The double-edged sword of digital self-care: Physician perspectives from Northern Germany

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ABSTRACT

Increasingly, patients are expected to take initiative and care for themselves through practices of digital self-care: by generating data, by looking for people who can help them make sense of the information, and by being the main actors in disease prevention. Equipped with smart phones and other tools to collect data on various aspects of their bodies and lives from brain waves to activity to diet, patients are expected to prevent lifestyle diseases and diagnose their own medical problems, heralding an entirely new model of care within doctor-patient relationships. In this article we explore physician perspectives on how digital self-care practices are encountered, understood, and incorporated (or not) in the health care system. We carried out in-depth, semi-structured interviews with 15 doctors in Northern Germany in 2018 in order to explore how they included digital data in clinical decisions, how they understood practices of digital self-care, and how they saw these practices affect doctor-patient relationships. Our findings indicate notable frictions between narratives of 'e-patients' and digitally-empowered people in public media and scholarly literature on the one hand, and what doctors reportedly experience in their own practice on the other. We conclude that tech-forward ideas surrounding lay practices of medical emancipation do not 'travel lightly' across different contexts, but are taken up unevenly in and outside of the clinic. Moreover, the personal relationships through which digital self-care practices are undertaken remain central to the meaningful and safe application of new technologies and applications – something that often escapes debates over patient empowerment and digital technology.

1. Introduction

Traditionally, doctors have been the content experts that support patients as they deliberate over different treatment options. However, against the backdrop of precision medicine approaches as well as digital surveillance and prevention regimes, increasingly patients are expected to take initiative and care for themselves – by generating data, by looking for people who can help them make sense of the information, and by being the main actors in disease prevention (Dow Schüll, 2016; Goetz, 2010; Oudshoorn, 2011; Prainsack, 2017; Sharon, 2017). In reflecting on the "datafication of health" (Ruckenstein and Dow Schüll, 2017), scholars have identified the expectation that patients, equipped with smart phones and other tools to collect data on various aspects of their bodies and lives, will be increasingly asked to prevent lifestyle diseases (Goetz, 2010) or even diagnose their own medical problems (Lupton and Jutel, 2015). Proponents of techno-utopian visions of

digital health have argued that this trend could herald an entirely new model of care within doctor-patient relationships (Topol, 2016, p. 13). The digital revolution that has accompanied the proliferation of personal devices and digital applications in medicine has brought about new expectations for patient engagement and practice (Lupton, 2013a), giving rise to emerging forms of 'digital self-care.'

Digital self-care encompasses a broad range of practices undertaken by patients that include both novel practices (those that became possible through the datafication and digitization of patients' bodies and lives) and more traditional forms of participation that moved from the analog to the digital world. Many digital self-care practices have been enabled by the near ubiquity of the Internet and portable technologies such as smartphones, by major shifts in the collection and use of biomedical data, as well as by Do-It-Yourself (DIY) movements in the realm of technoscience. These shifts have moved practices that were previously performed by clinical experts to the hands of patients. They

entail changes in patient-provider relationships, including differing expectations for how health data will be used (Fiore-Gartland and Neff, 2015), and opportunities for open-ended and reciprocal engagements through digital technologies (Piras and Miele, 2017).

Many of these practices have been explored in health science and social science studies, including: searching for health information online (Bidmon and Terlutter, 2015); engaging in internet-based discussion forums or using social media platforms, using Youtube to share or consume information (Harris et al., 2014; Madathil et al., 2015), participating in patient platforms such as PatientsLikeMe or CureTogether (Wyatt et al., 2013), engaging with telemedicine (Nicolini, 2016; Oudshoorn, 2011; Pols and Willems, 2011), the use of home self-monitoring tools, apps, wearables, self-trackers (Ajana, 2018; Fotopoulou & O'Riordan, 2017; Lupton, 2016; Neff and Nafus, 2016; Sharon and Zandbergen, 2017), diagnostic apps (Aboueid et al., 2019; Lupton and Jutel, 2015), or sharing code or instructions for patient and hacker communities (Zhang, 2019). Scholars working in the area of critical digital health studies have examined patient perspectives on self-care and digital tool use, and the role of telemedicine in reshaping care practices (Oudshoorn, 2011; Roberts and Mort, 2009). They have addressed the effects of digital health and self-care practices on inequalities (Turnbull, 2019), the effects of datafication in health (Dow Schüll, 2016; Lupton, 2014b, 2017; Lupton and Jutel, 2015; Roberts et al., 2019) and challenged the tacit assumption that digital self-care is typically an individual practice (Brewster and Cox, 2019; Kingod, 2018).

However, while prominent voices have embraced digital health technologies in the medical and health sciences (Topol, 2013, 2016), studies indicate significant discontinuities on the part of practitioners on issues of patient engagement (Barello et al., 2012), patient safety and quality of digital technologies (Jiang et al., 2020; Wicks and Chiauzzi, 2015), regulation (Greenbaum, 2015), and more. Only very few studies so far have addressed digital self-care practices from the perspective of doctors, such as a recent interview study with Belgian doctors (Gabriels and Moerenhout, 2018).

Given the relative dearth of empirical studies on the perspective of doctors, this article explores physicians' experiences of how digital self-care practices are encountered, understood, and incorporated (or not) into the health care system. 'Techno-utopian' discourses on the possibilities of digital health technologies often ignore the ambivalences that practices like self-monitoring raise for both patients and health care providers (Lupton, 2013a), or the ways that patients and providers negotiate relationships through technologies like self-tracking (Piras and Miele, 2017). In contrast to the sometimes enthusiastic and speculative portrayals of digitized, democratized medicine in the scholarly literature and media, we sought to investigate the views of healthcare professionals in a region that is relatively wealthy and where healthcare standards are high, but which is not located in a technology hub. Specifically, we worked with physicians in Northern Germany to explore their experiences with, and views on, patients who have purchased online genetic testing, or are doing their own rare disease research, device hacking, or treatment alteration based on at-home health applications. How did these doctors understand such practices of digital self-care? Are the resulting data or techniques being incorporated into clinical decisions and medical care? How are digital self-care practices changing doctor-patient relationships, from the perspective of these physicians? In addition to making an empirical contribution to scholarship in this field, we seek to contribute to conceptualizations of digital self-care within a specific health care context, in a country that is expected to have rapid uptake of digital health practices (Ärzteblatt, 2019; Blasel, 2019; Gigerenzer et al., 2016).

