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Becoming data. Patient perspectives on using an eTool in physiotherapy sessions

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The purpose of this investigation was to gain insights into how patients experience using an electronic tool as part of their physiotherapy assessment, goal setting, and treatment planning.

The research data were generated through close observation of eight clinical encounters in primary health care, where the electronic tool was used. Observations were followed by interviews with physiotherapists and patients involved. This manuscript elaborates on the patient informants' perspectives. The analyses, inspired by postphenomenological theory and research, sheds light on patients' concerns whether reliance on what they perceive as fragmented and incomplete data generated from PROM tools will obscure health matters rather than provide health benefits.

By various means, including translations, adaptions, and editing together with their physiotherapist, patients were often able to manage their data into, for them, an acceptable, recognizable form.

The investigation highlights that for patients to have confidence in this technology, and particularly the methodology of PROMs, they need to trust the way data is handled and interpreted.

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Ehealth; postphenomenology; clinical encounter; FYSIOPRIM

Introduction

A core tenet of evidence-based health care is that practice should incorporate the perspectives and opinions of patients. Despite ideals of shared decision-making, Greenhalgh, Howick, and Maskrey (2014, p. 5) point out that "... patients can be left confused and even tyrannized when their clinical management is inappropriately driven by algorithmic protocols, top-down directives and population targets."

This paper presents a qualitative analysis of empirical data generated in a primary health-care setting. As reflected in the paper's title, the analysis sheds light on a particular experience for patients of "becoming data" at the physiotherapist's. As part of their therapy, they are asked to register electronically, via an App on a tablet, various questions and questionnaires regarding their health. We refer the "Tablet-App-withquestionnaires" as the eTool. Table 1 lists the general content of the eTool. The majority of the items is comprised of Patient-Reported Outcome (PROMs).

The research question we thus address in this paper is: How do patients experience using an eTool intended for electronic registration of patient data? To our knowledge, the aspect of relating to digital technologies as part of a clinical encounter has not been comprehensively investigated. Considering the ongoing influx of various digital tools into health practices, we see this void as important to research.

Before the arrival of modern medical technology at the start of the 19th century, patients' narratives played the central role in almost every medical encounter (Hofmann, 2008). Understanding patients' history and concerns was seen as an art all medical practitioners needed to master. Over time, the introduction of technology gradually changed the encounters significantly. Implementing the stethoscope enabled the clinician to reveal bodily phenomena that the patient herself perhaps could give an account of, however in another language. Yet, the finding interpreted via the stethoscope came to be viewed as more "objective" and scientific. As Svenaeus (2001, p.31) notes:

Medical technology makes the meeting 'scientific' . . . the stethoscope enabled the physician to 'listen' to the patient without making any inquiries about his symptoms, thoughts and feelings. The body spoke a far more objective and exact language about disease than the voice of the person.

Since the introduction of the stethoscope in 1816, Western medical practice has equipped itself with an endless stream of tools, devices, instruments, and technologies. This has enabled increasingly sophisticated actions and interventions. In sum, clinicians today tend to rely more on measurements and readings

Table 1. Outline of elements in «The FYSIOPRIM».

Name of entry in App	Description or wording in App	Response option a	nd scoring in App	
Demographics				
Sex	Patient's sex	Female		
		Male		
Age	Patient's age	Age in years		
Referral	Is the patient referred?	Y/N		
ICPC code	Category and code	Therapist may add	free text	
Referral, detailed	Who referred the patient?	List of options		
Complaint	Why is the patient seeing a physiotherapist?	List of options		
Date of referral	Date the patient was referred to physiotherapy	Date (dd/mm/yyyy)		
Date of first appointment	Date of first appointment w/physiotherapist	Date (dd/mm/yyyy)		
Waiting time	How long has it been since the patient contacted a physiotherapist for an appointment?	1 week 1–2 weeks	3–6 months 6–12 months	
	appointments	2–4 weeks		
		4 w-3 months	1 year	
Priority assignment	The physiotherapist's priority assignment (1–4)	1.Quick start of inte	nuontion is assential	
Priority assignment	The physiotherapist's phonty assignment (1-4)	and waiting time		
			negative consequences 2. Good treatment outcome is	
			early intervention	
			expected to have	
			start of treatment	
		can wait up to 1		
		4. Intervention is		
			l improvement of	
			living, but start of	
		•	wait without any	
		significant conse	•	
Body regions	Mark the relevant body region(s) for your complaint (multiple answers possible)	Head	Tailbone	
, 3		Jaw	Shoulder	
		Columna	Hand	
		Neck	Hip	
		Thorax	Knee	
		Low back	Ankle/foot	
		Pelvis	Widespread/	
			complex pain	
Comorbidity	Specify diagnosis (if applicable) (multiple answers possible)	Myalgia	Lymphedema	
		Tendinopathy	Headache/	
		Pain ≥6 months	migraine	
		Mental health	Dizziness	
		Arthrosis	Trauma	
		Rheumatology	ligament	
		Heart disease	Trauma fracture	
		Asthma/lung	Trauma muscles	
		Stroke	Surgery/post-	
		Neurology Cancer	surgery rehab Elderly w/	
		Caricei	impaired	
			function	
			Dementia/	
			cognitive deficit	
Height and weight	Cm and kg		cognitive dentit	
Smoking	Do you smoke?	Y/N		
Education	Highest level of education	Primary school or lo	ower	
244441011	inglication of caucation	High school		
			college/university	
		More than 4 year		
		university	3~	
Ethnicity	Place of birth	,	North America	
		Europe	South/middle	
		Africa	America	
		Asia	Oceania	
Marital status		Married/cohabitant		
		Divorced		
		Widow/widower		
		Single		
Living situation		Lives in own home	alone	
3		Lives in own hon		
		Lives in institution		
Care of children	How many children under 18 years are in your daily care?	Number of children		
Network, support	1. Do you have family or friends who can offer you help when needed?	Y/N		

Table 1 (Continued)

