




Changing Categorical Work in Healthcare: the Use of Patient-Generated Health Data in Cancer Rehabilitation

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Abstract. Categorical work in chronic care is increasingly dependent on digital technologies for remote patient care. However, remote care takes many forms and while various types of digital technologies are currently being used, we lack a nuanced understanding of how to design such technologies for specific novel usages. In this paper, we focus on digital technologies for patient-generated health data and how their use changes categorical work in chronic care. Our aim is to understand how categorical work changes, which novel forms of categorical work emerge and what the implications are for the care relation. This paper is based on an ethnographic study of healthcare professionals' work at a pelvic cancer rehabilitation clinic and their interactions with patients. In this setting, supportive talks between patients and nurses are central. To understand the complexities of categorical work in chronic care when patient-generated health data are introduced, we contrast the traditional supportive talks with supportive talks where the nurses had access to the patients' patient-generated health data. We identify and analyze challenges connected to novel forms of categorical work. Specifically, we focus on categorical work and how it can undergo changes. Our empirical findings show how changes occur in the way patients' lived experience of the chronic disease aligns with the categories from chronic care, as well as in the way the nurse works with clinical categories during the talk. These insights help us further understand the implications of patient generated-data use in supportive talks. We contribute to an improved understanding of the use of patient-generated health data in clinical practice and based on this, we identify design implications for how to make categorical work more collaborative.

Keywords: Categorical work, Chronic care, Ethnography, Patient-generated health data

1. Introduction

The increased use of patient-generated health data (PGHD) in clinical practices is currently changing how patients and clinicians collaborate (Piras and Miele 2017). For instance, by supporting a continuous production and flow of data from patients to healthcare professionals, PGHD technologies change the traditional episodic collaborative practices between healthcare professionals and patients. However, it is not yet fully understood to what extent existing practices are changed, and which novel challenges are introduced when implementing, and using PGHD (Kaziunas et al.

2017). Meaningful use of PGHD goes beyond simple statements that patients “only have to use” a mobile application to generate PGHD and that data will “simply inform” both patients’ and clinicians’ decisions (Katz et al. 2018). Instead, the use of PGHD requires additional work both from patients and from healthcare professionals to be able to generate, use, translate and make sense of data for treatment and care purposes (Mentis et al. 2017; Islind et al. 2019a). Patients are expected to become skilled and active data producers, and healthcare professionals expert data analysts (Schroeder et al. 2017; Lindroth et al. 2018). While there are a few papers on these issues, little attention has been paid to the use of PGHD in complex care processes and care situations where it is not clear what particular data should be tracked and how to use the data to support the care process.

In this study, we were interested in understanding how PGHD affects the categorical work of healthcare professionals and patients, and to identify the challenges they face. With categorical work we mean the work of negotiating and managing multiple meanings of categories. Categorical work is central to healthcare practices pervaded by standards and classifications and, as Bowker and Star (Bowker and Star 2000) have shown, categorical work is highly difficult, political and messy but yet critical in healthcare practices. The aim of the study was to derive design implications for supporting and improving the use of PGHD. To address that aim, we formulated the following research questions:

1. *How does the use of PGHD change the categorical work of patients and nurses?*
2. *How should collaborative systems be designed to support nurses’ and patients’ use of patient-generated health data?*

To address our research questions, we have conducted an ethnographic study on the categorical work in supportive talks at a cancer rehabilitation clinic at a Swedish hospital before and after the implementation of a mobile application (hereinafter called App) for PGHD. We studied how PGHD came into play during the supportive talks. Patients enrolled at the clinic do not suffer from cancer anymore, they are considered officially healthy and are no longer part of primary cancer care. However, they are still in need of specialized care as they live and deal with the effects of pelvic cancer treatment (primarily radiation-induced problems) which often cause severe, complex chronic health problems, such as high defecation and urination frequency. The clinic supports these patients through pelvic rehabilitation care in the form of visits and telephone conversations with specialized oncological nurses. The supportive talks during the telephone calls are very critical for the patients’ well-being and quality of life. To improve this interaction, a project team designed and implemented an App that can be used by patients to report relevant data to be used during the supportive talks. Our research has focused on how the use of PGHD from the App affects and changes the supportive talks between nurses and patients with attention to categorical work.

Our findings show that in the traditional supportive talks, the nurse engages in categorical work to elicit information from patients. Accordingly, categorical work

builds on the nurses' ability to provide patients with access to relevant categories. The patient's ability to report verbally about her experience is central here, as it allows the nurse and the patient to collaboratively try to 'align' the patient's lived experience with the nurses' categories. As a result, the introduction of the App and PGHD shifts the focus and aim of categorical work: while patients are delegated to perform categorical work on their own by reporting data in the App, nurses need to understand how this work has been performed in order to interpret the data. Consequently, the supportive talk with PGHD builds on the ability of the nurse to find out how the patient has been able to 'align' her own experience to the categories in the App. The patient's ability to relate and make use of the categories while using the App as well as communicate her App use to the nurse becomes central during the supportive talk.

Our study makes two contributions to CSCW research. Firstly, we document and present a detailed description of how nurses and patients engage in categorical work during supportive talks, and how this work changes with the introduction of PGHD. Secondly, we provide design implications to inform the design of collaborative systems for PGHD in chronic care.

2. Related Work

The increasing diffusion of digital tools to support self-management (e.g. mobile applications and wearable technologies designed to facilitate documenting behavior and symptoms) and healthcare professionals in their decision-making processes reconfigure the information and communication practices of patients and of healthcare professionals and the way they interact. While traditional e-health, telecare and telemedicine studies have a longstanding history within CSCW, more recent CSCW research engages with issues related to the datafication of healthcare (Ruckenstein and Schüll 2017). Datafication of healthcare is used to indicate that healthcare is becoming more engaged and preoccupied with quantifying lived experiences. In this study, we were particularly interested in the datafication of patient-health professional collaborative practices driven by PGHD. In the following sub-section, we describe how the literature approaches PGHD in patient-health professional collaboration. After that, we outline the core concept of categorical work.