In the broadest sense, self-care has referred to practices undertaken to protect or promote health without formal medical supervision, long before the digital era (Bruttomesso et al., 1989; Dean, 1989; DeFriese et al., 1989; Strasser and Mahr, 2017). Self-care in a health context involves decisions surrounding how to care for oneself, both independent of, and in conjunction with, institutionalized healthcare. However, with the rise of the 'digital revolution' in medicine, new forms of digital self-care have emerged that could shift the boundaries between lay/expert or clinical/public domains. Digital self-care likely will have implications for how clinical data are produced, for relationships between doctors and patients, and for the status of health care services and data – whether as a consumer product, open source platform, or public good.

While the boundaries of the term 'digital self-care' are continually shifting, it is useful to briefly outline the range of practices under consideration in this study. We are interested in the application of new forms of technological innovation that enable the sensing, measuring, visualizing, and recording of bodily phenomena that were previously impossible outside of clinical settings (Lupton, 2014a, 2017). Examples include using smartphone as otoscopes, as ECGs, or dopplers; and applications for the detection of HIV, certain cancers, prostate antigens, CVD, STIs, or uroflometry, all done at home. These practices mark the changing boundaries of what is considered "clinical", as they no longer require patients to physically enter a specific professional or technical space: The clinic is no longer something that they go to, but something that comes to them (for critical perspectives, see Langstrup, 2013; Will and Weiner, 2013, 2015; Williams et al., 2018).

Another area of digital self-care involves the creation of online communities that facilitate the collection, sharing, and shared interpretation of medical data, such as patient-to-patient and patient research-led platforms like PatientsLikeMe. Often these digital platforms enable, and are enabled by, large-scale data collection, patient self-reporting and sharing of clinical data as well as symptoms. What is referred to as citizen science or patient-led research includes practices ranging from "genuine" patient-led studies (where patients shape the research design and decide what happens with the results) to studies where patients are little more than data collectors in other people's projects (Prainsack, 2014).

The digitization of formerly analog methods of self-tracking has led to a proliferation of wearable devices to assist with posture, heartbeat, mood, glucose, exercise, hydration, and more. Self-monitoring can be oriented towards wellness or self-improvement, as well as clinical interventions including hacker movements for monitoring diabetes (Omer, 2016), or elder care (Broekens et al., 2009). Pointing to the need for finer grained accounts of how different users ascribe meaning to the data they generate (Sharon and Zandbergen, 2017), scholarship in critical digital health studies has examined the implications of self-monitoring practices (Ajana, 2018; Neff and Nafus, 2016), the experiences and practices of self-trackers, and the unintended effects of encouragements to become an 'empowered consumer' through data, changes in self conduct, and concerns around 'digital labor,' data privacy, and sharing (Dow Schüll, 2016; Lupton, 2019; Till, 2014). This scholarship has demonstrated that digital technologies of self-care both empower and disempower patients: they increase possibilities for some (often, the healthier and wealthier) while limiting control and agency for those who are excluded from using these technologies due to economic or social barriers (Prainsack, 2019). Sometimes, they move control away from *all* patients and limit their privacy – for example, when they require that patients share details of their bodies and lives that formerly were not datafied, and without giving patients a say in who can use their data, and how.

Another vein of practices falls into the category of DIY. DIY can mean many things, from online medical tutorials (e.g., homemade fake teeth, brain stimulation, gut swaps), to the creation of labs for the public (Ratto et al., 2014), or following dietary regimens or using over-the-counter pharmaceuticals for health reasons (Will and Weiner, 2013). Some DIY participants emphasize digital innovation, using open platforms for software development, 3-D Printing, online sharing of instructions for assistive technologies, bio-hacking, or alternative means of biomedical imaging. For example, in the "maker movement," individuals work to create surgery robots or alter medical equipment,

such as walking aids for the visually-impaired (RevRYL, 2013). Many such ventures commit to the accessibility, reproducibility and share-ability of these technologies, often with the goal of making technologies available for individuals without access or who are living in resource-poor settings.

While some digital self-care practices center on patient education by a health professional, in this study we were most interested in digital practices that were initiated by patients, that go beyond established protocols and hierarchies (e.g., making something new, adapting a procedure, starting a research study) and that are often completed outside of medical supervision or instruction. To this end, we included two vignettes in our interviews that give examples of digital practices initiated by patients. We will provide further details on our methods in the following section.

2. Methods

To answer the questions of the study, we carried out in-depth, semi-structured interviews with 15 doctors in Northern Germany.

Following ethics approval by the Christian-Albrechts-Universität (D 548/17), informants were recruited by email. Informants were selected using a snowball method, with several respondents recommending others who were interested in topics relating to digitization and self-care. The interview guide was pilot-tested. The interviews followed a semi-structured format, and lasted 30 to 90-min. Prior to commencing, respondents gave informed consent to participate and have their responses audio-recorded. They were informed that their information would be made anonymous, and were offered the opportunity to review their interview transcript and resulting texts.

All digital recordings were transcribed verbatim and coded independently by two of the authors. Data were evaluated using the principles of qualitative content analysis and grounded theory (Charmaz, 2014), in order to identify novel themes from the data. Subsequently, the authors discussed coding results and refined subthemes to ensure a high degree of inter-coder reliability. Points of overlap and dissent in coding the transcript were identified, discussed, and then aggregated into higher-order themes.