Name of entry in App	Description or wording in App	Response option a	nd scoring in App
Health services	Have you had treatment for your complaints during the last 12 months?	No General practitioner Physician, specialist Chiropractor Manual therapist Physiotherapist	Psychomotor physiotherapist Psychologist Alternative/ complementary therapist
Main goal	Main treatment goal (set by patient/therapist collaboration, evaluated at follow- up)	Free text	
Planned treatment	Treatment planned to reach main goal (set by patient/therapist collaboration, compliance evaluated at follow-up)	Free text	
Disability and function Diagnosis by therapist PSFS	Functional diagnosis defined by the therapist Patient Specific Functional Scale; 3 activities identified by the patient in collaboration with the physiotherapist	Free text NRS: 0–10: 0 = unal activity and 10 = perform activity	
EQ5D-5 L	EuroQol-health related quality of life: 5 items; mobility, self-care, usual activities, pain, anxiety/depression		ndex score:0–1;
15D COOP/WONCA	Health related quality of life, 15 items; mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, usual activities, mental function, discomfort and symptoms, depression, vitality, sexual activity 6 items of physical fitness, feelings, daily activities, social activities, change in	Each item has 5 res Summarized as ir 0 = death and 1 5–6 response categ	ponse categories ndex score:0–1; = full health
ADL	health and overall health To what extent are your activities of daily life reduced due to pain or complaints?	Quite reduced Slightly reduced Not reduced	
Walking aid Time spent sitting	Do you use any walking aids? How many hours during a regular day do you spend sitting? (Both work and leisure time)	Y/N 0–24 hours	
Physical activity frequency	How often do you exercise during a week?	Never Once Less than once	2–3 times Approximately every day
Physical activity intensity	How intensely do you exercise?	Light without sweating and getting breathless Getting breathless and sweating Almost to complete exhaustion	
Physical activity duration	For how long do you exercise each time?	Less than 15 min 15–29 min	30 min-1 hour 1 hour
Risk of falling	 Previous falls last year? Problems w/balance or walking? Unable to get up from sitting to standing without use of hands? Parkinson disease or stroke? Three or more chronic diseases? ≥5 medications per day? Reduced cognitive function? Reduced vision? Body mass index 20? Fear or worry of falling? 	Question 1–9:Y/N	Question 10: Not at all worried Slightly worried Quite worried Very worried
Floor to standing mobility	1. Can you get down on the floor on your own?2. Can you get up from the floor on your own?	Yes No Do not know	
Employment/work Employment status	What is your current employment situation? (multiple answers possible)	Paid work Student Retired Disability pensior	Work allowance pension Non-paid work Unemployed
Employment percentage Sick leave percentage Disability pension percentage Work ability index – 1 item	Specify the percentage of employment Specify the percentage of sick leave Specify the percentage of disability pension What is your current work ability compared with the lifetime best?	0-100% 0-100% 0-100% NRS: 0-10; 0 = canr 10 = working at	
Pain Current pain intensity	Mark the number that indicate your current pain intensity	NRS: 0–10; 0 = no pain and 10 = worst imaginable pain	
Pain intensity last week	Item 2 from Ørebro Screening Questionnaire: How would you rate the pain that you have had during the past week?		pain and 10 = worst

(Continued)

Table 1. (Continued).

Name of entry in App	Description or wording in App	Response option and scoring in App	
Pain duration	Item 1 from Ørebro Screening Questionnaire: How long have you had your current pain problem?	0–1 week 9–11 weeks 1–2 weeks 3–6 months 3–4 weeks 6–9 months 4–5 weeks 9–12 months 6–8 weeks >1 year	
Pain drawing Temporal aspects of pain	"Mark areas in the body drawing where you have pain" 1. Is the pain continuous? 2. Does the pain intensity vary? If yes on 2: 3. Describe the temporal aspects of the pain:	Total of marked areas, range: 0–112 Yes, I can feel it all the time No, it is on and off Yes No, it is stable It varies during the day and night It varies from day to day Other	
Onset of complaint	How was the onset of your complaints?	Acute Gradually	
Analgesics	Have you used pain medication the last week? If yes: What medicines? (Three categories defined from active ingredient: Based on paracetamol, acetylsalisyl acid or ibuprofen)	Yes No 1. Paracetamol, Paracet, Panodil, Pimol, Pinex or Perfalgan 2. Albyl-E (500 mg), Aspirin, Bloboid or Dispril 3. Ibuprofen, Ibux, Ibuprox, Ibumetin, Brufen, Naproxen, Naprosyn	
Medicines	Daily medicine intake	4. Others 0 1–4	
		5 or more	
Psychosocial factors HSCL-10	Hopkins Symptom Check List; 10 item version	Range: 1–4; 1 = not at all and 4 = very much (extremely), mean item score is calculated	
Fear of movement Tampa	Single item: How much fear do you have that these complaints would be increased by physical activity? Tampa Scale of Kinesiophobia; 13 item version	NRS: 0–10; 0 = no fear and 10 = very much fear Range: 13–53; higher score indicates	
Ørebro-10 item	Ørebro Screening Questionnaire; 10 item version	higher level of kinesiophobia Range: 0–100; higher score indicates higher levels of estimated risk for developing pain related disability	
Pain self efficacy Treatment expectancy	Pain Self Efficacy Questionnaire; 2 items: 1. I can do some form of work, despite pain (work includes housework and paid and unpaid work) 2. I can live a normal lifestyle, despite pain I believe physiotherapy will improve my function	Range: 0–6; 0 = not at all confident and 6 = completely confident, total range: 0–12; higher score indicates higher level of self-efficacy Totally agree Agree Neither agree nor disagree	
BACQ	The Brief Approach/Avoidance Coping Questionnaire	Disagree Totally disagree Range: 1–5; 1 = disagree completely and 5 = agree completely, higher score indicates use of more approach-oriented coping strategies	
Family and friends	Do you have family or friends that can give you help when needed? Do you have family and friends with whom you can talk confidentially?	Y/N Y/N	
Short FES-I	The Short Falls Efficacy Scale-Internationally	Range: 7–28; higher score indicates severe concern about falling	
Disease- or region specific o NDI	questionnaires Oswestry Disability Index	Range: $0-100$; $0 = no$ disability and	
STarTBack	Keele STarTBack screening tool, subgrouping of patients into 3 a priori treatment		
Hannover	options Hannover Functional Ability Questionnaire; 12 items	risk groups based on the scoring Range: 0–24; higher score indicates poorer function	
SPADI	Shoulder Pain and Disability Index	Range: $0-100$; $0 = \text{no disability and}$ 100 = 100% disability	
Quick-DASH	Shortened version of the Disabilities of the Arm, Shoulder and Hand Score; 11 items	Range: $0-100$; $0 = \text{no disability and}$ 100 = 100% disability	
PGQ	Pelvic Girdle Questionnaire; 25 items	Range: 0–100; 0 = no problem and 100 = to a large extent	

(Continued)

Table 1. (Continued).