2.1. PGHD in Patient-Healthcare Professional Collaborations

PGHD is defined as "health-related data including health history, symptoms, biometric data, treatment history, lifestyle choices, and other information-created, recorded, gathered, or inferred by or from patients or their designees (i.e. care partners or those who assist them) to help address a health concern" (Shapiro et al. 2012, p.2). PGHD is based on the understanding that patients' trends, events and experiences outside of the clinics are as relevant to their health and disease patterns,

as the brief snapshots provided during the episodic clinic visits (e.g. visits when they need to, with gaps without monitoring in-between the visits). In implementing this idea, patients are given the role of active data producers in their everyday life, a change which has several implications. Firstly, patients need to learn to produce, for them often new types of data, by using and mastering new types of tools. This task was previously handled by healthcare professionals as it requires medical expertise (Nafus and Sherman 2014; Neff and Nafus 2016; Nunes et al. 2019). The patient needs to further understand how her contribution can be both meaningful and actionable for the healthcare professionals (Andersen et al. 2018; Isind et al. 2019b). Thus, patients need to engage in both data production and data interpretation. For instance, Figueiredo et al. (2017) show how women in fertility care need to obtain information to understand the health indicators that they are expected to track in order to generate meaningful data. Furthermore, research has shown that in order to obtain high-quality patient-generated data, data should also be actionable for patients. This means that patients need to be able to recognize the value of the PGHD for their own care.

Secondly, to perform this work patients need to allow for both time and space in their daily lives. Data generation is work that can be considered 'invisible digital labor' (Lupton 2016a). Figueiredo et al. (2017) finds that patients do not have a 'fixed' engagement with data but engage with data in a variety of ways: from positive, burdened, obsessive, trapped, and abandoning and they transition between these modes of engagements. Research has also given attention to how patients actively engage in data generation practices through unexpected usages of self-tracking technologies. For instance, Piras and Miele (2017) argue that unexpected use enables patients to negotiate a desired relationship with healthcare professionals. Similarly, Kaziunas et al. (2017) show that active maneuvering of data can promote empathy, relational intimacy, and compassion.

Thirdly, PGHD changes the way patients perceive their illness experience. Lupton (2016b) argues that self-tracking is a data practice where gathering and interpreting information about oneself becomes a means of exerting control and of managing the complexities of bodies and lives. Similarly, Mishra et al. (2019) find that the use of PGHD in self-management practices can trigger reflections on personal information.

In addition to the reviewed literature on patients' use of PGHD, there is an extensive body of work regarding patient-reported outcomes (PRO) and patient-reported outcome measurements (PROMS). This literature comes primarily from the medical field and refers to the systematic collection of patients' symptoms by making surveys that are standardized (Snyder et al. 2012) for symptom management reporting. The use of PRO/PROMS has the dual aim of supporting both the patient and clinical work and can be used both in descriptive, explanatory, or prognostic purposes (Fitzpatrick and Ellingsen 2013; Seow et al. 2012).

Furthermore, research has also addressed the perspective of healthcare professionals by showing, for instance, the emergence of new professional roles dedicated to dealing with the increased production, focus on and interpretations of data. Bossen

et al. (2016) suggest the term ‘data work’ to indicate not only “working on data,” i.e. producing new data in accounting for, and recording care work that has been done, but also as the work whose execution, articulation and appraisal deeply and intensely rely on data, i.e., “working by data”. Grisot et al. (2019) show how nurses’ data work in remote care is not only about analyzing the data elements accumulated in the system, but also includes the work of selecting what is relevant data, and discerning which incoming data signal calls for a follow-up action for each specific patient. Lindroth et al. (2018) show how PGHD provides clinicians access to specific details about the patient’s condition e.g. by monitoring vital signs and how these shape and inform the creation of patient narratives in clinical care.

Moreover, PGHD contributes to shifting traditional qualitative measuring practices to making quantitative measurements (Cerna et al. 2018). Due to this shift from narratives to numbers, clinicians need to engage in knowledge production practices beyond the system itself to incorporate the data into their decision-making process. For healthcare professionals, it is important to collect information that is clinically relevant and hence actionable. For instance, Huba and Zhang (2012) point out that data can be relevant to different clinicians for diverse reasons and purposes, and that it is, therefore, difficult to know which data should be generated. Chung et al. (2016) find that while patients collect data they deem appropriate in their context, that data may not be of relevance to healthcare professionals. Thus, they argue that data generation practices should be collaboratively defined to identify which data should be gathered and shared. Islind et al. (2019a) show how data work with PGHD requires translation work, where the patients and healthcare professionals have to work together to make sense of, and guide use of the data both in clinical work and in self-management. Thus, new forms of patient-healthcare professional collaborative practices emerge around and on data. In clinical settings, these give rise to novel forms of therapeutic alliances and collaborative reflections (Marcu et al. 2014). However, critical studies, from outside of healthcare contexts, point out how these alliances may translate to ambivalent relations and forms of ‘dataveillance’ where the professionals’ gaze is expanded beyond what was originally planned for (van Dijck 2014; Zuboff 2015). Moving these grand ideas into a healthcare context could mean that the healthcare professionals’ reach can be extended into the patients’ life, rendering patient bodies observable in invasive ways. Additionally, what is ‘personal’ is being redefined and negotiated as it is closely connected to the patient’s competence in relation to management of their health (Piras and Miele 2017).

In sum, the literature points to the complex reconfiguration process triggered by the introduction of PGHD in patient-healthcare professionals’ collaborations. A new geography of responsibilities emerges, not as at one point in time when the patient simply “becomes” responsible, but rather as a complicated and nuanced process of negotiations over time (Schwennesen 2017). Different stakeholders in chronic care have different needs, and it is not a straightforward process to align those needs through the digital tools. Rather, the different needs have to be negotiated and figured out in order for the system to support the alignment (Andersen et al. 2018). There is

thereby a difference, and potential challenges, between the needs and understandings of the clinicians and those of the patients (Chiang and Wang 2016; Islind 2018; Cerna et al. 2019). In this study, we approached the use of PGHD by focusing on categorical work. Our aim was to learn more about how nurses and the patients can draw on the potential of the data in supportive talk and in the next section we elaborate on the concept of categorical work.