Specialties of interviewees included geriatrics, neurogeriatrics, diabetology, pediatric diabetology, obstetrics, clinical genetics, dermatology, neurology, radiology, psychiatry, pediatrics, neuropediatrics, gastroenterology, emergency medicine, internal medicine, and general practice; some individuals had additional training in medical business management and telemedicine. Six women and nine men were interviewed. Respondents had two to several decades of clinical experience. Identifying information revealed in respondent answers has been changed or omitted, and gender neutral pronouns have been substituted throughout the text. Interviews were conducted in English. Idiosyncrasies in grammar and syntax have been preserved in the quoted text; all respondents had a high degree of English-language fluency, but spoke German as a first language. Completing interviews in English enabled the use of quotes verbatim without losing meaning in the process of translation. The interviewer was a cultural anthropologist, trained in ethnographic and qualitative research methodologies, and an English native speaker.

Interviews focused largely on physician and expert perspectives on digital self-care, and were divided into two phases. In the first, conceptual understandings of self-care were elicited with open-ended questions, including what the term meant to respondents, examples encountered in practice, and changes in self-care practices over the course of their professional tenure. This portion of the interview was intentionally open in order to elicit respondent reflections on 'self-care' without leading respondents to examples of 'digital self-care.' In the second phase, two hypothetical scenarios involving the use of direct-to-consumer diagnostic testing and self-tracking devices were used to stimulate discussion on the integration of digital self-care practices in medicine. In response to each example, participants were asked to share

their reactions, discuss potential benefits and concerns, and consider if they had encountered similar practices in their own work. The vignettes were developed based on situations described in the scholarly literature and public media (Chettle, 2018; Ducharme, 2019), intentionally illustrating two distinct scenarios. The use of vignettes in qualitative research is well-suited to eliciting practice-based responses in medicine (Gourlay et al., 2014), because it enables respondents to define the situation in their own terms and explore actions in context (Barter and Renold, 1999).

2. 1Hypothetical scenarios presented in interviews

Vignette A	Marta, a 26-year old woman, sees an advertisement online for a "Do-It-Yourself" alternative to the pap smear. Intrigued, she clicks on the link to learn more. For a fee of €136, Martha can get a test kit that can be used at home. The device uses mRNA to detect HPV. She likes the idea that it is a "patient centered" technology, and promises an "accurate and painless way to check yourself for precancerous changes in the cervix, so that you can do something before it is too late." Even though Marta's insurance enables her to get a regular pap smear with her physician every two years, she decides to buy one and try it herself just to be sure. The purchase includes a free phone consultation to discuss the results, which are reported as positive, negative, or inconclusive.
Vignette B	John is a 56-year old man who runs a large company and often works long hours. Always busy in meetings, last year John bought a fit-bit – a device worn on the wrist to help keep track of his daily exercise, sleep patterns, and heart rate. Since then, he logs 10,000 steps every day, analyzes his sleep patterns upon waking every morning, and does breathing exercises to keep his heart rate down in meetings when he notices it rises above what the fit-bit says is "normal." His partner sees it as an "obsession," noting that he even uses his fit-bit and checks the app on the phone on weekends and vacations, but John says it makes him feel "empowered" to see the statistics generated about his body.

2.2. Findings: encountering digital self-care in practice

When asked to define what self-care meant to them, more than half of the respondents spoke of the personal self-care *of doctors* when first asked (i.e. the medical professional needs to get enough sleep, maintain a good work-life balance, etc.). Several noted that they had not previously considered the topic at all. When specifically asked about the digital self-care practices of patients, answers nearly always reflected the specialty of the respondent; for instance, one doctor who specialized in geriatric care indicated that because all of their patients were over 80 years of age, they had no familiarity with the vignette examples. Others, however, were already very familiar with the use of patient-driven practices, such as debates over patients using apps to identify skin irregularities in dermatology or DTC genetic testing. Interviewees from specialties such as genetics, dermatology, or diabetology were more familiar with digital practices led by patients – with the exception of data sharing among patients, which none of our respondents mentioned. Patients were generally considered to be information seekers rather than sources of information by our respondents. As one geneticist put it,

> my understanding of self-care is that patients try, well in my field of expertise, try to get information on genetic conditions, try to get information on genetic tests and then often come with their ideas what, for example, they could have for a disorder […] which tests would be relevant for them, and ask advice, or also ask me to take that self-diagnosis into consideration. (Interview 1)

For some doctors, self-care marked a decided shift in hierarchical approaches to the provision of care, stating that "self-care is handing […] over the […] paternalistic approach to medicine." This respondent described how doctors had long been seen as the "*God in white*," referencing a phrase in German where the doctor is presumed to be all-knowing and simply "tells the patient what to do, and the patient just complies with it." For this respondent, self-care meant "a different

approach whereby the patient him or herself looks after his or her disorder, and sort of becomes more independent of the doctor," citing the use of apps to record symptoms in the management of chronic diseases, or participation in virtual self-help groups. Describing the usefulness of self-care in refining treatment for migraine care, another physician noted that, in the process of recording how often they took migraine medication each month, and reflecting on how their recorded symptoms, weather, or diet information coincided with the onset of migraines, patients became

> … almost better experts than their doctors, because they observe themselves, and they observe their symptoms every day, and they know exactly how well acute medications work and when they work, and when they don't work. And they know what symptoms trigger their migraine, and there's a huge amount of knowledge that these patients with chronic disorders accumulate. (Interview 4)

Similarly, another respondent noted that self-care was contributing to a shift from patients seeing doctors as all-knowledgeable to seeing them as consulting service providers.

