

Personal health communities: a phenomenological study of a new health-care concept

Johanna Wilhelmina Maria Aarts MD PhD,* Femke Vennik MSc,† Willianne L. D. M. Nelen MD PhD,‡ Martijn van der Eijk MSc,§ Bastiaan R. Bloem MD PhD,¶ Marjan J. Faber PhD** and Jan A. M. Kremer MD PhD††

*Gynaecologist in Training, ‡Senior Researcher, ††Professor, Gynaecologist, Department of Obstetrics and Gynaecology, Radboud University Nijmegen Medical Centre, Nijmegen, †Researcher, Institute of Health Policy & Management (iBMG), Erasmus University Rotterdam, DR Rotterdam, §Researcher, ¶Professor, Neurologist, Department of Neurology, Radboud University Nijmegen Medical Centre and **Senior Researcher, Scientific Institute for Quality of Healthcare, Radboud University Nijmegen Medical Centre, Nijmegen, the Netherlands

Abstract

Correspondence

Johanna W. M. Aarts, MD PhD
Department of Obstetrics and
Gynaecology, route 791
Radboud University Nijmegen Medical
Centre
PO BOX 9101
6500 HB Nijmegen
the Netherlands
E-mail: a.aarts@obgyn.umcn.nl

Accepted for publication

14 January 2014

Keywords: health reform, Internet,
patient empowerment, patient
participation, quality of care

Context Fragmentation of care, complexity of diseases and the need to involve patients actively in their individual health care 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 health care process. Once gathered, the patient and health care 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 health care.

Design Qualitative phenomenological study.

Participants Eighteen respondents, consisting of women experiencing infertility ($n = 5$), persons with Parkinson's disease ($n = 6$), a gynaecologist, 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 health care 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 health care. It warrants further research to study its effect on concrete health outcomes.

Introduction

Current health care faces some serious challenges. Due to complexity of diseases, health care services are increasingly distributed across multiple clinicians in different specializations and institutions.^{1,2} Health care has evolved into multidisciplinary teamwork of various physicians, nurses and other care providers, who often work in different departments and organizations.³ This poses challenges not only for health-care professionals, but also for individual patients, as it demands a more active role in the organization of their own health care.^{4,5} 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.⁶ Additionally and importantly, many patients also express the wish to be more actively involved.^{7,8} However, current health care is not prepared to respond to these developments adequately for several reasons. First, health care is primarily organized from the health care 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 health care providers could be improved.⁹ Thirdly, so far, interventions to activate patients and put them in the heart of the health system are not yet well developed.^{5,10–12}

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 health-care professionals from different health care 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 health care.

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.^{13–18} On the website www.patientslikeme.com, patients can discuss their medical data online with 'patients-like-them'.¹⁷ 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 transparent* for both the patient and his or her health care providers. Third, to have access to the PHC, health-care 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.¹⁴ Finally, in many of the aforementioned systems, patients missed the *opportunity to communicate with others*, and in particular health-care professionals, about their medical data.^{15,16} Combining medical data with the possibility to communicate with others seems required to meet self-management goals¹⁹ and is possible within PHCs.

Although many studies are conducted into the development, implementation and use of PHRs and EHRs, for example,¹⁵ to our knowledge, there is no information about the consequences for health-care 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 health-care professionals. The research question is threefold: (i) How do patients and health-care 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 health care? A qualitative research design can ideally answer this question, because one can go in-depth to capture the complexity of data.²⁰

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.^{21–24} Phenomenological analyses do not discover causes.²¹ 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 health-care 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 health care 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 health care. 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. Health-care professionals need to use their national electronic identification for health-care 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 gynaecologists. 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 gynaecologist 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 intracytoplasmic 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 health care). 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.^{25,26}

Dutch Parkinson's disease care

Parkinson's disease 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.²⁷ More and more, professionals are convinced that a multidisciplinary team approach is desirable for most PD patients.⁹ In the Netherlands, the lead physician is a neurologist, whereas Parkinson specialist nurses and a variety of allied health-care professionals, physical therapists, speech language pathologists and occupational therapists are regularly involved in treatment of PD patients.⁹

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.²⁸ 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 health-care 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 gynaecologist, 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 gynaecologist 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 health-care professionals was lack of experience with the PHC. Table 1 shows the background characteristics of all interviewees. By involving patients and health-care 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 health-care 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 interviewer was not involved in the patients' clinical care

Table 1 Participants' background characteristics

Patients	Gender	Age (yrs)	Primary health condition (since)	Current treatment	Health-care professionals involved into patient's health ^a
1	Female	31	Primary infertility (2009)	2nd IVF cycle	IVF team, gynaecologist (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	Gynaecologist
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

^aDifferent health care 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 gynaecologists, 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.

and did not speak before with the health-care 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 health-care 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 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 health-care professional population. However, the maximum number of health-care professionals who participated in the PHCs and agreed to take part in the study, were interviewed.

