the interviewees, but we will be sending a final report to them
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5 after the conclusion of the research project.
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8 9 10 ***Results***

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12 Our analysis of the interviews and the observations of the online communities allowed us to
13 distinguish three themes that were relevant for patients in the use of their online community.
14 These three themes included ‘the number of postings’, ‘coming across as a complainer’, and
15 ‘hesitating about legitimacy knowledge’. Below, we discuss the norms that exist around these
16 three themes, by presenting interview quotes and postings made on patients’ online
17 communities.
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28 *Number of postings*

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30 During the interviews, patients expressed that they were afraid to ‘bother’ their healthcare
31 providers with ‘too many’ questions. As a consequence, patients limited the number of
32 postings. They thoroughly screened their questions before actually posting them online.
33 Patients stated that they only posted questions they knew could be solved or issues that were
34 serious enough and needed immediate attention. In contrast, updates in the ‘diary’ section
35 were not subjected to the same scrutiny and were generally more elaborate. Patients
36 considered the ‘diary’ section as less intrusive to healthcare providers. Note that for the
37 ‘virtual meeting’ section, the online community automatically notified healthcare providers of
38 all new postings, whereas this was not the case for the ‘diary’ section. We conclude that
39 patients do not want to burden their healthcare providers with questions (demanding an active
40 response from the healthcare providers) but do feel the need to give them as much
41 information as possible (asking only passive consumption from healthcare providers).
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Coming across as a complainer

An important theme that came up in the interviews is the patient's fear of coming across as a complainer. Even though these patients have an illness with serious symptoms, they are afraid to emphasize that they suffer from this disease. One patient described this as follows:

"In my opinion, it quickly looks like you're complaining, if you say "I have this, I have that". If you put everything after one another, you think "boy, I'm such a nag". You don't have that as quickly in the consultation room" *Alicia – interview*

Patients considered even a simple listing of their symptoms within their online community as a form of 'complaining'. Most patients posted factual accounts of their well-being and did not express many of their emotions or feelings regarding their condition. In the interviews, patients stated that it was easier to discuss symptoms and emotions face-to-face with their healthcare providers. The non-verbal communication in this setting helped patients to express how they were actually feeling.

Hesitating about legitimacy of knowledge

To make decisions about treatments, healthcare providers and patients need to exchange knowledge and information. In contrast to face-to-face interactions, healthcare providers highly depend on patients to report symptoms, as healthcare providers can no longer visually observe them. However, patients were careful to make knowledge claims about their disease. Patients described their healthcare providers as ultimately having the knowledge required for making decisions about treatments. This is illustrated in the following excerpt from a patient's community:

1. Will, patient

By now I have begun with the second cycle of the phasing out of Sifrol. The uncontrolled movements have stayed, provided that they now occur during the hours of the evening (at about 6 pm-10:30 pm). When we had visitors I didn't notice anything.

I have the feeling that the overall condition is worsening. I have the impression that the prescribed medication (Sinemet) don't work together well. 11 am, 3 pm and 7 pm. The ability to move becomes worse/ less in between.

When walking I sometimes feel a bit insecure.

2. David, neurologist

This is imaginable with the decrease of Sifrol: this medication provides a basis on top of which the Sinemet has an effect. The decrease of Sifrol therefore gives less/shorter of an effect of the Sinemet.

I noticed that you are on my call sheet, we will discuss where to go from here over the phone.

3. Will, patient

Herewith an overview of medication use, as we discussed. I hope I understood it correctly. If not, can you adapt it?

[list medication, specified by time of intake]

Posting in 'virtual meeting'

In their online community, patients used phrasings that expressed humility in interpreting their symptoms. They presented their knowledge as an *opinion* that could be contested. In contrast, healthcare providers stated their interpretations of patients' symptoms factually and directly. This process established the knowledge of patients of their bodies as less legitimate than the professional knowledge healthcare providers possessed. Healthcare providers seemed to be the experts and to have the final say in determining changes in treatment plans.

Discussion

This study is among the first to examine the actual use of online communities rather than just their potential or limitations.¹⁰⁻¹² The main conclusion of this study reads as follows: even though online communities are an innovative, modern healthcare application that is widely expected to change power dynamics, the existence of traditional norms about patient-healthcare provider interactions prevents this change from occurring. Three themes appeared to be at play around these traditional norms. First, our study revealed that patients refrained from asking too many questions to their healthcare providers, but felt obliged to offer them regular updates. Second, patients scrutinized the content of their postings, being afraid to come across as complainers. Third, patients were cautious in making knowledge claims about their disease. Patients' use of their online community did allow them easier access to their healthcare providers, but did not result in full patient empowerment because of the way patients related to existing societal norms.