When asked to provide examples of self-care from their own clinical practice, doctors consistently cited activities such as patients "googling" their conditions, asking relatives for information, requesting a copy of medical reports, monitoring their own progress, participating in self-help groups, and going to regular appointments. Many cited the role of smartphones in facilitating the flow of information and improving registration of symptoms. Respondents contrasted this to previous reliance on paper documentation which was often forgotten at home, or lost. By entering symptoms, diets, or other triggers related to their health condition directly into an app, patients can record data on the spot rather than relying on memory recall, and have the option of sending it to their physician for integration in treatment plans. One dermatologist noted that this was particularly helpful for patients adhering to onerous skin care routines or for the management of co-morbidities that affect conditions like psoriasis.

Some respondents with a strong professional interest in the topic gave specific examples of digital self-care, either from their own practice or in reference to products under development, including: a "first responder app" to enable faster response times from a network of ambulance drivers; the use of avatars for hospital intake procedures; the development of speech recognition programs for hands-free documentation and safety checks in the operating room; flash sensors to detect arterial flutter; a voice analysis to detect Parkinson's disease.

2.3. Benefits: engaging more people with their own healthcare

2.3.1. Expanding services and limited applications

A principal benefit described by respondents was the possibility for digital self-care technologies to expand the reach of health care to hard-to-serve populations, possibly facilitating earlier disease detection. This was mentioned by several respondents as a way to improve healthcare services in resource-poor locations, echoing similar arguments made in the literature (Asi and Williams, 2018; Cowie et al., 2018; Topol, 2016). A majority of our respondents felt that the availability of a diagnostic test like the one described in vignette A would be appropriate in Germany. If, as some respondents argued, a woman was reluctant to regularly visit her gynecologist for routine check-ups, or if she were not able to go to the doctor's office for logistical reasons, then a self-diagnostic pap smear used at home would be beneficial. Noting that the appropriateness of the technology depended on the context in which it was used, another doctor also concluded that this could be helpful "but only if for very special population." In sum, the extension of services to new populations was cited as a benefit in relative terms, on the grounds that such a technology could fill a gap in places with fewer medical services in place.

2.3.2. Empowerment

Other respondents envisioned scenarios where specific digital self-care applications could contribute to the greater independence of patients, such as older adults, or overall improvements in health due to improved patient interest and engagement (such as in vignette B). Some noted the possibility of greater empowerment of patients, which was roundly seen as a positive outcome that aligned with clinical goals. As one physician observed, members of the professional health care team are consultants that should facilitate patient decisions, including helping them to navigate new approaches to managing illness. The respondent offered examples from a collaborative project across the EU which combines wearables with feedback provided by patients with Parkinson's Disease as well as caregivers, with the goal of increasing engagement through patient-centered diagnosis and treatment, and user-led electronic health records. On the surface, this could be seen as resonating with calls made in the literature for more 'patient empowerment' and 'activated patients' (Britnell, 2015; Hibbard and Greene, 2013), which capture the idea that patients can, or should, play a more active role in their healthcare (Lupton, 2013b; Nielsen and Langstrup, 2018). In our sample, however, the ability for patients to take greater control of their health and lives through digital self-care was understood as largely positive only insofar as it aligned with physician goals. As one doctor concluded, "it shouldn't be the experience of 'I have googled, and I decided to do [this] and that test' – there has to be a doctor-steered process."

2.3.3. Improved outcomes

One benefit described by respondents was the possibility for digital self-care practices to improve treatment and outcomes. Several doctors noted that technological advances in diabetes care have dramatically improved adherence to treatment regimens, including flash glucose monitoring which can notify patients at night of a fluctuation in blood sugar, or parents while their diabetic children are at school. When giving examples, some physicians also spoke from their own experience as patients. In one interview, a physician pulled out their phone, scanned their upper arm patch, and showed the interviewer the instantaneous blood sugar reading that was accompanied by an upward or downward arrow on the phone to indicate if it was rising or falling. The respondent described these advances as helpful in improving control of disease for an individual patient, and with the added benefit of pushing the doctor to stay on top of the newest treatment developments in a rapidly advancing field. Such claims of improved outcomes echo promises of digital self-care promoted in policy and industry that increasing amounts of data will provide important insights for improving both individual and population health outcomes, ranging from enabling lay people to take a proactive role in diagnosis (Riggare, 2018), increased disease prevention (Dow Schüll, 2016; Goetz, 2010; Oudshoorn, 2011; Sharon, 2017), or better patient engagement with medical care (Audrain et al., 2017; Lupton, 2013a). Also here, however, doctors only endorsed digital self-care practices that aligned patient practices with doctors' directions, even when they were drawing on their own experience as patients.

2.4. Concerns: the risks and costs of digital self-care

2.4.1. Appropriate technologies and individual specialties

When asked where they would draw the line for the appropriate use of digital self-care for diagnosis and possible alteration of treatment regimens outside of clinical supervision, respondents tended to classify the specifics of their own specialty as too complicated for unsupervised applications. For instance, although one respondent saw themselves as potentially open to advances in digital self-care in other areas, a geneticist noted that patients were likely to misunderstand risks associated with particular conditions. A dermatologist felt that the use of apps to identify skin cancers required expert guidance. Others with training in public health drew the line along contagious versus non-

contagious diseases. Beyond illustrating that decision making within their own specialty was too complex to be left to the digital self-care of patients, many respondents cited the degree of severity of the condition as relevant for determining its appropriateness for lay use (e.g., while they might be comfortable with a self-administered product to detect HPV, they would not be for HIV). One respondent concluded that, "I think tests which in the end lead to diagnosis and treatment should preferably be left in the hands of doctors." In cases of a known condition, however, "where you need ongoing findings to monitor treatment and where patients usually are enabled to make adjustments to that treatment," such applications could be beneficial. Such a response draws an important distinction between digital self-care technologies that enable practices of diagnosis and treatment from those that enable increased monitoring of the self, reiterating concerns that patients may not be able to appropriately interpret and contextualize data. This distinction reflects longstanding views within the medical profession that monitoring can be devolved to machines or patients under some circumstances, but that ultimately, diagnosis and treatment plans require medical training and professional expertise (Langlois, 2002; Ledley and Lusted, 1959; Reiss and Ankeny, 2016). Several interviewees also noted that high cost interventions should be left to expert discretion in order to avoid unnecessary use of limited resources.