Name of entry in App	Description or wording in App	Response option and scoring in App	
HOOS	The Hip Disability and Osteoarthritis Outcome Score	Sub scores for five domains: Pain: 0–100 Symptoms: 0–100 ADL: 0–100 Sports/Recreation: 0–100 OOL: 0–100	
KOOS	The Knee injury and Osteoarthritis Outcome Score	Sub scores for five domains: Pain: 0–100 Symptoms: 0–100 ADL: 0–100 Sports/Recreation: 0–100 OOL: 0–100	
OA-QI	Arthrosis Quality Indicator; 17 questions about treatment alternatives for osteoarthritis	3 response categories; yes, no and a third that varies between the questions, pass rates for each question are calculated and used as a quality indicator	
PCS	Pain Catastrophizing Scale	Range: 0–52; higher score indicates higher level of catastrophizing	
Physical functioning from SF-36	10 items of physical functioning from SF-36 related to activities in daily life	Range: 1–3 for each item; 1 = yes, limited a lot and 3 = no, not limited at all, domain score range: 0–100%; higher score indicates better function	
Vitality from SF-36	4 items of vitality from SF-36 related to activities in daily life	Range: 1–6 for each item; 1 = all the time and 6 = not at all, domain score range: 0–100%; higher score indicates better function	
ISI	Insomnia Severity Index; 7 items	Range: 0–4 for each item; 0 = not at all and 4 = extremely, total range: 0–28; higher score indicates greater insomnia severity	
Norwegian questionnaire for the assessment of body experience	64 items; 11 subscales of body awareness, body contact, body endurance, body satisfaction, balance, breathing, aversion, tension, bodily discomfort, distance/remoteness and physical distance/boundaries		
Evaluation of treatment GPE	Global Perceived Effect (1–7)	1 = very much better5 = slightly worse 2 = much better 6 = much 3 = slightly better worse 4 = neither better 7 = very much nor worse worse	
Fulfillment of treatment expectations	To what extent were your expectations to physiotherapy fulfilled?	To a very large extent To a large extent	
Benefit of treatment	To what extent have you benefited from physiotherapy?	To some extent To a little extent To a very little extent	

The above-listed items are a description of questions and questionnaires in the FYSIOPRIM. The FYSIOPRIM also comprises clinical tests and other items not listed here. For a comprehensive description, see (Evensen et al., 2018) Characteristics, course and outcome of patients receiving physiotherapy in primary health care in Norway: design of a longitudinal observational project. BMC Health Services Research 18: 936.

derived from technological artifacts than on patients' own stories or descriptions of their complaints. Numbers and measurements are given precedence over the patient's "subjective" view (Hofmann, 2002).

In recent years though, systematic attempts have been made to bridge the subjective-objective dichotomy by infusing patients' opinions and perspectives with "objective" connotations. Currently, efforts are under way by health-care researchers and stakeholders across the world to develop and validate PROMs, which are seen as having the potential to bring these two aspects together (Black, 2013; Higginson and Carr, 2001; Marshall, Haywood, and Fitzpatrick, 2005). PROMs

are defined as: "Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else." (National Quality Forum, 2017). In other words, PROM tools use questions in order to arrive at measures of what patients can do and how they feel.

The development of PROMs, and their use in both research and clinical work, is intended to clear away the uncertainty and untidiness associated with patients' opinions, concerns, thoughts or feelings. Hence, information derived from PROMs is seen as "pure" and "objective," since it comes directly from the patient

without "interpretation." Dawson, Doll, Fitzpatrick, and Jenkinson (2010) promote the routine use of PROMs in health-care settings, however stressing the importance of proper training for clinicians if tools are to be used meaningfully. While Majeed and Thabit (2018) question the added value of PROMs in routine clinical practice acknowledging that many PROMs are more appropriate for research purposes, they concede that PROMs seem to possess "incremental value," suggesting that use of PROMs is set to become an established feature of clinical practice. This is why we see it as vital to research the practical, face-to-face aspects of the clinical encounter, when the clinical encounter involves the use of technologies such as in our case; PROMs and tablets.

Postphenomenological framework

We conducted within our enquiry a postphenomenological framework, inspired by the work of Don Ihde (1990) and Peter-Paul Verbeek (2005). The explicit focus of this conceptualization of phenomenology is on the relationship between humans and technology. Postphenomenology builds on the perspectives on this relationship offered by Heidegger (2010) and Merleau-Ponty (1962). Ihde (2008, p. 7) primarily relies on existential phenomenology and is additionally influenced by pragmatism. In describing postphenomenology he writes that "... postphenomenology emphasizes both a strong sense of embodiment, including [...]situated knowledges, and a sensitivity to materiality." Ihde goes on and calls it an "inter-relational phenomenology," and in investigating practical technology use and technologies in use the phenomenal body is technological central, situated in the world. Postphenomenology views things and technologies as non-neutral contenders in human experience.

Indeed, digital technologies – of particular relevance to this paper - have already been explicitly addressed through the postphenomenological lens. Examples include empirical studies of image interpretation (Friis, 2017; Rosenberger, 2008); relations to computers (Rosenberger, 2009); and mobile phone use (Wellner, 2014). More theoretically based contributions within this tradition have been offered by Ihde (2010) and Wiltse (2014). For example, in an exploration of the distinctive features of digital technologies, Wiltse (2014, p. 158) argues that "when considering how digital materials mediate experience of reality, I understand this to be reality as constituted for an experiencing person." (Emphasis in original).