Our findings underscore that power processes between an individual patient and a healthcare provider do not exist in a vacuum. Instead, their relationship is embedded in larger societal dynamics (such as the medical education system, images about healthcare in the media, and insurance systems) that confine the way healthcare providers and patients interact. These societal dynamics inform the different norms about 'appropriate' communication between providers and patients, and in turn, impact the ways healthcare providers and patients interact when using online communities. Such power processes were readily visible within the online communities, because we had access to the content of actual, naturalistic discussions between patients and providers. We suspect, however, that similar power processes may also affect the interpersonal communication between doctors and patients in the consulting room, with a possibly adverse impact on the patient's ability to bring their own specific needs to the table.

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5 This study was not without limitations. First, the total number of patients included in this
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7 study was relatively small. Second, our sample was relatively well-educated. Such well-
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9 educated patients are more likely to have access to the Internet and to actively use an online
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11 health community. The patients included might therefore not be representative for the entire
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13 population of patients with Parkinson's disease. This bias was partly self-inflicted because we
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15 specifically sought access to patients who were using the online communities frequently.
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17 Note, however, that we believe that our selection might actually result in an underestimation
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19 of the power dynamics between patients and healthcare providers; the patients included in our
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21 study are expected to be the optimal group of chronically ill users of online communities, as
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23 they often possess the necessary technological skills and are of middle or high class. Since
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25 these norms and resulting power dynamics are already present within this group, we expect
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27 them to be even stronger among the patients not included in our sample, i.e. those that lack
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29 technical skills and who are of lower class. Such patients may be even more sensitive to these
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31 norms. Both drawbacks of this study should be addressed in future work, with inclusion of
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33 larger and more representative patient samples.
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41 Future work should also address whether the power dynamics observed here are unique to
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43 Parkinson patients, or whether these extend to other patient populations as well. Persons with
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45 Parkinson's disease are not representative for all patients, as they represent – on average – a
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47 relatively elderly patient group (the average age in this study was 63 years). Because of the
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49 era in which they grew up in, younger patients may be more familiar with technology and,
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51 simultaneously, might be relatively less sensitive to strict hierarchical boundaries. Therefore,
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53 younger patients could be better able to reap the benefits of using an online community.
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57 Moreover, Parkinson patients might experience specific symptoms (such as tremors or
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3 cognitive issues) that influence their use of the online communities. The extent to which the
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5 Parkinson-specific elements have a true impact deserves further study, for example by doing a
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7 comparative analysis of the use of online communities by different patient groups. Pending
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9 such evidence, and knowing that many chronic illnesses develop during and persist
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11 throughout later phases of life, the elderly age group remains an important and growing target
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13 group for the use of online communities. Developers of online health communities should
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15 take this elderly group into consideration in their design of the technologies. And, more
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17 importantly, physicians and other healthcare professionals should be more consciously aware
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19 of the implicit power dynamics that affect the communication with their patients.
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25 Online communities, similar to the ones under examination here, are starting to become more
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27 popular, and are often supported by large insurance companies, such as Kaiser Permanente in
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29 the US.³⁰ Therefore, we conclude by offering some practical guidance to improve the use of
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31 online communities especially in the ways that they can support healthcare providers (and
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33 patients!) in the shared decision-making regarding patients' care. Importantly, the power
34
35 dynamics identified here will not change automatically when a technological innovation is
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37 introduced. Rather, a much larger shift in the culture of medicine is necessary for such a
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39 change to be accomplished. A first step in this process could be that healthcare providers and
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41 patients engage in an open dialogue about their expectations and wishes with regard to using
42
43 the online communities. This dialogue might make each party more aware of the internalized
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45 norms they have in terms of using the technology. This awareness of internalized norms can
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47 be a first step toward changing them. A second step would be to address power processes and
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49 implicit norms in the training of young professionals during their medical curriculum. Finally,
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51 with regard to the technological design, we suggest changing the system to encourage two-
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53 way knowledge exchange. In their current state, the online communities mostly promote the
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3 information provision by patients, without a clear way for them to gather information from
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5 their healthcare providers, other than the occasional knowledge exchange taking place during
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7 a virtual meeting. For example, one might think of adding a section where healthcare
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9 providers can post general information relevant to the disease stage the patient is in, or to
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11 share information about the latest possible treatments, for patients to look at. Such two-way
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13 knowledge exchange could give patients additional resources to gain more control over their
14
15 own care, and would represent an important step forward in the creation of a much needed
16
17 new “participatory health” climate in healthcare.¹
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20 21 22 ***Contributorship statement***

23 LV gathered and analysed the data, drafted and revised the manuscript. IB analysed the data,
24
25 drafted and revised the manuscript. YB analysed the data, revised the draft manuscript, AvR
26
27 analysed the data, revised the draft manuscript, BB drafted and revised the manuscript.
28