2.2. Categorical Work

In this study, we focus on categorical work to understand the patient-nurse interactions during supportive talks. Categorical work is a concept proposed by Bowker and Star to foreground the work of negotiating and managing the multiple meanings of categories (2000). Specifically, categorical work is defined as “the juggling of meanings” occurring when categories have different meanings in different communities, yet are needed to support some form of collaboration or cooperation (Bowker and Star 2000). In our study, nurses needed to learn about and understand the particular patient’s problem. However, problems cannot be objectively and easily described by the patient. Rather, the nurse and the patient collaboratively must make sense of the patient’s rich experience through their interactions. In these interactions, categories play a central role. Categories may for instance come from classifications systems, clinical terminology, measuring systems. Categories are thus a form of codified knowledge captured through processes of classification and standardization (Bowker and Star 2000).

Categorical work and categorization in general have been a core theme in CSCW research. Collaborative work demands collaboration and cooperation among different communities which need to negotiate meanings (e.g. Schmidt and Bannon 1992). Early on, Suchman pointed out that categories are not neutral devices, but are rather devices of social control that carry specific intentions (1993). Similarly, Star and Bowker argue that while classifications and categories may look universal, each category and each standard performs political work by valorizing some points of view while silencing others. Accordingly, classification work is “a spatio-temporal segmentation of the world”, an attempt to organize the world “to do some kind of work”, for instance, knowledge production (Bowker and Star 2000, p. 10). Classifications and categories are thereby a site of political work and they are not “objectively” given, but rather created and shaped by the interests of the people who designed them, and negotiated in practice through social interactions (Bowker and Star 2000).

3. Research Approach

The research approach for this paper draws on ethnographic data that were collected at a pelvic cancer rehabilitation clinic at a regional hospital in West Sweden. The research project that this paper is based on was a multi-disciplinary project involving

researchers and practitioners from the following disciplines: pedagogy, informatics, epidemiology and nursing. The research project aimed at improving care work and ultimately the quality of life of patients who received radiation treatment in the lower pelvic area and are living with the consequences of that treatment (al-Abany et al. 2002; Dunberger et al. 2010). The pelvic cancer rehabilitation clinic is led by three specialized oncological nurses who provide the main care and support for patients who need follow-up rehabilitation care. A majority of the patients are women between the age of 55 and 75. The patients that come to the clinic share similar symptoms and suffer from problems (ranging in severity) in their bowel, bladder, lymphedema and sexuality-related issues. Traditionally, the nurses meet patients in face-to-face meetings (the first meeting) and follow up with telephone calls. During meetings and follow-up, the nurses engage in supportive talks with patients. Supportive talks are the focus of our study and described in detail in section 3.1.

The clinic has limited resources so that the extent of patients' follow-up on a monthly basis depends in part on the severity of the condition. Due to the limited access to the clinic, a mobile App for PHGD was developed (reported in Cerna et al. 2019 and also Islind et al. 2019c). Both nurses and patients were involved in the design of the mobile App. The App supports patients in collecting data about their defecation and urinary frequencies, medication intake, abdominal pain and stool or urinary leakage. The App provides two types of questionnaires that the patient can answer: (i) a set of questions, answered once per day as a summary of the whole day, or (ii) a set of questions to answer as they experience a symptom (e.g. pain). This questionnaire can be answered many times per day (see Figure 1 for an overview of the App). The reporting of data about defecation uses the Bristol scale with categories of stool consistency (Figure 1a). The last two screenshots show how pain location and intensity are documented (Figure 1b, c).

The nurses have access to the data portrayed as graphs via a web-interface (see Figure 2).

3.1. Empirical Setting

At the pelvic cancer rehabilitation clinic, chronic care builds on the collaboration between nurses and patients. More specifically, it builds on the supportive talk between a nurse and a patient that usually first takes place face-to-face and then as a follow-up, over the phone. The purpose of the supportive talks is to provide the patient with personalized care that matches her individual needs. The nurses help patients become more independent in their own care by guiding them in understanding how to manage their symptoms. As these patients suffer from the consequences of pelvic cancer treatments, their bowel and bladder do not function properly. These symptoms and how they are experienced are difficult to trace and to describe. Furthermore, there is no single indicator that shows how critical the condition is. To provide personalized care, the nurses need relevant and detailed information about each patient's health status and symptoms development. This information is

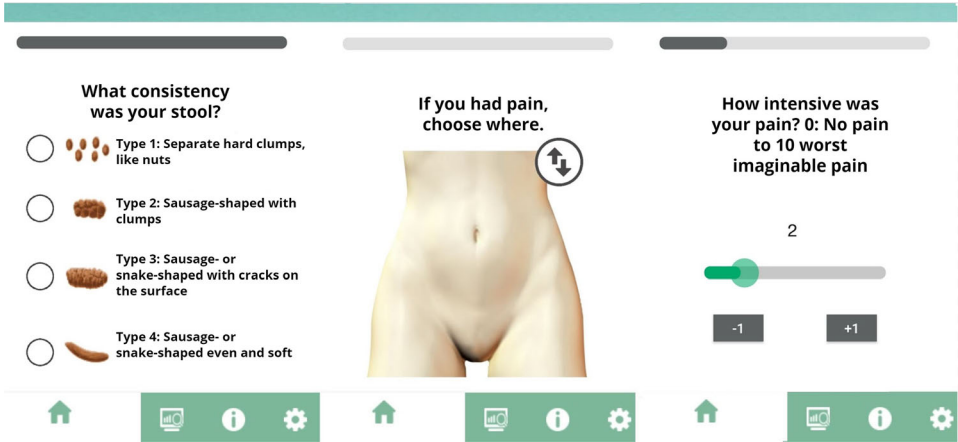


Figure 1. **a** A screenshot from the App. This particular question presents the patient with Bristol scale, where they should input which stool they had. **b** A screenshot from the App. On this screen, the patient can express where they experience their pain. **c** A screenshot from the App. On this screen, the patient can express the intensity of their pain.

collected through various means. An extended survey is given to patients when they first contact the clinic (described elsewhere, cf. Cerna 2019; Isildn 2018). The nurses also give patients a form to track urination habits i.e. when and how much they urinate. In addition, nurses ask patients questions to elicit detailed information. Based on the information collected during the supportive talk, the nurse proposes an intervention, often a medical one. Interventions are discussed and agreed upon together with the patient. They are then further followed up during the phone conversations. Consequently, the supportive talks have the double purpose of providing the nurse with needed information, and at the same time of giving the patient advice on how to manage their symptoms.