In this paper, we make use of Ihde's (1990) concepts of embodiment and alterity relationships with technology. In an embodiment relationship, the technology in question mediates the experience in a transparent manner. Here, the user incorporates the technology as if unaware of the "non-human" presence; human and technology are connected in an effortless way. In an alterity relationship, in contrast, the user experiences the technology as "another." Throughout, the user is aware of the technology, which is not incorporated, and the whole experience has the potential to become disturbing and/or disruptive. Alternatively, an alterity relationship may have more positive consequences, perhaps encouraging a sense of involvement, inclusion, adherence, and flow on the user's part. Even so, its nontransparency rules it out from being an embodied human-technology relationship.

Interrogating physiotherapy practice from within a postphenomenological framework, we are able to approach the field critically, yet constructively. Kiran (2012, 2015) discusses the ways in which subject constitution in relation to artifacts and technologies is connected to the perceived possible uses of a specific artifact or technology. This in turn has consequences for, as in our case, how patients perceive their options and the possibilities opened up by the artifact or technology. This then influences how they come to understand their role as patients. It is in this sense that we perceive the eTool as a device with agency: as something which "plays" an active part in the three-way interaction between physiotherapist, patient, and technology. Kiran (2015) elaborates on the two-sidedness of technologies, stating that the relations between human and technology are indeed situated and dependent on the technology's affordance. Imagine the material features of the artifact to grasp the concept; in our case the inbuilt functions, where to press on the smart screen, the order of the questionnaires, the wording of each question, etc. This technology's affordance would mean different things, different possibilities to each user - physiotherapist or patient. When engaged with the technology, Kiran elaborates that the experience could be both enabling and constraining; functional and helpful or more like an obstacle or getting in the way. The experience could be both revealing and concealing; helping shed light on matters perceived relevant, or providing space for matters less relevant and thereby perhaps taking up space for other significant matters.

Phenomenology sees subject and object as intertwined; they shape one another. As Verbeek (2005, p.112) explains:

Human beings can only experience reality by relating to it (...) As consciousness (perception, experience) can



only exist as consciousness of something, reality is always reality for someone; in their engagement with reality, human beings always disclose it in a specific way.

To explore such "engagement with reality" from the field of eHealth, and the relations between physiotherapists, patients, and digital devices, we conducted a study in which we observed a number of encounters involving all three "players." Our aim was to identify mediating features or concepts that seemed to shed light on how patients anticipated their roles and responsibilities when an eTool was in use.

Method

Participants for our study were recruited via physiotherapists who were associates of the Research Program for Physiotherapy in Primary Health Care (FYSIOPRIM) (Evensen et al., 2018; Lillehagen, Vøllestad, Heggen, and Engebretsen, 2013). These practitioners were already contributing to the development of a patient cohort database, compiled and managed through the FYSIOPRIM. Roughly 60 physiotherapists, all of them private practitioners, were sent an e-mail inviting them to help with the recruitment of patients eligible for participation in the cohort study. They were also invited to participate in the first author's qualitative study (the results of which are discussed in this paper). Consent forms for therapists and for patients were attached to the e-mail. In order to broaden the recruitment pool, the first author also presented her research proposal at a meeting involving about 50 municipally employed physiotherapists.

Recruitment took place from April December 2016. During this time, the first author kept in touch with around 20 physiotherapists who were inclined to contribute to the qualitative study. After eight physiotherapists and eight patients had participated in this research, the first author deemed the material to have produced sufficient "experientially rich accounts" (Van Manen, 2014, p 353) to provide insights into the phenomena of interest and shed light on the research question.

The first author was present at all eight clinical encounters involving the use of the eTool. Six encounters took place in physiotherapy clinics, while two took place in patient's homes. The first author gained patients' prior consent for her presence during their physiotherapy assessment and for her interviewing them after the session. This included permission to audiotape the interviews. Four patients also gave written consent for the videotaping of their session.

The first author was present throughout each encounter, either in the treatment room or in patients' homes. During the registration phase of each encounter, the first author observed how the tablet and App were actually used. All eight patient-therapist couples completed the part of the registration process designed for collaborative entries with the first author present. She was also invited to observe three patients entering data on their own, in the "patient part" of registration (these observations all took place in physiotherapy clinics). The two patients who received physiotherapy at home completed a slightly different version of the FYSIOPRIM; all their entries into the tablet were made together with their physiotherapist during assessment.

Ahead of sessions, the first author prepared herself to maintain a conscious presence geared to observing as closely and openly as possible. While sessions were in progress, she sought to keep note-taking to a minimum, on the assumption that taking notes would be more disruptive than 'just being there.' At the same time, she was aware that she was by no means 'invisible' and that she would certainly have an impact on the encounter (Fox, 2016).

Following the first author's close observation (Van Manen, 2017, 2014) of each physiotherapy session in which the eTool was used, she interviewed each patient, focusing on particular moments and/or ways of using the eTool that seemed to shed light on the research question. During interviews, the first author encouraged patients to recount their experiences in as much detail as possible. An interview guide was prepared in advance to enable the first author to cover all topics considered relevant, but the main idea was to let the patients talk freely about their experience of using the eTool and to reflect on their future use of similar technology.

Field notes were written after each observation and interview, and were integrated into a reflexive journal, which was updated as the observations and interviews progressed. The journal was utilized as a source for revising and adding themes and analytical options throughout the data generation period. The work continued to inform the writing process as the findings from the study were identified, formulated, and reformulated.

With one exception, each interview was audiotaped and then transcribed verbatim. The reflexive journal was revised and reorganized as new themes were identified or existing themes reworked. In line with Van Manen (2014) and Crowther, Ironside, Spence, and Smythe (2017), an analysis was developed through a process of reading, writing, talking, reflection, re-reading, rewriting, and keeping new insights in play. Analysis of the data was inspired by hermeneutical phenomenology, in particular the work of Crowther, Ironside, Spence,

and Smythe (2017), Spence (2016), and Van Manen, 2017; Van Manen, 2014; Van Manen, 2017. We are inspired by these authors' use of anecdotes. In line with a hermeneutical approach, patients' stories and experiences comprise the data from which themes have been identified and developed.