29 30 ***Competing interests***

31 All authors have completed the ICMJE uniform disclosure form at
32
33 www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the
34
35 submitted work; no financial relationships with any organisations that might have an interest
36
37 in the submitted work in the previous three years; no other relationships or activities that
38
39 could appear to have influenced the submitted work.
40

41 42 ***Funding***

43 Prof. Bastiaan R. Bloem's research time, in general, was supported by a research grant of the
44
45 National Parkinson Foundation. However, the work presented here was not supported by any
46
47 external research grant, and no funding body had influence on the present research.
48

49 50 ***Data sharing statement***

51 In this article, three excerpts from a larger dataset of interviews and observations are
52
53 presented. They illustrate points present in the entire dataset, but because of space limitations
54
55 not all relevant excerpts are displayed. If necessary, the authors may provide other relevant
56
57 parts of the data. Such requests should be sent to the corresponding author via email.
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Table 1: Overview descriptive statistics of patients included in the study.

	Patients
Sample size – n	18
Gender - n (%)	
Women	9 (50)
Age - mean (SD)	63.1 (16.4)
Job status ^a (%)	
1 [low]	1 (5.6)
2	2 (11.1)
3	9 (50.0)
4 [high]	6 (33.3)
Years since diagnosis – mean (SD)	7.1 (3.7)
Months since use of the community – mean (SD)	28 (5.3)

^a based on the 4 skills levels as described in the ISCO-08

Coreq check list	Page number
Domain 1: Research team and reflexivity	
Personal Characteristics	
1. Interviewer/facilitator	7
2. Credentials	7
3. Occupation	7
4. Gender	7
5. Experience and training	7
Relationship with participants	
6. Relationship established	6
7. Participant knowledge of the interviewer	7
8. Interviewer characteristics	7
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and theory	8
Participant selection	
10. Sampling	6
11. Method of approach	6
12. Sample size	6
13. Non-participation	6 + 7
Setting	
14. Setting of data collection	7
15. Presence of non-participants	7
16. Description of sample	6 + 18
Data collection	
17. Interview guide	7
18. Repeat interviews	7
19. Audio/visual recording	8
20. Field notes	8
21. Duration	7
22. Data saturation	6
23. Transcripts returned	8 + 9
Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	7
25. Description of the coding tree	7
26. Derivation of themes	7
27. Software	7
28. Participant checking	7 + 8
Reporting	
29. Quotations presented	9 + 10 + 11
30. Data and findings consistent	9 + 10 + 11 + 12
31. Clarity of major themes	9 + 10 + 11 + 12
32. Clarity of minor themes	9 + 10 + 11 + 12

BMJ Open

Do online communities change power processes in healthcare? Using case studies to examine the use of online health communities by Parkinson's patients

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-012110.R1
Article Type:	Research
Date Submitted by the Author:	01-Aug-2016
Complete List of Authors:	Visser, Laura; Radboud University, Institute for Management Research Bleijenbergh, Inge; Radboud University, Institute for Management Research Benschop, Yvonne; Radboud University, Institute for Management Research van Riel, Allard; Radboud University, Institute for Management Research Bloem, Bastiaan; Radboud university medical center, Department of Neurology and Parkinson Center Nijmegen; Radboud university medical center, Donders Institute for Brain, Cognition and Behaviour
Primary Subject Heading:	Patient-centred medicine
Secondary Subject Heading:	Health informatics
Keywords:	patient empowerment, online communities, Parkinson-s disease < NEUROLOGY, e-health, foucault

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3 **Do online communities change power processes in healthcare? Using case studies to**
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5 **examine the use of online health communities by Parkinson's patients**
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25
26
27 **Total number of words:** 3,934

28
29 **Key words:** patient empowerment; e-health; online communities; Parkinson's disease; Foucault
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Abstract

Objective: Communication technologies, such as personal online health communities, are increasingly considered as a tool to realize patient empowerment. However, little is known about the *actual* use of online health communities. Here, we investigated if and how patients' use of online communities supports patient empowerment.

Setting: A network of primary and secondary care providers around individual Parkinson's patients.

Participants: We conducted case studies to examine our research question. We interviewed 18 patients with Parkinson's disease and observed the use of online health communities of 14 of them for an average of one year.

Primary outcome measures: We analysed the interviews and the online conversations between patients and healthcare providers, using Foucault's framework for studying power processes.

Results: We observed that patient empowerment is inhibited by implicit norms that exist within these communities around the number and content of postings. First, patients refrained from asking too many questions to their healthcare providers, but felt obliged to offer them regular updates. Second, patients scrutinized the content of their postings, being afraid to come across as complainers. Third, patients were cautious in making knowledge claims about their disease.