Figure 2. An interface portraying defecation frequency and Bristol scale data overview accessible to the nurses through web-interface.

During the face-to-face supportive talks at the clinic, the nurse often summarizes the collected medical information, and together with the patient plans the first steps of the treatment. Supportive talks over the phone take place throughout the whole treatment, which varies in length. A phone conversation can last from 5 min up to an hour and usually involve following up on previous interventions and how symptoms have developed. Face-to-face meetings and phone calls are scheduled in advance. However, patients can also call the nurse in case they have urgent questions.

3.2. Data Collection and Analysis

This study draws on an ethnographic engagement of the first author with the nurses' work before and after the introduction and implementation of the App. The study has lasted for 4 years and the first author was involved in continuous ethnographic engagement with the nurses for the duration of the whole project. In addition to the data described further on, the engagement involved participating in project meetings (together with the nurses), conducting a range of formal, informal and group interviews with the nurses as well as continuous discussion of our findings with the nurses (performed by the first and the third author). For the purpose of this study, we draw from data collected at the beginning (2015, called starting phase in Table 1) and at the end (2018, called ending phase in Table 1). During the starting phase, an observation study was conducted for 3 weeks at the clinic. The first author was shadowing the nurses during their whole work day, 8 hours a day, 5 days a week. The focus was on the clinical work of the nurses, who had been working at the clinic between 2 and 3 years. Field notes, audio and video recordings, photographs and various artifacts (such as urination tables and clinical questionnaires) were collected during this period. After the App implementation in 2018, we video and audio recorded supportive talks with patients who had access to the App over the period of 1 year (more details in Table 1). The audio recordings and video material from both phases were listened to several times and transcribed verbatim.

Table 1. The empirical data overview.

Phase	Meeting type	Data gathering method	Count	Access or no access to PGHD	Duration of collected material
Starting phase	Physical meeting	Video recording	3	No access to PGHD	3 hours
Starting phase	Phone call	Audio recording	8	No access to PGHD	3 hours
Ending phase	Physical meeting	Audio recording	1	Access to PGHD	1 hour
Ending phase	Phone call	Video recording	2	Access to PGHD	40 min
Ending phase	Phone call	Audio recording	20	Access to PGHD	6 hours

The empirical data were analyzed in several steps with an approach informed by interaction analysis (Jordan and Henderson 1995). Interaction analysis builds on the assumption that “knowledge and action are fundamentally social in origin, organization, and use, and are situated in particular social and material ecologies.” (Jordan and Henderson 1995, p.41). In other words, we can understand categorical work through studying social interaction in detail and reconstructing how the social order was achieved in the social interaction. Firstly, based on the field notes and the transcriptions from the starting phase, the first author prepared a detailed description of the work practice before the introduction of the mobile application and after. Second, we compared the transcriptions of supportive talks between nurses and patients with and without the App to understand the differences between these two types of interactions. As these differences were related to how the participants were making sense of their experience in relation to the categories provided to them by the nurse or in the App, we chose the concept of categorical work to interpret the interaction between the participants. We then looked through the material where the App is being used and looked for examples where the categorical work became problematic for the interaction participants (for example, when the nurses switched back to their traditional techniques even though they had access to the patient’s data).

The steps of the analysis of the particular excerpts were informed by Ten Have’s approach (1990). First, the chosen transcriptions were interpreted by using our own knowledge (in the text presented in the form of the ethnographic descriptions or transcriptions). In the second phase of analysis, the interpretations were made sense of by connections to the wider context of the clinical practice. The data excerpts have been presented in several data sessions, where the researchers watched the video sequences several times and discussed analytic points together, also by inviting in other researchers who were not a part of the multi-disciplinary project. This study has been approved by a local ethical committee. The App is currently in use in the clinical practice described below, and the design implications derived, and tested. The data has been anonymized, and pseudonyms have been used.

4. Findings and Analysis

The following section presents the findings of our study. We first contrast the traditional supportive talk with the novel situation by analysing how categorical work changes with the use of the App. Second, we present the challenges emerging in the novel categorical work when the nurses and the patients use the App for patient-generated health data.

4.1. Changes in Categorical Work

In this section we illustrate the changes in categorical work based on two excerpts from patient-nurse conversations during supportive talks. We focus on how categories are used by the nurse and the patient to understand the patient’s condition.

4.1.1. *Categorical Work in the Traditional Supportive Talk*

In the traditional supportive talk, the interaction between the nurse and the patient takes place during a phone call and relies on the oral accounts of patients who may have taken some notes. As the patient's bladder often is affected by the cancer treatment, one common issue is urination urgency or incontinence. One of the nurses' daily tasks is to talk to different patients about their bladder related problems in order to understand the extent of the problems, propose a diagnosis, and suggest remedies. In the following example, the nurse needs to know how often the patient urinates to be able to decide the extent to which the bladder has been affected by the cancer treatment. The patient struggles to recall the information and the nurse helps her remembering by asking questions:

Excerpt 1

1 Nurse: I have seen [here] that you have a little bit of problems with urination
can you tell me more
2 Patient: Yea but now it feels much better actually
3 Nurse: that's good
4 Patient: I think it is okay
5 Nurse: but if I ask you several short questions about your urination
6 Patient: yea
7 Nurse: how many times a day do you go and pee
8 Patient: oh (short silence)
9 Nurse: approximately (.) sort of (.) you can take a good day and a bad day
10 Patient: This is difficult. I go and pee a lot at night so just to count that
it would be
11 Nurse: at night how many times do you go at night
12 Patient: three
13 Nurse: yes
14 Patient: so I also sleep badly I think I do not want to feel like peeing so I
go up and pee
15 Nurse: five ten twenty
16 Patient: ye:: no not twenty
17 Nurse: no
18 Patient: somewhere between five and ten
19 Nurse: yea (.) five is normal and ten is a little bit too much so there it is
(.) when you pee do you empty the whole bladder

At the beginning of this excerpt, the patient provides the nurse with an evaluation of her situation (line 2). The nurse knows that this evaluation might not be exact, and she tries eliciting more information from the patient about her problem (line 5). To be able to describe her experience, the patient has to recall quite precise information about the frequency of her symptoms, in this case how often she urinates during the day and night. Because recalling such information is a challenging task, the nurse tries helping the patient through formulating various questions, such as questions about frequency (line 7), contrasting good and bad days (line 9), or providing the patient with a range of possible answers (line 15).