Patients have been completing PROMs on paper for years, so what is unique about completing PROMs via digital means? When completing PROMS on paper, the responses are delivered as marks - which could be written in all kinds of fashions, quite freely - on a sheet of paper. When completing PROMs via digital means, as in our case working within the App, there is only one way to respond; tick the box, and one cannot easily skip questions or move to other parts of the setup. For instance, if you want to reflect on something and get back to that. It is not possible to nuance your answers – you cannot write a note beside a ticked box, for instance. When completing PROMs via digital means, your responses become data. An irrevocable entry into internet, which for laymen represents a hazy, blurry entity; not so easily comprehended. We believe that this particular feature of "becoming data" makes completing PROMs via digital means unique and worthy of interrogation.

One recurrent theme to emerge from the data was that of the eTool's ability to "make people think." For most of our patient-participants, entering their responses into the App seemed to have the potential to start a process of reflection.

A second salient theme concerned the appropriateness, correctness, or "validity" of PROM data in clinical settings. During interviews, many patients raised this theme. Whether via rhetorical questions, selfcontradictions, straightforward exclamations or subtle questions or hints, they interrogated the use of this novel device. Did it make sense? What was it for?

The variability and context dependency of the experience of using an eTool in a clinical setting are evident in the patient case studies presented below. While patients' experiences vary, we seek to highlight certain shared elements which we see as having the potential to inform practice. These elements also have relevance for theoretical issues regarding the use of PROMS, digitalization, and development and implementation of digital devices in fields such as physiotherapy.

In addition, patients' narratives invite reflection on the part of readers. As Van Manen (2014, pp.390-391) observes.

In phenomenologically-composed texts, the human being recognizes, creates, and imagines forms of being, significations of humanness. This means that

phenomenology does not only describe what something is, it also explores what this phenomenon can mean by offering possible interpretations. (...) Sensitive phenomenological texts reflect on life while reflecting life.

Presented below are extracts from interviews with four patient-participants, whom we call Dora, Erica, Adam, and David. Their accounts offer a variety of experiential meanings; indeed, these four individuals provided particularly rich experiential accounts.

In the italicized sections of these extracts, the first person singular is used to underscore the presence of the first author and the fact that this is a record of her experience of the narratives. Some observational data are included here to provide context for readers. Dora, the first patient-informant we present below, did not allow for the interview to be audio taped. To enhance readability, we chose to, nonetheless, write the "dialogue" between the first author and Dora "verbatim style," similar to the other three stories depicted below.

In the discussion which follows each case study, the first person plural is used to denote that the analysis was developed as a collaborative effort between the first author and the coauthors.

Findings

Dora: an experience of suddenly realizing her current situation

Dora, age 83, has been referred to the physiotherapy services in her municipality for an assessment following a fall five weeks ago. Dora is back home after a hospital stay, and is about to have a session with Cornelia, her physiotherapist. Cornelia is seeing Dora for the first time today.

Dora will not allow me to bring the video camera inside her house, so I leave all the equipment on the steps outside. She gives her written consent that I can observe the assessment and interview her afterward. However, because she is skeptical about "machines," she does not want me to audiotape the interview. I accept her terms and we start the interview once her physiotherapy assessment (including electronic registration) is over.

I: I am curious ... you wouldn't allow me to bring the camera inside your house and you didn't want this interview to be audiotaped ... you told me you are skeptical about what you call "machines" ...?

D: Yes. One has to use one's abilities!

I: Okay.? And by that, do you mean that we should not be reliant on machines to do things we could do just as well ourselves.?

D: Quite so!



I: So tell me, then, what was it like to use this eTool?

D: ... Now that I think of it, it actually was quite nice to see it in print – on the screen there just now – to actually get a sort of proof of how bad things are with me these days. This made me realize why I have been feeling so down and out lately.

During registration, Cornelia plotted Dora's answers into a number of items in various questionnaires regarding health-related quality of life and daily activity. Dora did not want to "operate the machine" herself. I noticed that Dora rated her current abilities regarding mobility, self-care, vitality, and sleeping quite poorly.

The process of being asked all the standardized questions, answering by choosing between the various options, and then getting visual "proof" from the tablet's screen as her responses are entered has an impact on Dora. Through this process, she seems to gain a new awareness of her situation, of why she has been "feeling so down."

Our wider interpretation of Dora's answer is that she is experiencing the eTool as a sort of new ally. By relating to the eTool, she realizes that she has been passing through particularly tough times – perhaps tougher than she was aware of. Dora is experiencing the eTool as a witness of sorts, one able to put her recent struggles into words (something she has been unable to do herself).

The postphenomenological concept of an alterity relation offers an additional perspective on this encounter. The epiphany Dora experiences by looking at the tablet's screen enables her to relate to the eTool as an ally. This ally gestalts as "another," one that offers comfort and explains why Dora has been feeling so "down and out" lately.

We could also interpret Dora's account as an embodied experience of the eTool. Dora experiences the eTool as something that articulates her troubles really clearly; it is almost as if the machine is doing something she could do just as well herself – in fact, the eTool is actually doing it better than she could. It's as if the eTool is becoming a part or extension of Dora, enabling her to get to grips with her current situation. Kiran and Verbeek (2010, pp. 218-219) note that:

Technologies aid our intentionality, our manner of being in the world; they are part of us, but not body parts. The tool, or the entity taken as a tool, is taken as a tool not just because it affords us to do something we ourselves are not able to do, but because it affords us to perceive and act in the world in a different manner.

Dora and I discuss further the use of electronic devices in the clinic. Dora believes that what she calls "machine use" should generally be kept to a minimum. She has already stated that humans should not let devices take over their capacities.

D: ... but this thing here that you are testing on me wasn't that bad after all. But I tell you, devices like that one [tablets] will never enter my home!