Conclusion: Changing implicit norms within online communities and the societal context they exist in seems necessary to achieve greater patient empowerment. Possibilities for changing these norms might lie in open dialogue between patient and healthcare providers about expectations, revising the curriculum of medical education, and redesigning personal online health communities to support two-way knowledge exchange.

Strengths and limitations of this study

- This study is among the first to examine the actual use of personal online health communities rather than just their potential or limitations;
- This study uses a complex framework for understanding power, drawn from the social sciences;
- The sample for this qualitative study is relatively small (we have interviewed 18 patients and observed 691 postings of 14 of them), but the length of the observation (a year on average) allows for studying these power processes in-depth. Further work

remains needed to fully comprehend the power processes for Parkinson patients with a wider range of disease severity and disease duration.

Introduction

The healthcare sector increasingly calls for patients to become more actively involved in their own care provision.¹ Such patient empowerment to date has been rarely achieved for which a number of reasons have been identified, including lack of knowledge, unwillingness, or disease-specific limitations on playing an active role²⁻⁴ Better empowered patients might result in decreased costs as well as increased quality of care,^{1 5 6} and allows patients to become active participants in their care rather than passive subjects.^{7 8} Implementing new communication technology to support communication between individual patients and their healthcare providers has been introduced as a possible new way to achieve these goals, because technology can provide increased access to care and the social and human capital required for patients to play an active role in their care.⁹⁻¹³ A wide variety of tools have been introduced, ranging from peer-to-peer support for patients,^{14 15} and large communities of patients and healthcare professionals asking and answering general health questions,^{16 17} to online communities that are tied to specific hospitals.¹⁸ Existing research tends to focus on the reasons why patients and healthcare providers do or do not use communication technology.¹⁹⁻
²¹ This research shows that data security and decrease in workload are important issues that determine whether or not healthcare providers adopt new technology.¹⁹ For patients, privacy is important, next to the technical skills necessary for using the Internet.¹²

However, little is known about the actual use of online health communities, and the behaviour of patients and providers therein. This is especially true for communities that allow for personal communication between patients and their own healthcare providers. In this study, we examine such personal online health communities which have a transformative potential

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2
3 because they integrate communication, previously conducted dispersedly among one patient
4 and her or his own healthcare providers, into a secured online forum. Knowing *how* patients
5 and healthcare providers use these online communities (rather than *why*), allows us to
6 demonstrate the possible relationship between personal online health communities and patient
7 empowerment, and to identify possible barriers as well as facilitators. Therefore, this article
8 questions if and how patients' use of online health communities supports patient
9 empowerment.
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21 To answer our research question, we examined personal online health communities used by
22 patients with Parkinson's disease. This degenerative chronic illness provides a relevant test
23 case to examine the use of online communities.¹⁸ The chronic nature of this disease²² ensures
24 that Parkinson patients build a long-term relationship with their healthcare providers, and thus
25 have a greater need to track their illness longitudinally. This makes it potentially more
26 gratifying for such chronic patients to invest in communicating online. Moreover, most
27 patients receive multiple therapies (offered by a range of different professional disciplines),²³
28 and the online communities potentially offer a convenient way to connect the different
29 healthcare providers.¹⁶
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43 Personal online health communities, which have been developed specifically for this group of
44 patients, enable online communication between individual patients and their healthcare
45 providers.²⁰ Specifically, both patients and their team of healthcare providers can access the
46 community by logging onto a secure website. This website offers multiple options for posting
47 healthcare-related messages.^{16 20} Patients can post diary entries to update their healthcare
48 providers, or start 'virtual meetings' where issues around their health can be discussed.
49 Furthermore, there is an option to post documents within an online library, and a list of
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3 individual health problems can be stored and updated when necessary. The patient is the
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5 formal owner of the community, and he or she is the person who invites others to join.
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10 To study patient empowerment via these communities, we draw from Foucault's framework
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12 for studying power processes.^{24 25} More conventional definitions of power focus on an
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14 individual's ability to steer someone else's behaviour, and patient empowerment is defined as
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16 healthcare providers (partly) giving this ability to patients so that they can make the 'right'
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18 choices.²⁶ In contrast, Foucault's work argues that power processes operate under the surface,
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20 through the distribution of norms that determine what normal and abnormal behaviour for
21
22 patients is. These norms are communicated via representation of healthcare provision in the
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24 news, TV shows, commercials, magazines, or medical textbooks.²⁷ These implicit norms
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26 make it seem natural how, for example, patients should approach their healthcare providers.²⁶
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28 There is no single person or institution that defines such norms, as all individuals in society
(unconsciously) engage in activities to (re)produce these norms. Therefore, actively changing
such norms is not possible for any individual healthcare provider or patient, but instead
requires (larger groups within) society to develop and adopt a new discourse about healthcare
provision. Our analysis focused on the norms around the use of online healthcare
communities and their effect on patient empowerment. In our understanding patient
empowerment is, therefore, not something that can be 'done upon' patients, but it is a concept
that needs to be translated to 'empowering spaces' where norms are changed by patients
actively defining their 'truth of care'.²⁸ By bringing in this social sciences perspective, this
article is an important addition to the current and lively debates around patient-centred
healthcare,^{1 29} as it applies a more sophisticated view on power processes.