2.4.2. Negotiating new burdens

Many respondents were concerned that diagnostic testing outside of the clinic would risk improper application, including potentially "disastrous" results. Consequences of misapplication could include poor medical outcomes or harm to patient wellbeing if a condition was not detected due to technical problems with the test, or because a false positive result was given. Voicing concerns in cases where a test could have a high false positive rate, one respondent noted that, besides being harmful for patients, such tests could burden the healthcare system. Imagining a scenario where a patient used a diagnostic test more often than recommended, this respondent said:

> I mean if then every other six months she turns up at her gynecologist and then of course requests more intensive care than she is entitled to because she has these positive findings on the mRNA screening, then of course it would be a healthcare burden [] which would also not be fair on the broader society, so … if such a test would exist well then it should be only given out to a very special sort of population, like girls who have [had] a trauma, and would never go to a gynecologist for a regular pap smear. (Interview 1)

Thus, while self-care diagnostics could prove important for special populations, on the whole many respondents did not see them as a welcome addition to the patient-led domain. Such concerns echo conversations in the area of direct-to consumer genetic testing and personal genomics, where one study found the rate of false-positives in raw data to be as high as 40% (Tandy-Connor et al., 2018). The caution expressed by respondents surrounding the role of patient-led diagnostics was largely in line with concerns expressed in scholarship on the availability of DTC testing, including the potential for psychosocial harm for consumers (Moscarello et al., 2019).

In the literature, some authors see self-care diagnostics as an example of how digital health technologies could not just empower patients and consumers, but also physicians – therefore potentially giving rise to new forms of patient-provider relationships and fundamentally reshaping the role of providers (Mesko and Győrffy, 2019). However, as our responses suggest, new forms of empowerment will not necessarily follow easily or directly for providers either; rather, many providers will also require training in order to increase their comfort and confidence in working with patients engaged in digital self-care applications (Hoffman et al., 2019). Others may resist the idea of patients having access and control over diagnostic testing. Some respondents argued that there was no legitimate medical need for digital self-care because all medically necessary matters would be covered by the compulsory or private German health insurance systems. Respondents also voiced concerns that optional tests were commercially, rather than medically, motivated. While this indicates that our interviewees had high levels of trust in the processes and metrics in place for cost-effectiveness and reimbursement decisions within the German healthcare system, they also felt it would be unfair to expect patients to cover costs for additional services and technologies out-of-pocket. Some expressed doubt that digital self-care applications would ever be widely used given the added cost they represented for individual patients. One individual noted that the cost could be particularly problematic for patients who have anxiety around a given condition. As a dermatologist, they imagined a scenario where the use of a digital app for diagnosing a mole could raise unnecessary fear, anxiety, or even compulsive behavior. The respondent did not want to operate in a system where one patient would say to another: "did you scan your skin already with the app?" (Interview 10).

2.4.3. Validity

A major concern cited by nearly all respondents was the validity of testing available for use outside of the clinic. As one doctor said,

> That's something, I, to be honest I don't, don't like very much. Because most of these diagnostic tests are either not very robust and validated, or they are but they require special knowledge for proper interpretation. And usually patients can't do that […] we have the same phenomenon in for example allergy testing. There are many tests around that people see on the internet or [for example] microbiome testing, and then they get results that worry them, but they don't really understand them and then they come to us and then we [must] interpret a test that we have not done ourselves, that we sometimes not even know. (Interview 12)

This doctor went on to note that such tests could cause more confusion and worry for the patient than relief or relevant information; further, they could lead patients to falsely believe that they are healthy simply because one DTC application indicated that they are. The respondent concluded that they would prefer if patients first asked about a test they were interested in, and in order for the doctor to make a recommendation, because "at least here in our setting I would say that all established tests are really available through the physicians in clinics, so any test that is out there that we don't offer is probably […] not validated, not reliable." The respondent cited a hypothetical example of a parent whose child suffers from a skin condition, who then puts the child on a restrictive diet for a year without medical basis, resulting in extra effort and expense, or worse, harm to the patient.

2.4.4. Person-to-person conversations and the interpretation of results

Concerns were consistently raised throughout the interviews about both the validity and reliability of digital self-care options available outside of clinical supervision, and the capacity of patients to appropriately interpret the results. Over half of respondents noted the growing number of online self-help and patient groups available for patients living with various health conditions. Generally, respondents were pleased that there were new avenues of support available, but concerned about the quality of information. One physician who manages a chronic illness of their own noted that while they were able to discern valid from invalid information on a patient forum due to their medical training, that others were likely not able to do so. Other respondents noted that many patient-to-patient support groups had no moderation or filters to prevent the circulation of false information. Respondents thus echoed concerns regarding the quality of health information online (Nuffield Council on Bioethics, 2010), and reiterated worries around low health literacy in the population (Schaeffer et al., 2017) and how this might be exacerbated by the digital divide, leading to even lower digital health literacy at least in some patient communities (Neter and Brainin, 2012).

Several respondents also had difficulty with the idea that a phone

conversation could replace an in-person conversation. One noted that the narrow focus of some digital self-care applications could lead a patient to miss other relevant pathology, that would have been discovered if the procedure were performed by a professional (e.g. missing another viral cancer present in a pap smear when the self-care test was only designed for HPV). The doctor-patient relationship was seen by many as essential to facilitating good medical care.