She elaborates on this by talking about a safety alarm the municipality wants to install in her home, following her recent fall. She has rejected the offer:

D: That thing [the safety alarm] will never enter my home, either! I will just have to manage without

To Dora, "managing without" seems a sensible solution; her default position is not to engage with digital technology. Dora's perceived distrust toward machines could suggest that she lacks the confidence to place her trust in technology, and that building up her confidence might enable her to more fully realize the eTool's - and ultimately any other technological device she will encounter in the future - potential. Exposure to new technological solutions might be one way of encouraging patients to make use of devices like the eTool. In Dora's case, actually trying the new device ("thing") seemed to reduce her negativity toward it. All the same, she remained ambivalent and reluctant. Kiran and Verbeek (2010, p 422), argue that "... trusting technology becomes a deliberate act of confidence." Maybe facilitating such "deliberate acts of confidence" could spur on important implementation procedures.

Erica: an experience of re-relating to pain and everyday obstacles

Erica, aged 56, has osteoarthritis in both knees and this is impeding her everyday life. Today she's having her first session with physiotherapist Amanda at the clinic where Amanda works.

During the interview, I ask Erica to tell me what it was like to use the eTool.

E: Well, in a way, one starts reflecting more, putting things into a form like that. There's ... kind of ... no way to avoid ... thinking about things when you are forced to formulate something regarding how things currently are ...

Erica's use of the phrase "no way to avoid" when describing how she relates to the eTool appears to underline the eTool's agency: its ability to initiate and drive human action. Erica's response suggests that she is experiencing an alterity relationship with the eTool. As with Dora, the experience is an enlightening one, in line with the theme "it makes people think." At the



same time, the eTool is "forcing" Erica to turn her attention inwards. The "objectifying gaze" of the eTool, as we conceptualize it, is a distinct feature of the eTool's agency. It is a strong gaze: directive and imperious. The gaze is so powerful that it is hard to say what makes it so convincing. For Erica, relating to this eTool, with its built-in rating methodologies, is a novel experience, but she has a notion it could change her current situation in positive ways:

E: It makes sense, actually, now that I've tried it. I keep repeating myself here, but as I start reflecting more on things, I kind of feel that I'll start relating to my pains and movement troubles in a different way.

I: Okay. Could you explain to me what the difference would be?

E: Mhm ... I think ... probably ... thinking in scales and those things ... It has something to do with awareness, I think. I'm probably going to be more attentive toward those kinds of things [rating pain and function] now, I guess. I'll be thinking more in those ways.

I: So ... what is going to be different for you now ...?

E: Well, I don't think I have the exact words ... it's hard to explain ... I'll just have to give it a try, I guess ...

While Erica seems to have undergone a small epiphany, she is as yet unable to identify the actual workings of this new coping method. She is now aware of the usefulness of identifying activities and rating them from 0 to 10. She is also starting to believe that rating her activities (as she did when filling in the Patient-Specific Functional Scale (PSFS) with her physiotherapist) might get her somewhere.

Applying a postphenomenological lens, we conceptualize Erica's experience as an alterity relationship with the technology. By filling in the PSFS, she has gotten a glimpse of something. But whereas Dora relates to the eTool as an ally, Erica's relation is characterized by a subtle shift in how she relates to everyday obstacles. The vagueness of the experience is what comes to our attention; its intangible character seems illustrative of the appeal of the "objectifying gaze." For Erica, there's not yet a clear, concrete, idea of "how to." Instead, she is left with a hunch.

We talk about the way Amanda introduced and handled the eTool and her management of the answers given by Erica. The conversation turns toward technology use in general:

E: I have nothing against technology! But it shouldn't become ... some sort of ... "quick fix", to rely on tools like this. It is important that it isn't replacing anything ...

I: Uhuh.? Are you having something particular in mind ...? Was it anything you experienced today that gave you a feeling of a "quick fix"?

E: Well, it has partly to do with the ... amount of questions and questionnaires ...

It seems that the sheer quantity of questions emanating from the eTool is what makes Erica think of a "quick fix." When it comes to her health, she rejects simplification. As she sees it, too much reliance on the eTool might result in important matters being overly simplified; short cuts might be resorted to. We see Erica's statement as her way of saying that this thing here, the eTool, is hardly the solution in itself.

As we interpret these statements further, Erica seems to be talking about something that also troubled Dora. Is there a way we can know when human abilities are superior to those of technology? If so, how can we identify those situations? For Erica, the eTool seems to have certain inherent traits which make her think of "short cuts" or "quick fixes." From a postphenomenological perspective, we can understand her experience as an alterity relationship comprising several ambiguities. For her, there is an opaque quality to the technology. Kiran and Verbeek (2010) argue that when we relate to technologies with suspicion, we tend to separate ourselves from what those technologies might offer.

In Erica's case, placing her trust in this technology and how it manages the data she keys into the tablet takes some courage. As Amanda's patient, Erica has already delegated some responsibility for her own health to an unknown individual. It becomes a double challenge for her to overcome her doubts and trust this new technology. It remains unclear whether re-relating to pains and everyday obstacles via the eTool will provide Erica with a route to recovery. Although hesitant, she seems willing to give it a try.

David: an experience of giving yourself a 'digital diagnosis'

David, aged 58, suffers from pain in his neck and shoulder. He has been on sick leave for over three months. Today is his first session at the clinic, with physiotherapist Martin, whom he has not met before.

When David has completed the questionnaires, including the "patient part," I ask him about his experience of using the eTool.

D: Mm. Yes, this was really simple. I had no trouble understanding all the questions, answering correctly, doing it right, and getting my diagnosis right.

I am a bit puzzled by his answer; to me it had not seemed as if he had found registration a "simple" matter.



Watching the screen as David tapped his responses into the tablet, I had noticed that he had moved back and forth between questions before entering his response. Several times he had edited his initial answer or replaced it with a different response. He had often paused to look up in the air or straight ahead, as if arguing with himself.

I: Uhuh . . . ? Could you tell me more about what it was like ...?

D: I actually think this could have been done in a much simpler manner - with more questions but fewer alternatives regarding the answers! (.) It's not like you are passing or failing, directly, but you do give yourself your own diagnosis, so it's really important that we get this right. When you're giving yourself a digital diagnosis in this way ... It's ... I don't know ... If someone applies this through and through, it's a bit like ...

I: Do you think a great deal is at stake . . . ?

D: Yes, definitely!

David goes on to tell me about his most recent visit to his GP. He says that the thorough way Martin has looked at him and questioned him today is very reassuring. In contrast, his GP only looks at the computer and never really checks him for anything.