Methods

Participants

Semi-structured interviews and observations were conducted between October 2012 and February 2014, involving 18 patients with Parkinson's disease (see Table 1 for some demographic information). All patients participated in a trial at four hospitals in the Netherlands where Parkinson nurses supported them in setting up a personalized online community (total number of patients included in the trial was 150, of which about 50 were active using it). We used a purposive sampling technique by asking the Parkinson nurses to identify patients that actively used their online communities. We specifically asked for such patients, because their active use signified the intended use of the communities. Limiting our sample to these patients allows us to see how such intended use affects the possibilities for patient empowerment. No other inclusion or exclusion criteria were applied, and we stopped including more patients when data saturation was achieved. In this article, we use aliases to protect the patients' privacy.

Interviews

We used semi-structured interviews to encourage patients to reflect on their use of the online health communities. The patient interviews were conducted face-to-face in the patients' homes, and they lasted on average 60 minutes and were performed by the first author (LV). LV, a woman, was a PhD candidate in her early twenties at the time, with previous experience interviewing elderly people. Her academic position might have affected the interviewee process with some of the patients who had lower educational levels. At the same time, her gender and age allowed the interviewer to come across as non-threatening. To further reduce the unbalanced relationship between interviewer and interviewees, the interviewees were conducted in the patient's home, rather than a space 'owned' by the interviewer. The

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2
3 interviews were conducted between the interviewer and patients, although in some cases,
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5 patients' partners were also present in the home (often in another room). An interview guide
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7 was used that involved questions about how patients experienced the use of their online
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9 community, the relationship with their healthcare providers, and their role in the care
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11 provision. The research team's interest in power, however, was not explicitly discussed
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13 during the interview, nor was it mentioned in the introduction to the interview to prevent any
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15 bias in the interviewees' responses.
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20 21 *Observations*

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23 Next to collecting data, the interviews with patients were also used to inform them about the
24
25 authors' intent to observe the communication within the online health communities.
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28 Ultimately, 14 patients gave LV access to their personal online health communities. The 4
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30 patients that we could not observe either declined (n=2), or were no longer reachable after the
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32 first interview (n=2). The period of observation for the remaining 14 patients varied between
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34 1 – 1.5 year. In total, 691 postings were made during this period in the online communities of
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36 these 14 patients, either by the patients themselves or by their healthcare providers. In our
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38 observations of these postings, we analysed the placement, content and timing of postings,
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40 who authored the postings, and the content and timing of responses.
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45 46 *Analysis*

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48 The tape-recorded interviews were transcribed verbatim and screenshots were taken from the
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50 webpages of the online communities. Qualitative analysis on the data (in Dutch) was
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52 performed using ATLAS.ti.³⁰ Using qualitative analysis methods has allowed us to gain an in-
53
54 depth understanding of power processes, a complex concept difficult to adequately capture in
55
56 standardized questions in a survey.³¹ Framework of analysis was Foucault's definition of
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3 power.²⁴ In contrast to more conventional definitions of power (as the individual's ability to
4
5 steer someone else's behaviour), Foucault poses that power processes operate under the
6
7 surface, through processes of normalization, which determine how we see the social world
8
9 and what normal and abnormal behaviour is. This definition of power has received limited
10
11 attention in medical journals,^{26 28 32 33} but is widely used in healthcare research in the social
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13 sciences.^{34 35} Foucault's definition of power is useful for understanding patient empowerment,
14
15 because it understands changing power processes not just as changing positions or relations
16
17 between individual patients and healthcare providers, but as the creation of 'empowering
18
19 spaces' for shifting knowledge about appropriate relationships and behaviour in care and
20
21 wider society.^{26 28} Therefore, when we examine power processes within the use of online
22
23 communities, we analyse where such norms are communicated "that determine what can be
24
25 said by whom and when",³⁶ using a discourse analysis approach.³⁷ This approach requires
26
27 noting when respondents used phrases such as "I should", "I have to" or otherwise talked
28
29 about the 'appropriateness' of the content or timing of their postings. Furthermore, we
30
31 analysed how suggestions or ideas were articulated and who uses which phrasing. For
32
33 example, the use of "I suggest" or "I would like to ask" shows different norms about the
34
35 legitimacy of one's ideas than using phrasing such as "I feel" or "my impression is". Our
36
37 analysis of the transcribed interviews was not returned to the interviewees, because a
38
39 validation of the analysis would require knowledge of Foucault's work and access to the
40
41 entire dataset to understand the patterns we identified. However, we will be sending a final
42
43 report to the interviewees after the conclusion of the research project. All the data were
44
45 analysed in Dutch, and only the quotes that were ultimately used in this article were translated
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47 into English.
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Validity