2.4.5. Regulatory concerns and clinical ethics

Another major area of concern for our respondents pertained to the regulation of digital self-care technologies. With the increasing availability of products for purchase online, one doctor noted that this would raise specific concerns for health authorities as the use of technologies by patients would be difficult to control. Referring to the growing availability of diagnostic digital self-care tests as a potential "problem," one doctor noted that,

> I think German authorities would have to think how to regulate these tests, and give very clear recommendations on the false positive and the false negative rate, and how to use them, when to use them, and then perhaps have care-workers in the healthcare system [that] might also council about it, but that's just speculation. (Interview 1)

Besides a generalized worry about a loss of control over the quality and interpretation of the data collected by patient digital devices, some respondents also drew attention to the difficulties emerging from a lack of harmonization of approval and oversight standards. Several doctors working in diabetology reported that they had patients who had purchased blood glucose meters in the United States that were not on the market in the European Union, which created a number of ethical, legal, and practical problems for the medical team.

One significant set of regulatory issues was raised by the practice of device hacking (e.g., #WeAreNotWaiting, a movement of health hackers in type 1 diabetes communities). Using guidance that is available among patient groups and online, some patients and advocates hack medical devices to access data and use open-source code to automate monitoring and management for diabetic patients. This includes integrating pumps with other devices and software – a technical advance that improves individual control by creating a closed-loop pump (Omer, 2016). In this case, a market-approved device becomes a liability for the medical team. As our respondents told us, the moment the supervising physician sees on the computer that a patient has hacked or altered their pump, they are no longer legally able to supervise the patient. In the words of one doctor: "We can just say: 'As long as you use this product, I'm very [sorry but] you have to leave this outpatient clinic, and you have to be treated anywhere else, but we cannot do that,'" (Interview 14). Here, engaging in digital self-care that improves clinical outcomes also unintentionally puts clinical teams in a position of discontinuing care for liability reasons. This was despite the fact that doctors understood their patients' motivations: "I really can understand the parents because their children are now under 18 and they would like them to [grow up to be] 80, that they grow up healthy, have children, family and no problems with late effects of diabetes" (Interview 6).

Regulatory gaps around emerging medical technologies present well-established challenges (Fiske et al., 2019a), as does the hacking of medical devices (Barnard et al., 2018; Farrington, 2017; Lewis, 2019). What our study shows is that these regulatory gaps create not only legal but also ethical problems for clinical teams. Physicians may want to continue caring for patients with unregulated or hacked devices, but they may feel that they cannot, because they may become liable. Moreover, our respondents voiced concern about the lack of clarity about a range of issues connected to the use of unregulated devices by patients, including: how this affected their fiduciary duties to these patients; whether they should actively discourage patients from using such devices even if the devices led to better outcomes; and whether

they could incur any liability if they kept treating such patients. Following the completion of our inteview study, a legal opinion by experts commissioned by the German Diabetes Association interpreted existing law to mean that doctors are not allowed to actively support patients in the use of uncertified or tampered devices, and they are obligated to inform patients about the risks of using such devices. They are allowed, however, to keep caring for such patients (Deutsche Diabetes Gesellschaft, 2018).

There will doubtlessly be many new questions that emerge with the ongoing use of digital devices by patients; for example, the use of devices that are not classified as medical but that are nevertheless used for healthcare purposes. Examples are digital apps such as fitness trackers or pedometers, which typically do not fall within the remit of medical device regulation (Kao and Liebovitz, 2017; Lucivero and Prainsack, 2015). This does not only mean that the use of these devices remains unregulated in healthcare, but it also means that the acquisition of these devices, and the medical advice on the basis of information obtained through them, cannot be reimbursed. This was addressed by some of our respondents who noted that the current reimbursement paradigm in medicine prevented certain new technologies from being fruitfully integrated into the healthcare system. Describing a situation where an individual using a smartphone screening tool finds that a skin lesion is suspicious, one doctor said that:

> Many of these new devices they have a [] preventive approach, right? And unfortunately, our healthcare system is not so much into preventions. So we physicians are used to see[ing] patients that are already ill, and this is what we get paid for. If now people that are otherwise healthy come to us and ask us 'Do you think this or that tool is good for me to help me stay healthy?' then we won't get much money from the insurance company for these consultations. So we would probably in parallel [] need [] a slight modification of the whole healthcare system, so that prevention is paid better also for physicians that take part in preventive measures.

In their view, a healthcare system that meaningfully supports the proactive and preventive use of technologies, in particular for early diagnosis, would necessitate revising models for financing and reimbursement:

> Right, I mean now if a patient makes an appointment he or she is usually asked [by our receptionist] 'What is your problem?' then the patient say[s], 'Yeah I have a rash' or whatever. But if the patient says 'I want to have some advice on an Apple tool,' then I'm not sure that our people here would give this patient an appointment. [] Because we always have to make a diagnosis, which stands for disease, to get money, to get paid for, and we can diagnose this as a healthy individual and this individual only needed some advice. I'm not sure if he could … if the physician would get paid for this. (Interview 12)

In a similar case, a geneticist noted that if a patient came in with a DTC genetic testing report that indicated that they had a polymorphism increasing likelihood of osteoporosis, that the doctor would consult with the patient and likely proceed with further testing. The respondent noted that this would raise an interesting problem where they would be unsure if they should charge the patient directly, or if the test would be covered by the health insurance company.

2.4.6. Dr. Google v Dr. Human

Many doctors described frustration with patients turning to online resources instead of, or before, professional advice. While our respondents considered themselves supportive of self-care in general terms, they consistently advocated the use of digital self-care tools only, or largely, under physician guidance. One example given was a program for patients who were candidates for obesity surgery, which required them to show six to nine months of data including daily weightings, endocrinologist and other specialist visits, and laboratory

work. Successful completion demonstrated commitment and capacity for self-care. However, as one doctor noted, participation in the program was done under medical supervision, and not simply because the patient decided to take part on their own initiative (Interview 3).