D: He [his GP] is stuck in his paperwork! He seems to have no escape from that pile. So I like this development with the digital stuff. But I think there must be easier ways to do this.

I: Uhuh? I would love to hear your thoughts on that! Can you think of easier ways we could manage this and similar procedures in health practices ...?

D: I don't know . . . It was disappointing that there were only three lines on a chart after I completed all these questionnaires. There should be at least eight to illustrate me!

I: (laughing) OK, so ... what improvements would you suggest to the researchers currently developing this tool?

D: Well, we landed on the Moon back in '69, didn't we? So I wouldn't have thought it would be that much of a problem to produce several charts and give me my digital diagnosis!

As we explore David's perceptions of the methodology the eTool represents, we understand his hesitation and reservation as an explicitly disembodied experience. He relates to the eTool as a device he imagines has the capacity to actually produce a digital diagnosis. He then finds out that the technology is flawed; it seems to obscure matters rather than analyzing "correctly" the data he has entered. It seems to be giving him a sense of alienation; the eTool's output seems to represent only a meager version of himself, one with which he is uncomfortable.

Kiran's (2012, 2015) discussion of subject constitution in relation to technologies sheds further light on David's experience: In the context of the clinical encounter, David sees the eTool's representation of himself as actually limiting his prospects for recovery with physiotherapist Martin. By registering his personal data via the eTool, David experiences a transfer of responsibility for his own physiotherapy assessment from his physiotherapist to himself. For him, this is quite unsettling. It is as if the output from the eTool decides how he can be "present to the world," as Verbeek (2005, p. 112) puts it. In line with the experiences of Dora and Erica, David is also confronted with the objectifying gaze of the eTool, which focuses on what he perceives as his fractional self. This fractional self, moreover, is impeding his access to an appropriate physiotherapy plan.

David is critical of the process by which he is asked standardized questions and given only limited response options. He is disappointed that the eTool's features are not more sophisticated. While uncertain of how a satisfactory digital version of himself might be produced, he is certain that this is not it. For him to be able to embody this device, the technology would need to produce his avatar in a more complete, recognizable gestalt.

Adam: an experience of getting a fake digital diagnosis

Adam, aged 37, recently underwent surgery, and is attending physiotherapy to recover from a period of inactivity prior to his operation. Today he is seeing physiotherapist Patrick for the second time. Together with Patrick, Adam fills in the part of the questionnaire which deals with identifying aims and activities to work on together. Patrick then leaves Adam to fill in the "patient part" by himself, after explaining the entering process once more. Patrick warns Adam that some of the questions may seem marginal or irrelevant, and advises "Just answer as best as you can."

When Patrick leaves the room, Adam continues filling in the questionnaires. He turns to me a couple of times to consult me on how to interpret the Likert scales regarding function and pain. We discuss briefly the problem of using questionnaires and scales that do not quite fit his situation. When he has finished, we start the interview.

I: So, tell me ... what was it like to do this registration?



A: Nothing difficult about this; the technical solution and everything works just fine. It's just that the questions do not really fit my situation, that's my only concern (...) Everything is so very much focused on pain! Almost every second question is related to pain, and since I don't have any pain ...

I: Yes, I know that there are several questions regarding pain ... how did you resolve that ...?

A: Well, my physio told me to answer "as best as I can" ... so I guess that's what I did ... I answered all the questions and entered all the ratings but I'm not so sure that will give the correct picture. I'm not so sure that the data I provided for the research were correct ...

Adam carried out his somewhat surreal task by rating his functional problems as "pain": in other words, through an act of translation. Only on this basis was he able to fill in and complete all the PROMs and questionnaires. His concerns about the quality of the outcome are concrete and real. Viewed through the postphenomenological concept of technological mediation, we see Adam's experience as a disrupting mediation where he, the human, is being adaptive in order to satisfy the technology (which is far less flexible).

As Wiltse (2014) points out, digital material can only respond to the particular action it has been programmed to accept: in this case, pressure on pre-determined slots on the touchscreen. In what appears to be another example of an alterity relationship with the eTool, Adam (like David) experiences being forced to enter what for him are insignificant, even faulty, "non-sense" data into the eTool.

Adam reflects on the "validity" of this action. He wishes he could have done also the "patient part" of registration in dialogue with his physiotherapist, since that would have allowed him to calibrate his answers:

A: If I tell him [Patrick], I'd be reassured that my answer was given based on a scale that has a correct reference for my physiotherapist. That we'd have a mutual understanding that it is not pain, but my situation as a whole that we're talking about ... (...) So that would be more I'd feel that things would be more accurate then.

While David finds it challenging to relate to what he perceives as a fractional digital diagnosis, for Adam it is not just the fractionality that is problematic: the whole experience of "faking it" throughout the registration is what bothers Adam. In this case, it is not simply a case of experiencing the objectifying gaze of the eTool. It is also the fact that the eTool puts a very twisted image of Adam on display.

Despite this, Adam is not discouraged from continuing with physiotherapy treatment. He has a lot of confidence in Patrick, he tells me. He is familiar with many of the questionnaires he just filled in, since he encountered them when he was admitted to hospital and during his hospital stay. He tells me that he learned that doctors are "in and out in just seconds." He gets the feeling they tend to rely too heavily on fragmented data. Given the busy situation on the ward, he also wonders if he had conveyed all relevant information to the medical staff.

A: I think there is a danger in moving things in that direction all over, sort of. As a consumer of health services, I think this could result in services of lower quality. With too "efficient" use of tools like that. And just sitting and looking at the screen instead of ... I'd feel that I wouldn't be able to make use of ... I wouldn't be able to make use of that person - that person's competence, always.

Adam is experiencing the eTool as partly or potentially blocking access to people who are professionally equipped to help with his recovery process. He does not want to become "too systematized"; he perceives an "exaggerated digital scenario" as alienating and is concerned that a health worker placing too much emphasis on data from this eTool will not deliver services that will actually benefit him. We interpret this as a further instance of skepticism toward relying on the eTool's output. There are similarities here with David's questioning the validity of what he sees as "too few" lines on a chart.