We ensured validity of our analysis through two different ways of triangulation.³⁸ First, we applied methodological triangulation, using both interviews and observations to collect our data and analyse the use of the online communities. Second, we applied investigator triangulation by analysing the data with multiple members of the research team.

Results

Our analysis of the interviews and the observations of the online communities allowed us to distinguish three themes that were relevant for patients in the use of their online community. These three themes included ‘the number of postings’, ‘coming across as a complainer’, and ‘hesitating about legitimacy knowledge’. Below, we discuss the norms that exist around these three themes, by presenting interview quotes and postings made on patients’ online communities. The interview quotes and postings we display here are illustrations of larger patterns in our data. We could not include all examples due to space restrictions.

Number of postings

During the interviews, patients expressed that they were afraid to ‘bother’ their healthcare providers with ‘too many’ questions. As a consequence, patients limited the number of postings. They thoroughly screened their questions before actually posting them online. Patients stated that they only posted questions they knew could be solved or issues that were serious enough and needed immediate attention. In contrast, updates in the ‘diary’ section were not subjected to the same scrutiny and were generally more elaborate. Patients considered the ‘diary’ section as less intrusive to healthcare providers. Note that for the ‘virtual meeting’ section, the online community automatically notified healthcare providers of all new postings, whereas this was not the case for the ‘diary’ section. We conclude that patients do not want to burden their healthcare providers with questions (demanding an active

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3 response from the healthcare providers) but do feel the need to give them as much
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5 information as possible (asking only passive consumption from healthcare providers).
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10 *Coming across as a complainer*

11 An important theme that came up in the interviews is the patient's fear of coming across
12 as a complainer. Even though these patients have an illness with serious symptoms, they
13 are afraid to emphasize that they suffer from this disease. One patient described this as
14 follows:
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16

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18 *"In my opinion, it quickly looks like you're complaining, if you say "I have this, I
19 have that". If you put everything after one another, you think "boy, I'm such a nag".
20 You don't have that as quickly in the consultation room" Alicia – interview*
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29 Patients considered even a simple listing of their symptoms within their online community as
30 a form of 'complaining'. Most patients posted factual accounts of their well-being and did not
31 express many of their emotions or feelings regarding their condition. In the interviews,
32 patients stated that it was easier to discuss symptoms and emotions face-to-face with their
33 healthcare providers. The non-verbal communication in this setting helped patients to express
34 how they were actually feeling.
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45 *Hesitating about legitimacy of knowledge*

46 To make decisions about treatments, healthcare providers and patients need to exchange
47 knowledge and information. In contrast to face-to-face interactions, healthcare providers
48 highly depend on patients to report symptoms, as healthcare providers can no longer visually
49 observe them. However, patients were careful to make knowledge claims about their disease.
50 Patients described their healthcare providers as ultimately having the knowledge required for
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3 making decisions about treatments. This is illustrated in the following excerpt from a patient's
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5 community:
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8 **1. Will, patient**

9 By now I have begun with the second cycle of the phasing out of Sifrol. The
10 uncontrolled movements have stayed, provided that they now occur during the hours
11 of the evening (at about 6 pm-10:30 pm). When we had visitors I didn't notice
12 anything.
13

14
15 I have the feeling that the overall condition is worsening. I have the impression that
16 the prescribed medication (Sinemet) don't work together well. 11 am, 3 pm and 7 pm.
17 The ability to move becomes worse/ less in between.
18

19 When walking I sometimes feel a bit insecure.
20

21
22 **2. David, neurologist**

23
24 This is imaginable with the decrease of Sifrol: this medication provides a basis on top
25 of which the Sinemet has an effect. The decrease of Sifrol therefore gives less/shorter
26 of an effect of the Sinemet.
27

28
29 I noticed that you are on my call sheet, we will discuss where to go from here over
30 the phone.
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34

35
36 **3. Will, patient**

37 Herewith an overview of medication use, as we discussed. I hope I understood it
38 correctly. If not, can you adapt it?
39