Excerpt 1 shows that by formulating various questions, the nurse offers the patient categories that can help her make sense of her symptoms. The nurse provides the patient with categories such as frequency, good and bad day, specific number ranges

that come from the nurse's own clinical experience at the clinic. However, these categories do not make immediate sense to the patient, and both participants have to engage in categorical work. The patient tries aligning her chronic disease experience by comparing her symptoms to the categories the nurse is providing (asking about urination frequency). When the patient is not able to fit her experience to the provided categories in the first question (line 7), the nurse can change the categories she provides. By providing the patient with more nuanced categories, the nurse guides the patient in reflecting on her chronic disease experience, and in turn makes visible those experiences that the nurse needs to know about (such as the time of urination) in the given context (that is, pelvic cancer rehabilitation).

In Excerpt 1, the nurse thinks that the patient might have a problem with her bladder. To further understand the extent of the problem, the nurse asks the patient to conduct a special measuring for which the patient gets a measuring cup and a paper-based table. The patient is asked to urinate in the measuring cup and record the approximate amounts of urine in the table, together with dates and times for 2 days (each table containing 24 hours). She is also asked to fill in the table the approximate amount and type of beverage she drinks (see Fig. 3). These measurements indicate the approximate difference between how much they drink and pee. This measurement entails a different work for the patients, as they do not have to interpret the data to be able to document them. After the 2 days, the patient sends the tables back to the nurse via post.

The nurse then reviews the table and then talks about the results with the patient during a phone call. She can for example say:

Nurse 1: Sometimes you go and urinate even though you have only one decilitre in the bladder. Do you know how often it was those times, did you feel urgency or did you urinate for safety reasons, or how did you think there?

The nurse needs additional information from the patient to make sense of the data in the table, and she uses the specific data entries to pose more specific questions for example connected to the reasons why the patient urinated even though physiologically there were no reasons for her to do so. Even though the table allows the patient to produce more concrete values, the values cover only 2 days. However, the patients' health problems develop over a longer period of time. In addition, the nurse still needs the patient to recall what was happening in that given situation to understand the patient's problem.

Time	Amount of urine	Leakage	Reason for leakage (e.g. physical activity, urgency)	Time	Drinks (dl)
23.45	100 ml				
02.20	210 ml	+	trängning		
04.10	250 ml	+	-		
07.30	200 ml	+	-		
08.50	100 ml			09.00	4,5 dl
11.45	125 ml			14.00	2,0 dl
14.45	110 ml			17.00	4,0 dl

Figure 3. An excerpt from a urine measuring table.

To recall information about how often and how much one urinates is a challenging task. The measurement table covers only 2 days and it is not possible for the nurse to see trends. However, it still provides the nurse with some indication of the extent of the problem. The paper-based tool is specifically adjusted to the knowledge needs of the nurses and provides the patient with access to the clinically relevant categories. Having access to the categories in the table allows the patient to produce more accurate information than by recalling during a talk. The practice of recording the measurements does not require extensive interpretative work from the side of the patient, as she “only” writes down the values that she had measured. The categories in the table (e.g. urination volume) are specific and the patient knows exactly what to look for in her chronic disease experience - a number, that is possible to measure. These values are collaboratively interpreted together with the nurse during the supportive talk.

4.1.2. *Categorical Work with PGHD*

In the novel situation, the patient is provided with the App to record her symptoms. The patient uses the App for about 2 weeks prior to the scheduled supportive talk. Before calling the patient, the nurse accesses and reviews the data in the web interface. In the following excerpt - excerpt 2 - the nurse and the patient talk on the phone about problems with defecation based on the reported App data.

Excerpt 2

1 Nurse: I see when I look through it anyways, when you registered the last time, among other you registered that you had a dull pain a lot the second to the fourth November
 2 Patient: yes
 3 Nurse: and you have even noted blood on paper five times
 4 Patient: yap, that was then when it was a lot of toilet visits
 5 Nurse: and you have a lot of uncontrolled gasses Berta
 6 Patient: yes but it has also gotten better
 7 Nurse: Do you take any Minifom?
 8 Patient: yes I still take Minifom
 9 Nurse: How many?
 10 Patient: ah it is still six tablets per meal time three times a day

In this example the nurse presents the App reported data during the phone call. First, she reads out from her screen and makes a summary (line 1 and 3) and an interpretation of the collected data (line 5). Each of the readings is reported as a statement. The patient reacts to the nurse’ statements in various ways: first a short answer that confirms the data, an answer that confirms and explains the data, and finally an answer that questions the data. The nurse then follows up with questions about medications.

This conversation unfolds differently from the previous one. In contrast to the first excerpt, the nurse does not have to elicit information from the patient about her chronic disease experience. Instead of formulating questions about how the patient experienced certain symptoms, she can proceed by presenting summaries or interpretations of the data to the patient. The nurse does not have to provide the patient with the relevant categories - the patient made use of the categories through the use of

the App instead. However, this also means that the categorical work that the nurse used to lead is now shifted to the patient. The patient now needs to recognize and evaluate the symptoms on her own in relation to the categories in the application. Next, she has to align her chronic disease experience to the categories, so she can in turn record the results in the App. In contrast to the traditional supportive talk, the patient has to engage in this categorical work without the support of the nurse. For example, when reporting on the stool consistency she has to look in the toilet, assess her stool and select one of the categories on the Bristol scale. The patient has to fit her experience and understanding to the categories as they are presented in the App. The Bristol scale is not adjusted to the particular patients' needs, but to the clinical needs of the nurses.