Adam's experience reveals how the transparency and functional validity of a device can be lost when technology becomes a plain 'thing' or artifact, one that obscures intentions and hinders human interaction. This can occur not only in the moment; it can also plant in a patient a lingering sense of insecurity and doubt.

Discussion

This paper aims to shed light on the experiences of patients using an electronic registration device in the physiotherapy clinic. The four case studies presented here illustrate the non-neutrality of the eTool in question and the multifaceted, variable ways in which individuals experience it.

Digital technologies appear to open up exciting possibilities regarding the processing, analysis, storage, and presentation of data. They have the potential to present output in different languages and in ways that relate to patient's lives and desired functional outcomes. Wiltse (2014, pp. 155-156) goes as far as to argue that digitally enabled activities - such as entering one's own patient



data into an App – and the visible traces this produces, makes "a claim to represent reality that is unique". Understanding this, it is easier to understand a somewhat hesitant relation to such technologies.

The findings from our study suggest that users often have a more nuanced view of digitalization, though. This is in line with the findings of Essén and Oborn (2017), whose informants were aware of the limited ability of numerical data to accurately describe reality.

The eTool we investigated was depicted by users as, at one and the same time, too simple and not simple enough. Viewed through a postphenomenological lens, this appears typical of the ambivalence associated with the use of technology. As Ihde (1990) puts it, technology is something we both want and do not want. We want technologies to be transparent, functional, fulfilling, and helpful. We want them to do things for us in such a way that we are hardly aware of them. But as the findings of our study illustrate, we cannot avoid being in relation to technologies. The eTool can respond to only one activity: the touch of a finger pressing pre-determined spots on a screen. Data collected and transferred via this eTool represent only certain dimensions of the individual pressing the screen. A press of the "Finished" button on the screen sends this personal data elsewhere. For the patient, no visible trace of their data remains on the screen. The answers they have given become transformed into "my graphs" or "me as data." Yet, somewhere, the data is still there, stored on a server in a vague and hazy form.

For patients registering their data via digital technology, "getting it right" is a clear priority. The patients in our study asked: "Is it truly 'me' that comes out the other side?" By various means, including translations, adaptions, and editing together with their therapist, patients were able to manage their data and present it in a way that seemed recognizable and in tune with their lived experience.

Commenting on the challenges involved in using digital technology in health settings, Langstrup (2018, p.7) notes that "... meaningful data work can be established when data can be seen to further a clinical logic and a normative vision of patient involvement." She however envisions some challenges related todaily practical dealings with for instance PROMs. The findings of our postphenomenological analysis suggest that while patients may have some familiarity with using new technologies, including digital devices, they still need an opportunity to calibrate, edit and interrogate this "datafication" of their health. Scope for such fine-tuning needs to be taken into consideration when developing and implementing electronic tools in clinical settings. In line with Ihde (1990) and Kiran (2015), the patients in

our study experienced the eTool as both enabling and constraining, both revealing and concealing.

For Verbeek (2005, p.362), functionality lies at the heart of a commonsense view of technology; after all, the role of technology is to "solve a problem or fulfill a need." The question then becomes one of determining what problem and/or need a specific technology seeks to address. Høyer (2019) highlights the vagueness of the current discourse around datafication and digitalization, arguing that the power of the discourse is benefitting from partly overly optimistic, not yet fulfilled promises of intensified data harvesting.

While our informants were unable to pinpoint what exactly it was about using PROM data they found troubling or confusing, all of them were reluctant to fully accept the data-generating aspect of the eTool. Instead, the eTool was experienced as somewhat "unrelated," or as overly "systematic," or as "insufficient." This should sound a note of caution for developers, researchers, and clinicians alike.

As new tools, organizational arrangements and accountability structures become woven into existing health-care arrangements, PROMs (along with other patient-centered technologies and initiatives) will impact the lives of patients and health professionals in multiple ways, with consequences that are as yet unknown. It remains to be seen whether the eTool we investigated will prove a useful addition to the clinical toolbox or more of a Pandora's box, generating unforeseen dilemmas for both clinician and patient. When using the eTool, patients could find themselves face-toface with highly contingent, contestable versions of themselves. Alternatively, they might experience the technology as helpful and illuminating. Kiran (2012, pp. 92–93) elaborates on the possibilities and constraints of technologies thus:

Being influenced, shaped, even constituted by our surroundings, social or technological, is not necessarily (although it can be) oppressive and determining. [...] There is no mutual exclusion between possibilities and constraints; both aspects require situatedness, both aspects only appear in mediation, and both aspects are only understandable in relation to each other. Technological presence, therefore, offers us opportunities, possibilities, and reveals to us potential actions, potential forms of life, and potential ways of relating to our social and physical surroundings. Technical mediation is a way of realizing our own potential by actualizing an item's potential.

The challenges involved in making "data work meaningful in local practice" (Langstrup, 2018, p.1) are increased by the apparent shift away from interest in patients' narratives to the commodification of patient



outcomes (Lupton, 2014). There is a risk that the use of PROM data could limit and cloud insights, rather than provide health benefits for patients. A pertinent question, based on the findings of this study, is whether the application of PROMs in clinical settings is having the intended beneficial impact.

Confidence in technology also involves trusting the way data is handled. While the process of "becoming data" could offer patients reassurance and greater clarity, it could equally well introduce uncertainty and confusion into the relationship between patient and therapist. Where the shortcomings of a specific technology become evident, this could even undermine patients' confidence in the therapy they are receiving. Preventing such scenarios is possible, however demanding joint ventures between all participants in health care, including patients.

Clarifying and coming to terms with what we can do and know on the basis of digital data helps us gain a better understanding of what we cannot do or know. Identifying and reflecting on the ways technological agency both enables and constrains can also help us "understand more pointedly the accidental humanness of being human" (Van Manen, 2014, p. 310). If we are to avoid a surfeit of digitalization in health services, we need to take a step back in order to contemplate a broader horizon: one in which unrealistic ideas and technological potentialities coexist and interweave. When it comes to health technology, ongoing collaboration between patients, clinicians, and researchers is vital. Governments and stakeholders, too, must be involved at every stage of planning, design, development, implementation, and evaluation.

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