40 [list medication, specified by time of intake]
41

42 Posting in 'virtual meeting'
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46 In their online community, patients used phrasings that expressed humility in interpreting
47 their symptoms. They presented their knowledge as an *opinion* that could be contested. In
48 contrast, healthcare providers stated their interpretations of patients' symptoms factually and
49 directly. This process established the knowledge of patients of their bodies as less legitimate
50 than the professional knowledge healthcare providers possessed. Healthcare providers seemed
51 to be the experts and to have the final say in determining changes in treatment plans.
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Discussion

This study is among the first to examine the actual use of online communities rather than just their potential or limitations.¹⁹⁻²¹ The main conclusion of this study reads as follows: even though online communities are an innovative, modern healthcare application that is widely expected to change power processes, the existence of traditional norms about patient-healthcare provider interactions prevents this change from occurring. Three themes appeared to be at play around these traditional norms. First, our study revealed that patients refrained from asking too many questions to their healthcare providers, but felt obliged to offer them regular updates. Second, patients scrutinized the content of their postings, being afraid to come across as complainers. Third, patients were cautious in making knowledge claims about their disease. Patients' use of their online community did allow them easier access to their healthcare providers, but did not result in full patient empowerment because of the way patients related to existing societal norms.

Our findings underscore that power processes between an individual patient and a healthcare provider do not exist in a vacuum. Instead, their relationship is embedded in larger societal dynamics (such as the medical education system, images about healthcare in the media, and insurance systems) that confine the way healthcare providers and patients interact. These societal dynamics inform the different norms about 'appropriate' communication between providers and patients, and in turn, impact the ways healthcare providers and patients interact when using online communities. Such power processes were readily visible within the online communities, because we had access to the content of actual, naturalistic discussions between patients and providers. We suspect, however, that similar power processes may also affect the

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3 interpersonal communication between doctors and patients in the consulting room, with a
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5 possibly adverse impact on the patient's ability to bring their own specific needs to the table.
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10 This study was not without limitations. First, the total number of patients included in this
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12 study was relatively small (18 patients were included, and 14 were fully analysed). We did
13
14 include an equal representation of men and women in this study. Mean age of included
15
16 subjects was 63 years, and their mean disease duration was 7 years. Second, our sample was
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18 relatively well-educated. Such well-educated patients are more likely to have access to the
19
20 Internet and to actively use an online health community. The patients included might
21
22 therefore not be representative for the entire population of patients with Parkinson's disease.
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24 This bias was partly self-inflicted because we specifically sought access to patients who were
25
26 using the online communities frequently. Note, however, that we believe that our selection
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28 might actually result in an underestimation of the power processes between patients and
29
30 healthcare providers; the patients included in our study are expected to be the optimal group
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32 of chronically ill users of online communities, as they often possess the necessary
33
34 technological skills and are of middle or high class. Since these norms and resulting power
35
36 processes are already present within this group, we expect them to be even stronger among
37
38 the patients not included in our sample, i.e. those that lack technical skills and who are of
39
40 lower class. Such patients may be even more sensitive to these norms. Both drawbacks of this
41
42 study should be addressed in future work, with inclusion of larger and more representative
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44 patient samples, especially a wider range of disease severity and disease duration, and also
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46 include patients who are possibly less "internet savvy" than the patients who voluntarily
47
48 participated in the online communities that we analyzed.
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3 Future work should also address whether the power processes observed here are unique to
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5 Parkinson patients, or whether these extend to other patient populations as well. Persons with
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7 Parkinson's disease are not representative for all patients, as they represent – on average – a
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9 relatively elderly patient group (the average age in this study was 63 years). Because of the
10
11 era in which they grew up in, younger patients may be more familiar with technology and,
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13 simultaneously, might be relatively less sensitive to strict hierarchical boundaries. Therefore,
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15 younger patients could be better able to reap the benefits of using an online community.
16
17 Moreover, Parkinson patients might experience specific symptoms (such as tremors or
18
19 cognitive issues) that influence their use of the online communities. The extent to which the
20
21 Parkinson-specific elements have a true impact deserves further study, for example by doing a
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23 comparative analysis of the use of online communities by different patient groups. Pending
24
25 such evidence, and knowing that many chronic illnesses develop during and persist
26
27 throughout later phases of life, the elderly age group remains an important and growing target
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29 group for the use of online communities. Developers of online health communities should
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31 take this elderly group into consideration in their design of the technologies. And, more
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33 importantly, physicians and other healthcare professionals should be more consciously aware
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35 of the implicit power processes that affect the communication with their patients.
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43 Online communities, similar to the ones under examination here, are starting to become more
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45 popular, and are often supported by large insurance companies, such as Kaiser Permanente in
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47 the US.³⁹ Therefore, we conclude by offering some practical guidance to improve the use of
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49 online communities especially in the ways that they can support healthcare providers (and
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51 patients!) in the shared decision-making regarding patients' care. Importantly, the power
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53 processes identified here will not change automatically when a technological innovation is
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55 introduced. Rather, a much larger shift in the culture of medicine is necessary for such a
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3 change to be accomplished. This shift in culture will have to be accomplished by both top-
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5 down (policy changes) and bottom-up (patient mobilization and healthcare professionals
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7 engagement) processes. A first step in this process could be that healthcare providers and
8
9 patients engage in an open dialogue about their expectations and wishes with regard to using
10
11 the online communities. This dialogue might make each party more aware of the internalized
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13 norms they have in terms of using the technology. This awareness of internalized norms can
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15 be a first step toward changing them. A second step would be to address implicit norms in the
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17 training of young professionals during their medical curriculum. Finally, with regard to the
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19 technological design, we suggest changing the system to encourage two-way knowledge
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21 exchange. In their current state, the personal online health communities mostly promote the
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23 information provision by patients, without a clear way for them to gather information from
24
25 their healthcare providers, other than the occasional knowledge exchange taking place during
26
27 a virtual meeting. One example is adding a section where healthcare providers can post
28
29 general information relevant to the disease stage the patient is in, or to share information
30
31 about the latest possible treatments, for patients to look at. Such two-way knowledge
32
33 exchange could give patients additional resources to gain more control over their own care,
34
35 and would represent an important step forward in the creation of a much needed
36
37 “participatory health” climate in healthcare.¹
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44 ***Contributorship statement***