Other positive examples that our respondents gave for patient self-care were the development of a migraine app and programs for adolescent diabetes patients; in every case patient-generated data were monitored and reviewed by a physician prior to making changes to an existing treatment plan. Physicians encouraged the use of these tools by their patients insofar as they facilitated existing clinical or wellness goals and did not involve independent decision making by the patient. As one doctor noted,

> … that's something we face every day, that people come in and have read a lot of things on Google and they think they know a lot of what they might have or what might not have. And if they then find a link where they click, and they get a diagnostic tool or something, […] maybe they don't need it at all, or this is not suitable at all for the patient, then they do things which are senseless. So, I think the consultation with a physician should be first, and then if it's really necessary and useful for the patient then it might be helpful that they can find support on that special disease somewhere else, yeah. But, [laughing] my personal idea is that it should be forbidden that patients Google their disease themselves [laughing]. (Interview 10)

One respondent went on to describe how very often, a patient 'googling' a condition translated to additional time in the clinical encounter, requiring doctors to explain why particular tests were not relevant, or correcting false information. While presented with humor, several interviewees had the same frustration. One respondent noted that the possibility for patients to obtain their own diagnostic testing would represent an "unnecessary burden" for doctors and the medical system because patients would most likely still require additional counseling or testing from their doctor. Another respondent noted that, in their view, when patients or relatives arrived in the office citing studies and treatments online, it showed that their trust in the physician had eroded.

2.4.7. Embodied changes and self-knowledge in patients

While generally positive about the use of personal trackers to improve physical fitness, wellbeing, or collect basic biometric information, one physician specializing in diabetes expressed a concern that over-reliance on technology could lead some patients to lose self-awareness. This doctor felt that the quantifying, data-generating practices of digital self-care ran the risk of eclipsing other forms of non-technologically mediated forms of self-knowledge. Describing how some patients can correctly tell without checking that, 'I have a blood glucose level which is between 80 and 90,' the interviewee feared that others will lose this learned ability to pay attention to bodily signals. "They can say 'Oh I'm something like 200 and 220 I can tell.' [Then] they do a blood test and it's right … this is a quite good thing yeah, this is better than any technical device," (Interview 6).

Paying attention to how one is feeling, such as knowing whether an oncoming headache is due to elevated blood pressure, independent of a device, was an important aspect of digital self-care that was at risk of becoming obsolete, according to this respondent. Several doctors noted that they felt that patients tended to focus narrowly on one indicator, at the expense of the overall context of their condition and health. They were worried about patients getting a false sense of security based on one indicator, or that patients were unable to interpret one indicator in relation to other measurements. The role of digital technologies in offering a 'window' into interior bodily processes, such that people can learn from information generated about their bodies has been central to conversations on self-tracking and changing approaches to the self and health (Lupton, 2013b, 2019; Neff and Nafus, 2016; Pink and Fors, 2017). While industry promotion has emphasized self-optimization through data that is supposedly 'truer' than sensory inputs, respondents

in our study emphasized the value in being able to know and trust one's own somatic clues – an observation that has also been noted in the self-tracking literature.

3. Discussion: implications for clinical practice and the double-edged sword of digital self-care

Across our respondents, we found different approaches to digital self-care practices. Many shared similar concerns surrounding the validity of testing, reliability of patient-generated data, and the appropriateness of patients using data to make treatment decisions. They felt that while such digital practices could be helpful, it was best that they remain within existing relationships of medical supervision. A few respondents stood out in their contrast to these views, namely those already working regularly with patient populations accustomed to using digital tools (e.g. diabetes care), or those who were explicitly interested in the integration of technology into clinical practice (e.g. technology transfer or dermatology). In these cases, greater faith was expressed in the ability of a patient to correctly mobilize new tools to improve health, or for digital self-care practices to be a complement to clinical practice.

Overall, we found that the experiences and narratives of the physicians that we interviewed were notably different from stories of 'e-patients' and digitally-empowered people that populate books and magazines. This shows that tech-forward ideas surrounding lay practices of medical emancipation do not 'travel lightly' across different contexts, not even within affluent health care and social contexts. It further highlights the need for more context-based studies of how digital self-care technologies are taken into practice, and the various contingencies, negotiations, and resistances that emerge in the process (Pols, 2012).

Our findings also resonate with earlier studies that found concern among clinicians that their expertise will be replaced by machines (Oudshoorn, 2011; Weiner et al., 2017). What our study adds to these findings is the great importance placed on personal relationships with their patients by the doctors we interviewed: resistance to the delegation of tasks previously done by doctors to digital technologies was not simply due to a reluctance to give up power and control. Such resistance was, at least in part, motivated by concerns about the safety and wellbeing of patients, which was best protected by an ongoing dialogue between doctors and patients where each had their role and would bring in their own expertise. The physicians in our study emphasized the joint work of patients and clinicians in deciding what tests to take, what data to generate, and what to do with the results. Such findings connect with work on self-tracking and telemedicine that points to the need for careful attention to differing forms of resistance on the part of both patients and providers (Weiner et al., 2017).

Although there were instances of some physicians protecting their own 'territory' by insisting that doctors were the only group of professionals competent to do this, overall, respondents painted a picture of empowerment as a relationship between patients and physicians, rather than as a zero-sum matter (Prainsack, 2017). Within that relationship, both parties could be challenged or pushed beyond their field of expertise, but any gaps of knowledge and understanding could at least be identified and addressed if they remained within the relationship – and were not relegated entirely to the realm of the patient's home or phone - what Nettleton (2004) called e-scaped medicine. That personal relationships through which digital self-care practices are undertaken remain central to the meaningful and safe application of new technologies and applications is something that often escapes debates over patient empowerment and digital technology.