Furthermore, there are various reasons why the nurse reads the data out loud. Although it is technically possible for the patient to access the data on her phone while talking to the nurse, the patient chose not to do that (Field notes). The phone has a small screen and the data are visualized as a graph - something that might be difficult to view on a small phone screen. The nurse wants the patient to know that she has read the data, and by reading what she sees on her screen, she makes the data accessible to the patient as well. Sharing summaries and her interpretations in this way also involves a pedagogical aspect that the patient would miss otherwise if she was only using the App. The patient learns from the nurse which data can be conceived as relevant and which categories are meaningful in the context of pelvic cancer rehabilitation.

Summing up, the use of the App changes the interaction between nurses and patients. Patients now generate data at home prior to the supportive talk. This requires them to make sense and use the categories without the help of the nurse. Thus categorical work does not take place in collaboration with the nurse, but in collaboration with the App which does not offer support to the interpretation work. This has implications for how the supportive talk unfolds. In the next section we will identify and analyse the challenges emerging in the novel situation.

4.2. Challenges in Categorical Work with PGHD

The previous section presented how categorical work changes when PGHD is introduced in the talk between a patient and a nurse. In this section, we focus on the challenges emerging in this novel situation and how they are addressed. Overall, the PGHD is discussed during the supportive talks, however, their use is not straightforward. The identified challenges relate to continuity, reliability, and problematic aligning in categorical work.

4.2.1. *Continuity in Categorical Work*

With the use of the App, categorical work is performed by patients as they input their data in the App's forms. The App allows nurses to receive data over time, and to analyse data trends. However, the analysis of trends is possible only if patients

continuously perform categorical work, and provide enough data for interpretation. However, often patients do not manage to register their symptoms as requested, because they forget or because dealing with their chronic disease during their daily life is a full-time task. Thus, often nurses lack data and this makes it difficult to identify trends in the data, which is an important aspect of the nurses' diagnosis work. The App introduces the challenge of continuity in categorical work, Continuity is critical for the nurse to be able to use the App data to define the appropriate patient's treatment. The following example illustrates how it becomes problematic to see trends when the patient does not manage to generate enough data. The excerpt is about using the App to categorize frequency and stool consistency using the Bristol scale.

Excerpt 3

1 Nurse: Yea yea, I am checking just the parts. I took between twenty sixth September and eight October now and like twenty sixth is one time consistency six, as in very loose, and then it is four times water thin. And it is the same twenty seventh September twice little bit little bit
 2 Patient: hm
 3 Nurse: and then it is water thin two times. Then something happens the fourth October, there it was one time minimally better five and then you were up in the other one, as in five times, na:h, seven times you went to the toilet yesterday
 4 Patient: hm but that is nothing unusual that is almost always
 5 Nurse: how is it could you estimate without the App is it seven that is the most or is it more?

In this case, the patient did not generate data in a continuous way for the nurse to be able to interpret it in a meaningful way. As she needs to elicit more information from the patient, she asks additional questions. However, when asking about the patient's problem she changes the question a little bit: instead of asking the patient "how many times did you defecate?" she extends the question by asking "was it 7 the most"? 7 is the highest number of defecations she can see in the system. Asking about maximal values is a way to elicit information from the patient (as in excerpt 1). But here the nurse can start from a concrete number. This number does not represent a trend but a concrete value that the nurse and the patient can talk about.

Even though the nurse in the end has to go back to her traditional strategies, the data presentation fulfilled another function. By reading the results out loud, the nurse has shown to the patient which categories are relevant in this context, but also how to make sense of them: as a sequence in time. The more the sequence is data-rich, the better. She shows how the patient can make sense of her documented experience by ordering the particular values in time, viewing the first ones first, and the last documented last. By reading the recorded values in the particular order, the nurse shows how the patient can make a connection between her chronic disease experience and the categories in the App. Reading these interpretations has an important function in the talk, as it contributes to motivate the patient to use the App in a continuous way. By providing the patient with a datafied version of their chronic disease through the categories that are relevant to the nurse, the nurse can draw on the pedagogical potential of the App to help the patient understand that it is important to collect data continuously.

4.2.2. *Reliability of Patients' Categorical Work*

With the use of the App, categorical work is performed by the patient alone, and not in collaboration with the nurse. This change introduces a challenge related to the reliability of the patient-generated data. In the following excerpt from a phone call the nurse is in a conversation with the patient about searching for a trend in the data as she reads it out loud to the patient:

Excerpt 4

1 Nurse: Yes. and then one can see anyway one can see a trend from seventh eleventh till now the thirtieth, so you have filled in how often you go. We are in the defecation form, you know, there where you fill in how many times a day you go.

2 Patient: yes exactly

3 Nurse: and there it varies between one to three times but I would say anyways Ola that from the 21st in my data it is more often as in it is more times that we can start seeing a trend in two to three times.

4 Patient: yes, it can sometimes happen that I got in too many times because the form was broken. Yes.

5 Nurse: and how do you think it [the situation] is?

6 Patient: but I know that it could have been two times when it was really good. More than one times and then it was a soft stool.

7 Nurse: hm. That is positive but one could wish it was more often.

The patient first agrees with the nurses' reading of the data, but when the nurse starts presenting the way she interprets the data (the trend in the data points to a recent worsening of the patient's problem), the patient reveals that the data points might not be correct, because the App was not always working correctly. This makes the nurse go back to her estimation routines and she formulates a question about the patient's own estimation of the problem. This suggests that she realized that she cannot rely on the patient's categorical work anymore.

In other words, the nurse presents the patient with a datafied representation of her chronic disease. This representation is based on the patient's lived experience and her categorical work, but it is organized through categories that are relevant for the nurse, such as trends. The nurse tries making sense of the patient's data by relating it to her categories. However, the patient does not accept the nurse's explanation, and provides an alternative explanation - the digital tool did not work, and the explanation the nurse is providing is therefore not valid anymore. Furthermore, this explanation makes the nurse realize that orienting to the category trend at this moment is not meaningful, and she has to retreat to her traditional strategies. This example illustrates how categorical work addresses the reliability problem of the data. If the tool does not work multiple times, the data will be skewed. Several things come into play here: If the patient did not mention that the App did not work properly several times and that the nurse would try to identify a problem from a smaller amount of data than she normally would, it could lead to incorrect identification of a trend that actually does not exist. It does not matter in terms of care - the dysfunctional technology will not lead to a break in the talk, because the nurse can always go back to her traditional routines. But it leads to a moment in the talk when the nurse does not want to use the data anymore.