Box 1 Interview guide for semi-structured interviews with patients and professionals		
	Patient	Health care professional
General	What is the course of your condition What is the type of treatment How many health-care 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 is your profession? What do you find important in the relationship with your patients?
PHC	What was the reason to create a personal health community? How long ago did you start?	Why did you decide to participate in the personal health community of your patient? How long ago did you start?
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? Who is currently participating? Who did you invite or wanted to invite? Why these people? Could you give some examples of information you uploaded? Could you give examples of questions you posted? Could you explain in what way the PHC is (dis) advantageous for you and your health? How do you experience the contact with your health-care professionals in the PHC? Did you talk about the PHC during a consultation with your doctor in the hospital?	How much do you use the PHC of your patients? In how many PHCs do you participate? What have you actively contributed to these PHCs (e.g. answering questions, uploading information)? Could you explain in what way the PHC could be (dis)advantageous for patients' health? How do you experience the contact with your patients in the PHC? Did you talk about the PHC during a consultation with your patient?
Quality of care ¹	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-centredness of care ²	Do you think that the introduction of a PHC could improve patient-centredness 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-centredness 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?

Box 1 Continued		
	Patient	Health care professional
Future perspectives	<p>What do you think that the PHC could contribute to future health care in relation to ...</p> <ul style="list-style-type: none"> your role in your disease management role of your care provider patient-doctor relationship your quality of life <p>What are the conditions to meet these future perspectives?</p>	<p>What do you think that the PHC could contribute to future health care in relation to ...</p> <ul style="list-style-type: none"> the role of your patient the role of you as a care provider task division between different health-care professionals patient-doctor relationship <p>What are the conditions to meet these future perspectives?</p>

¹Dimensions based on framework for quality of care of World Health Organization (2006).³⁸
²Dimensions based on patient-centredness framework, respectively in infertility of van Empel *et al.* (2010) and in Parkinson's disease of van der Eijk *et al.* (2011)^{39,40}.

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.²¹ The aim of the data analysis was to understand the complexity of meaning of the PHC to patients and health-care 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 determined²⁹ (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.²¹ (iv) Primary themes and subthemes

were determined, their interaction and the meaning of their interaction¹⁹ (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 health-care 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 PHC's for health care. We do this by making a distinction between PD- and infertility care and between patients and health-care 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 health-care 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 health care 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 Fig. 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 2. 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 health-care professionals; (iii) across all participants altogether.

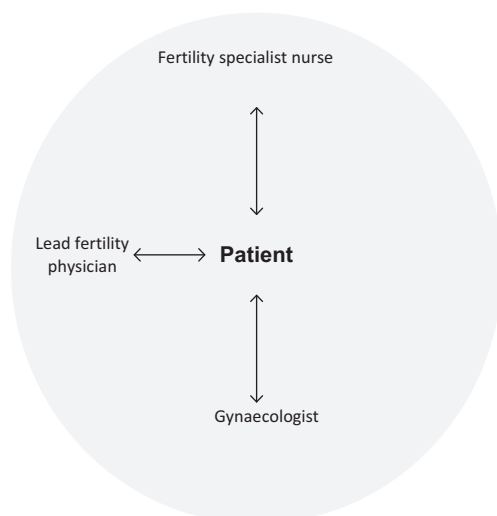
PD versus infertility

Particularly PD patients and health-care professionals expected that using the PHC could lead to better tuning, exchanging and collaboration between health-care 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'.

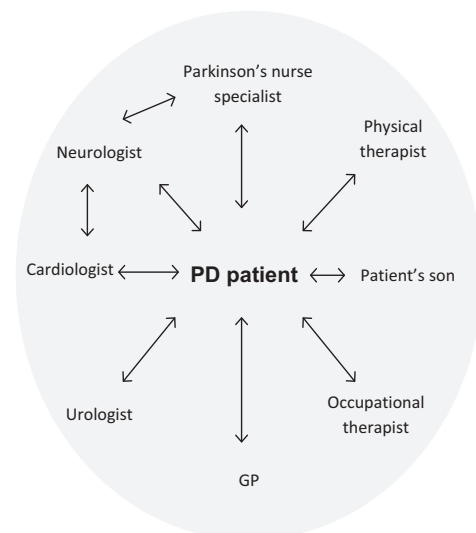
The main interesting part [of the PHCs] is in the first place that one another can find each other more easily; the consultation format could take place more easily. Also among different medical disciplines. That someone, a client, has a question and that all persons who're involved in the treatment 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 health-care 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



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 gynaecologist, her lead fertility physician and fertility specialist nurse for emotional support and tailored information provision.