45 LV gathered and analysed the data, drafted and revised the manuscript. IB analysed the data,
46
47 drafted and revised the manuscript. YB analysed the data, revised the draft manuscript, AvR
48
49 analysed the data, revised the draft manuscript, BB drafted and revised the manuscript.
50

51 ***Competing interests***

52 All authors have completed the ICMJE uniform disclosure form at
53
54 www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the
55
56 submitted work; no financial relationships with any organisations that might have an interest
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1
2
3 in the submitted work in the previous three years; no other relationships or activities that
4 could appear to have influenced the submitted work.
5
6

7 ***Funding***

8 Prof. Bastiaan R. Bloem's research time, in general, was supported by a research grant of the
9 National Parkinson Foundation. However, the work presented here was not supported by any
10 external research grant, and no funding body had influence on the present research.
11
12
13

14 ***Ethics approval***

15 The ethics committee of the two participating hospitals (Radboudumc in Nijmegen and
16 Martini Ziekenhuis in Groningen) approved our research protocol. All patients gave signed
17 informed consent for both the interviews and observations.
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22 ***Data sharing statement***

23 In this article, three excerpts from a larger dataset of interviews and observations are
24 presented. They illustrate points present in the entire dataset, but because of space limitations
25 not all relevant excerpts are displayed. If necessary, the authors may provide other relevant
26 parts of the data. Such requests should be sent to the corresponding author via email.
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Table 1: Overview descriptive statistics of patients included in the study.

	Patients
Sample size – n	18
Gender - n (%)	
Women	9 (50)
Age - mean (SD)	63.1 (16.4)
Job status ^a (%)	
1 [low]	1 (5.6)
2	2 (11.1)
3	9 (50.0)
4 [high]	6 (33.3)
Years since diagnosis – mean (SD)	7.1 (3.7)
Months since use of the community – mean (SD)	28 (5.3)

^a based on the 4 skills levels as described in the ISCO-08

Coreq check list	Page number
Domain 1: Research team and reflexivity	
Personal Characteristics	
1. Interviewer/facilitator	7
2. Credentials	7
3. Occupation	7
4. Gender	7
5. Experience and training	7
Relationship with participants	
6. Relationship established	6
7. Participant knowledge of the interviewer	7
8. Interviewer characteristics	7
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and theory	8
Participant selection	
10. Sampling	6
11. Method of approach	6
12. Sample size	6
13. Non-participation	6 + 7
Setting	
14. Setting of data collection	7
15. Presence of non-participants	7
16. Description of sample	6 + 18
Data collection	
17. Interview guide	7
18. Repeat interviews	7
19. Audio/visual recording	8
20. Field notes	8
21. Duration	7
22. Data saturation	6
23. Transcripts returned	8 + 9
Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	7
25. Description of the coding tree	7
26. Derivation of themes	7
27. Software	7
28. Participant checking	7 + 8
Reporting	
29. Quotations presented	9 + 10 + 11
30. Data and findings consistent	9 + 10 + 11 + 12
31. Clarity of major themes	9 + 10 + 11 + 12
32. Clarity of minor themes	9 + 10 + 11 + 12

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