These examples suggest that the nurse needs to have not only access to the PGHD, but also to information about how the patient was performing categorical work as she

was using the App, in order to be able to interpret the data in a meaningful way. This finding has been further confirmed during one of the workshops where nurses participated. The benefit of the App is that the patient can document the symptoms closer to the actual experience - in contrast to the traditional practice, where the patient's actual experience and her report about it are separated in time. When preparing for the workshop, we noticed that some of the patients were using the App in a different way than it was intended: instead of recording their defecations close to the time when they actually happened, they reported all the defecations at the end of the day (for 3–5 min). When the nurses were asked about this, this is how they reacted:

Nurse 2: e cause then it is not real data somehow it is actually a really big difference between the events and daily form cause for me daily form is about how it was before that they estimate half year back but events if they do it then I really find out about how it is (.) if it is estimation then it does not tell me that much

...

Nurse 2: I need to know how they used the App(.) and if they are good in precisising I had someone who ... then it becomes weird data for me

Researcher 1: so you need to know how they use the App to be able to interpret the data

Nurse 2: so that I can interpret them but it is important for me to ask how do you think it is in some way quite often I think they say something themselves well I did like this okey cause the idea was like this and this (.) as long as I know how they used it so it is okey that it was wrong

(Project workshop 8/10/2018)

In the excerpts above the nurse expresses that she sees a big difference between the daily form that builds on short term yet still estimation and the event reporting that allows patients to record their symptoms much closer in time. The nurse needs to know if the patient was using the App in the way it was intended in order to be able to interpret but also to be able to rely on the data. In other words, the nurse needs to know if the patient has managed to align the categories to her chronic disease experience in the way that the App was designed for, that is, if the patient recorded her symptoms when they were taking place and not several hours later. Both types of recording will allow the nurse and the patient to produce knowledge about the patient's problem, but it is crucial for the nurse to know how much she can and rely foremost on the data.

4.2.3. *Problematic Aligning of Categories*

As the previous section suggested the nurses sometimes have to deal with the patients using the App in unexpected ways. The following example illustrates the importance of why the nurse needs to know how the patient has been using the App to be able to interpret the data in a meaningful way. The phone call conversation in the example took place when the nurse made a phone call to a patient who has been using the App. The nurse inquired about how the patient experienced using the App and the patient provided her with feedback. One of the elements the patient found problematic to use was the Bristol scale:

Excerpt 5

1 Patient: And then actually even toilet visits. Cause I have a need, often I have several of those categories at the same time.

2 Nurse: several consistencies.

3 Patient: And then I chose to do in such a way that I press one time a little bit hard and I go in again and I press now it was a little bit lose like .. Maybe it is also interesting. But it can also be something to take care of that one can press several, cause I think that many with my problems have several of these categories at the same time.

4 Nurse: absolutely.

This short exchange illustrates yet another tension. The nurse and the patient talk about a Bristol scale - a scale that is commonly used in pelvic cancer rehabilitation to categorize stool. Stool categorization is an important step in the diagnosis of the patient's problem. However, the scale does not always match the actual experience of the patient. In the traditional practice, this tension is addressed by the patient explaining she experienced more than one category. However, when using the App, the patient is able to choose only one category at a time. In the example, when the patient was not able to find a matching category for her situation and thus align her experience with the categories in the scale, she decided to appropriate the tool to her own experience. Thus, instead of filling the form once, forcing her to decide which of the two different categories she would have to choose, she filled the form twice.

This patient's solution has a serious consequence for the nurse: because the questions about frequency and consistency are put into one question set, if the patient wants to answer about her consistency she also has to answer about the frequency. When the patient uses the App in the described way, the amount of the collected frequencies would be double as much as the actual amount. In this case, the design of the App restrained the patient in documenting her behaviour in such a way that would fit her chronic disease experience. For this reason, she chose to use it in a way that would be meaningful to her. This way of using the App produces data that are less accurate for the nurse.

5. Discussion

In the previous section we have reported on our analysis of how the use of PGHD has changed categorical work and the supportive talks between the nurses and the patients. We have specifically paid attention to how the nurses and the patients engage in categorical work while using the data to understand the patients' health problem. Building on our findings, we discuss the shift in categorical work and draw design implications to inform the design of collaborative systems for PGHD.

5.1. Shift in Categorical Work

The use of PGHD has introduced a range of changes in patient-health professionals relations. Research has shown that changes apply both to the patients' and the health

professionals' sides. For patients, the production and use of PGHD introduces new activities which require new expertise (Nafus and Sherman 2014; Neff and Nafus 2016; Nunes et al. 2019). Patients have to learn which data should be shared, collected and how to make sense of the data in a collaborative manner with the healthcare professionals (Chung et al. 2016). Further, the use of PGHD implies that patients engage in self-management activities to a larger extent than before (Islind et al. 2019a). On the clinicians' side, PGHD also requires new activities. For example, nurses have to perform data work by analyzing the data collected in the system but also making sense of it in the context of each particular patient and the clinical context (Grisot et al. 2019). These changes are relational, meaning that patients and health professionals need to adjust the way they collaborate in the care relation.

We contribute to the body of literature concerned with how PGHD changes the collaborative care relation between health professionals and patients by focusing on categorical work. Categorical work is a collaborative practice of “juggling of meanings” occurring when categories have different meanings in different communities (Bowker and Star 2000). Specifically, we have addressed the following research question: *How does the use of PGHD change the categorical work of patients and nurses?* Our findings show that the production and use of PGHD significantly changes the categorical work of patients and nurses. As we have shown, categorical work includes several activities directed at making categories relevant for patients.