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

Figure 1 Two examples of PHC composition representing a patient’s online health network.

(i.e. human factors). The latter group underlined that the PHC made health care 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,

Table 2 Participants' use of and participation in the personal health community

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 gain any experience with the particular function of the PHC.; *at time of interview.

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 h per 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 health-care professionals

By comparing the views of patients and health care professionals regarding the advantages and disadvantages of PHCs, it becomes clear that especially patients thought that health-care 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 health-care 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 health-care 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 health-care 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 health care 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, health-care professionals put more emphasis on the impact of using PHCs on current health care 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 fulfil 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 health care 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 health care.

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 health-care 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 health care. 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 health-care professionals. This is, for instance, convenient when the patient forgets easily, has changed from health-care 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 health-care 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 health-care 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).³⁰ This could, for instance, facilitate general practitioners or other health-care 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).^{31,32} These are not suitable anymore when looking at the above-mentioned future health care 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.³³ 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 health care providers outside traditional face-to-face care.

Second, in many EHR and PHR projects no clear role and position of the patient was defined.³⁴ 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 health-care professionals. This combination was missing in other EHR and PHR systems.¹⁴ 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 health care 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 health-care 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)³⁵ in a first pilot study can provide important information for future evaluations.³⁶ 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 health care 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 health care (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 health care. Despite the promising future perspectives, an adequate implementation strategy is needed acknowledging all barriers, possibly hampering its future success.^{14,15}

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.³⁶ To enhance credibility, we performed investigator triangulation,³⁷ 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 health-care 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 health care could lead to promising improvements in both the organization of care and care experience, according to the patients and health-care 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 health-care 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 health care. It warrants further research to study its effect on concrete health outcomes.

Acknowledgements

We want to thank all the interviewees for their time and provision of interesting and relevant data.

Conflict of interest

No conflict of interests to declare.

References

- 1 Corrigan JM, Donaldson MS, Kohn LT, Maguire SK, Pike KC. Crossing the quality chasm. In: National Academy of Sciences NaP (ed) *A new Health System for the 21st Century*. Washington, DC: Institute of Medicine, 2001; 2–5.
- 2 Wagner EH, Bennett SM, Austin BT, Greene SM, Schaefer JK, Vonkorff M. Finding common ground: patient-centeredness and evidence-based chronic illness care. *Journal of Alternative and Complementary Medicine*, 2005; **11**(Suppl 1): S7–S15.

- 3 Naik AD, Singh H. Electronic health records to coordinate decision making for complex patients: what can we learn from wiki? *Medical Decision Making*, 2010; **30**: 722–731.
- 4 Richards T. Enlist the patients' help. *BMJ*, 2011; **343**: d5827.
- 5 Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes *Journal of General Internal Medicine*, 2012; **27**: 520–526.
- 6 Van de Bovenkamp HM. *The Limits of Patient Power: Examining Active Citizenship in Dutch Health Care*. Rotterdam: Erasmus University Rotterdam, 2010.
- 7 Tomes N. Patient empowerment and the dilemmas of late-modern medicalisation. *Lancet*, 2007; **369**: 698–700.
- 8 Kremer JA, Van Der Eijk M, Aarts JW, Bloem BR. The individual formerly known as patient, TIFKAP. *Minerva Medica*, 2011; **102**: 505.
- 9 Nijkrake MJ, Keus SH, Kalf JG *et al.* Allied health care interventions and complementary therapies in Parkinson's disease. *Parkinsonism & Related Disorders*, 2007; **13**(Suppl 3): S488–S494.
- 10 Frosch DL, Elwyn G. I believe, therefore I do. *Journal of General Internal Medicine*, 2011; **26**: 2–4.
- 11 Hibbard JH, Mahoney ER, Stock R, Tusler M. Do increases in patient activation result in improved self-management behaviors? *Health Services Research*, 2007; **42**: 1443–1463.
- 12 Van de Bovenkamp HM, Zuiderent-Jerak T. An empirical study of patient participation in guideline development: exploring the potential for articulating patient knowledge in evidence-based epistemic settings. *Health Expectations*, 2013. doi: 10.1111/hex.12067. [Epub ahead of print].
- 13 Archer N, Fevrier-Thomas U, Lokker C, McKibbin KA, Straus SE. Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, 2011; **18**: 515–522.
- 14 Greenhalgh T, Wood GW, Bratan T, Stramer K, Hinder S. Patients' attitudes to the summary care record and HealthSpace: qualitative study. *BMJ*, 2008; **336**: 1290–1295.
- 15 Sheikh A, Cornford T, Barber N *et al.* Implementation and adoption of nationwide electronic health records in secondary care in England: final qualitative results from prospective national evaluation in "early adopter" hospitals. *BMJ*, 2011; **343**: d6054.
- 16 Zulman DM, Nazi KM, Turvey CL, Wagner TH, Woods SS, An LC. patient interest in sharing personal health record information: a web-based survey. *Annals of Internal Medicine*, 2011; **155**: 805–810.
- 17 Wicks P, Massagli M, Frost J *et al.* Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research*, 2010; **12**: e19.
- 18 Greenhalgh T, Stramer K, Bratan T, Byrne E, Mohammad Y, Russell J. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. *BMJ*, 2008; **337**: a1786.
- 19 Shachak A, Jadad AR. Electronic health records in the age of social networks and global telecommunications. *JAMA*, 2010; **303**: 452–453.
- 20 Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ*, 2000; **320**: 114–116.
- 21 Giorgi A. The phenomenological movement and research in the human sciences. *Nursing Science Quarterly*, 2005; **18**: 75–82.
- 22 Toscano SE, Montgomery RM. The lived experience of women pregnant (including preconception) post *in vitro* fertilization through the lens of virtual communities. *Health Care for Women International*, 2009; **30**: 1014–1036.
- 23 Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 2007; **17**: 1372–1380.
- 24 Reeves S, Albert M, Kuper A, Hodges BD. Why use theories in qualitative research? *BMJ*, 2008; **337**: a949.
- 25 Verhaak CM, Smeenk JM, Evers AW, Kremer JA, Kraaimaat FW, Braat DD. Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Human Reproduction Update*, 2007; **13**: 27–36.
- 26 Schmidt L. Psychosocial burden of infertility and assisted reproduction. *Lancet*, 2006; **367**: 379–380.
- 27 Langston JW. The Parkinson's complex: parkinsonism is just the tip of the iceberg. *Annals of Neurology*, 2006; **59**: 591–596.
- 28 Gibbs L, Kealy M, Willis K, Green J, Welch N, Daly J. What have sampling and data collection got to do with good qualitative research? *Australian and New Zealand Journal of Public Health*, 2007; **31**: 540–544.
- 29 Hycner RH. Some guidelines for the phenomenological analysis of interview data. *Human Studies*, 1985; **8**: 279–303.
- 30 Olsson L, Jakobson Ung E, Swedberg K, Ekman I. Efficacy of patient-centred care as an intervention in controlled trials - a systematic review. *Journal of Clinical Nursing*, 2013; **22**: 456–465.
- 31 Osborn CY, Mayberry LS, Mulvaney SA, Hess R. Patient web portals to improve diabetes outcomes: a systematic review. *Current Diabetes Reports*, 2010; **10**: 422–435.

- 32 Tuil WS, Verhaak CM, Braat DD, de Vries Robbe PF, Kremer JA. Empowering patients undergoing *in vitro* fertilization by providing Internet access to medical data. *Fertility and Sterility*, 2007; **88** : 361–368.
- 33 Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine*, 1978; **2**: 85–93.
- 34 Pluut B Het landelijk EPD als blackbox: besluitvorming en opinies in kaart Wetenschappelijke Raad voor Regeringsbeleid (WRR), 2010. Available at: <http://bettinepluut.nl/wp-content/uploads/2010/10/WRR-Webpublicatie-nr.-45-Het-Landelijk-EPD-als-Blackbox.pdf>, accessed 22 June 2013.
- 35 Campbell NC, Murray E, Darbyshire J *et al.* Designing and evaluating complex interventions to improve health care. *BMJ*, 2007; **334**: 455–459.
- 36 Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 2004; **24**: 105–12.
- 37 Polit DF, Beck CT. *Nursing Research Principles and Methods*. 7th edn. Philadelphia: Lippincott Williams & Wilkins, 2004.
- 38 Bengoa RK, Key P, Leatherman S, Massoud R, Saturno P. *Quality of care: a process for making strategic choices in health systems*. In: Organization WH (ed). Geneva: World Health organization, 2006; **10**: 10–20.
- 39 van Empel IWH, Aarts JWM, Cohlen BJ, Laven J, Huppelschoten A, Nelen WLDM, Kremer JAM. Measuring patient-centredness, the neglected outcome in fertility care: a random multicentre study. *Human Reproduction*, 2010; **25**: 2516–2526.
- 40 van der Eijk M, Faber MJ, Ummels I, Aarts JWM, Munneke M, Bloem BR. Patient-centredness in PD care: development and validation of a patient experience questionnaire. *Parkinsonism Related Disorders*, 2012; **18**: 1011–1016.