In the traditional supportive talks, categorical work is led by the nurses and relies on their ability to provide the patient with relevant categories during the supportive talk. The nurses draw on categories from their clinical experience which in turn can help the patient recall data and trigger reflections. This is a collaborative activity, performed by the nurses and the patients together, where the nurse helps the patient to sort out which of her experiences is relevant in the given context. Nurses guide the work by asking questions, for instance by asking for specific quantifications (e.g. how many times?), by introducing more nuanced categories (e.g. ‘bad day’ or a ‘good day’), and by offering additional measuring tools (e.g. patient filling in a table). This work is performed in order to support the patient in aligning her own experiences with the provided categories and in organizing the patient’s experience in relation to the clinical categories. In turn, the patient provides the nurse with the information needed to improve the treatment. Consequently, the patient and the nurses engage in categorical work with the aim of aligning the lived experience to the categories. As our case shows, this work is particularly critical in cases of complex conditions where the symptoms and how they are experienced are difficult to trace and there is no single indicator that shows how critical a condition is as in the context of pelvic cancer rehabilitation. As we have shown in our analysis, categorical work is not simple, and there is an apparent negotiation process between the nurses and patients to balance their different understandings through the categories.

The use of PGHD introduces a novel situation which changes how categorical work is performed. With the use of the App, patients produce health data on their

own at first. This means that the collaborative practice of ‘juggling meanings’ is performed by the patient without the support of the nurse. Patients’ work by aligning their experiences to the categories offered in the App as they experience the symptoms of their chronic disease on a daily basis. Thus, categorical work shifts from the context of the supportive talk to their own individual practices of generating and reporting data. Our findings show how this shift has consequences for how the supportive talk plays out and for how nurses relate to, and care for patients. Specifically, we have identified novel challenges in performing categorical work that show how this shift is not unproblematic. Similarly to Figueiredo et al. (2017) who have shown how patients need to have an understanding of how health professionals categories (i.e health indicators) work in order to generate meaningful data, our findings show that when patients are required to produce PGHD, they struggle to fully grasp the categories they are confronted with. Similarly, to the health indicators in Figueiredo’s study, the categories in the App are not easily interpreted by patients. Our findings therefore show that patients need to be supported in their ‘invisible digital labour’ (Lupton 2016a).

As previous research has pointed out, the introduction of digital tools for PGHD creates invisible work for patients who need to become skilful data generators (Lupton 2016b; Isind et al. 2019a). In our study, as patients delegate the work to relate their lived experiences to the App’s categories, it is also the ‘juggling of meanings’ that shifts from being collaborative to being invisible. However, categorical work is so central to the nurse and patient care relation that nurses need to use the supportive talks to unveil the categorical work that has been performed. Thus, our case shows how the ‘invisible digital labour’ of patients introduced by the App is problematic for health professionals. By delegating categorical work to patients, the App does not support the data interpretation process of health professionals. In the next section we will elaborate on these shortcomings by proposing design implications for PGHD Apps.

5.2. Designing for Novel Categorical Work with PGHD

The introduction of PGHD into an existing clinical practice and consequent changes in categorical work have introduced a range of challenges which need to be accounted for when designing collaborative systems supporting nurses’ and patients’ use of PGHD. Our findings indicate that the challenges are connected to continuity in performing categorical work by patients, reliability of patients’ categorical work and issues with aligning of categories. More specifically, patients are required to perform categorical work in a continuous way, in turn producing PHGD that are reliable by aligning App categories and their chronic disease experience in a way that is meaningful for both nurses and patients. Drawing on our findings and the identified challenges, we derive the following design implications.

First, to be able to provide nurses with data that are *reliable*, the patients need *continuous* support so that they can perform categorical work that makes sense in the context of chronic care. Although the nurses and the patients can be frequently in

touch, it is often not practically possible for the nurse to be accessible to the patient as frequently as the patient needs to use the App to monitor her symptoms. Hence, additional supporting mechanisms should be built into the App. For example, a chatbot built in the App could provide the patients with prompts to remember to use the App at relevant moments as well as provide the patients with relevant information on how to interpret the particular questions.

Second, PHDG are not automatically reliable, but have to be made into reliable data in the talk (Bossen et al. 2016). Hence, a collaborative system involving PHGD needs to involve mechanisms that allow patients and nurses to collaboratively work towards understanding reliability of the collected patient's data. Hence, the collaborative system should collect not only the PGHD but also meta-information on how the patient is using the App, for example, the time at which patients' data are collected. Having access to the exact time of data collection can for example support discussion between the nurse and the patient about frequency of the health issue, or if there were some other reasons why the patient registered her health problem so often (as in section 4.2.2). Even this meta-information should be presented in forms of trends to both the nurse and the patient, so that they can combine it with knowledge learned from the regular App data and together make sense of all the data during the supportive talk.

Third, a collaborative system should support the communication between the patient and the nurse about the patient's alignment of her chronic care experience to the categories in the App. Depending on the given chronic care context, a range of communication channels (phone call, text, chat in the App) can be combined together with prompts based on the above described meta-information. Establishing additional communication channels is also connected to the need for the nurse and the patient to negotiate the accessibility of the nurse to the patient and managing the patients' expectations about nurses' availability to them.

Finally, changes in the categorical work require changes in competences of both nurses and patients. In chronic care, nurses' role has traditionally focused on care and on patients' education (Chiang and Wang 2016). They explicitly support the patients in learning about their health problems with the aim of improving their self-management practices. When PGHD is collected through digital tools and used in chronic care, the nurses' traditional role as educators is challenged. Teaching patients how to use the App and in turn engage in categorical work goes above and beyond simple manual input as the nurse now also has to support the patients in using the App to make sense of their chronic care experience. This change should be addressed already during the development of the collaborative tool: not only by involving the relevant stakeholders in the process but also by providing them with space to explore and define their new emergent competencies.

6. Conclusion

In sum, we have conducted an ethnographic study of categorical work in nurses and patients' interactions, when they got access to the PGHD. More specifically, we illustrate how categorical work changes when a patient and the nurse get access to the

PGHD. These insights further the understanding of implications related to PGHD use for supportive talk purposes. We contribute to an in-depth understanding of the use of patient generated health data in clinical practice, and based on this, we contribute design implications to collaborative systems better suited for the consequences of changes in categorical work. In our future work, we will focus on the use of patient generated health data from the patients' perspective and unpack how categorical work is performed in patients' daily lives.

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