A consistent theme expressed by physicians who had less experience with digital self-care practices was the sense that patient engagement with digital practices would generate extra work for health care professionals, echoing explorations of the labor involved in mediating health data (Fiore-Gartland and Neff, 2015; Fiske et al., 2019b). Some

noted that this could unfairly burden the health care system through the rise in demand for services that were not medically indicated. Physicians understood a central part of their professional role as mediating the anxiety or confusion that medical testing and practices can entail, and helping patients to contextualize results within the broader picture of their health and life goals. Digital self-care was spoken of in some cases as a sort of 'Pandora's box' that, once opened, could spark compulsive, anxiety-driven behavior that was counterproductive to good health, also referred to as "cyberchondria" (Doherty-Torstrick et al., 2016). This finding resonates with Gabriels and Moerenhout's (2018) discussion of how Belgian doctors worried about increasing health obsessions among patients who engaged with digital self-care.

However, among those physicians who already had experience with the potential legal and ethical issues that can emerge when patients modify or hack medical devices, their concerns centered on how they could continue to provide the best possible medical care for their patients despite a regulatory system that had not caught up to technological advances. This points to the problem that the business interests of device manufacturers (who are protected from liability if patients modify devices) weigh more heavily than good patient outcomes. Doctors felt left alone with difficult decisions, as noted by two diabetologists who told their patients they could no longer supervise their care with a hacked or non-EU regulated pump. Concern emerged surrounding the possibility for patients who would remain without supervision after hacking a device, or potentially withholding important information from their physicians about changes made to their care plans or devices in order not to lose their care. These responses illustrate that the integration of digital self-care into the clinic will require rethinking the responsibility and liability of physicians in relation to practices conducted outside of the clinic, how physicians are compensated for their time, and how this could change the professional role of doctors. Ultimately, it may also require more of the burden of liability to be placed on device manufacturers, even in cases where patients tamper with devices to improve clinical outcomes.

Aside from these exceptions in diabetology, dermatology, and those already working on technology integration in the clinic, the majority of respondents described digital self-care practices as a hypothetical, futuristic scenario that was removed from their daily clinical work and patient population. Here, when the interviewer informed several respondents that products such as the HPV test in Vignette A have already been available for purchase, or that HIV tests are available in some areas of the US without prescription, some respondents appeared surprised. The fact that these forms of digital self-care were so far removed from the reality of clinical medicine in Northern Germany has implications for how technological advances are embraced (or not) by clinicians, including physician responses to patient-generated data, ability to support patient use of digital self-care, and the shapes that patient-provider engagements with digital self-care take (e.g., Fiore-Gartland and Neff, 2015; Gabriels and Moerenhout, 2018; Nielsen and Langstrup, 2018).

The same devices do and mean different things in different places (Oudshoorn, 2012). Most respondents were doubtful that digital self-care could provide a service or benefit that is not already offered in the German health care system, although there were differences in how they assessed the risks and benefits of specific digital tools. Digital technologies – namely those that 'put patients in the driver's seat' of diagnosis or decision making – were often seen as potentially harmful. Some felt these technologies could be helpful in under-resourced areas, as seen in the example of the DTC diagnostic service such as in Vignette A. This shows that our interviewees did not assess digital self-care practices in the abstract, but they considered them in the context of the socio-economic and healthcare-related configurations of specific settings. Physicians in Northern Germany operate within a system in which basic health care needs are, on the whole, met for most patients. While examples of diabetes patients' engagement with digital self-care show that it is relevant for some in this region, others felt that one

benefit of digital self-care is that low-cost services could potentially satisfy some health care needs in places where a broad base of services are not readily available to all. In this sense, respondents affirmed that context – especially in terms of the specific healthcare system they operate in (Koteyko et al., 2015) – remains central to the beneficial use of digital health applications (Lupton, 2017). This points us to the double-edged sword of digital self-care: while offering opportunities for patient engagement and initiative in directing and controlling medical treatments, data, and even improving overall wellbeing, individualized practices of empowerment cannot be a substitute for a shrinking provision of high-quality medical services available to all (Juengst et al., 2012).

4. Limitations

The sample for this study represented the experiences and opinions of a limited number of practitioners. While Northern Germany is an interesting setting to ask these questions, it is likely that the answers would differ significantly if the same study were conducted in a place with a different relationship to health technology, socio-economic status, and health care system.

5. Conclusions

Thus far, debates on digital empowerment have focused on the ability of new technologies to transform the possibilities available to individual patients in relation to their own health. This development has reframed and reconfigured patient practices, including self-care. Our study yielded the insight that while digital self-care presents opportunities for engaging more people with their own health and healthcare, it also entails significant risks and costs. Digital self-care was generally regarded as a set of practices that could be helpful, but only within the doctor-patient relationship, and when accompanied by physician guidance in order to prevent misdiagnosis and over treatment, and to correctly interpret results and manage potential anxiety or fears. Actual examples of the incorporation of self-care practices into clinical decision making were rarer than expected, given the imaginaries in current literature and reports from other healthcare systems.

However, while anticipating and indeed confirming some potential differences between tech-forward centers and Northern Germany, the interview results also point to an emerging rupture between the traditional sphere of expertise of the physician, and the growing sphere of expertise of patient work in relation to digital self-care, thus impacting and sometimes challenging the physician-patient relationship. The palpable unease in some responses points us to places where these two arenas diverge, or are increasingly in tension. Some apps and technological advances that are available to patients outside of medical supervision are present in this rift, charting an 'unknown territory' for future clinical practice. Moving forward, it will be increasingly important for physicians and other health care professionals to receive training in how to navigate these spaces, and to have opportunities to participate in the co-development of these tools (Fiske et al., 2019c). This is important so that clinical practice can successfully and productively co-exist with other areas of medical and health practice that are outside of the professional and legal responsibility of doctors.

Finally, our respondents highlighted that the incorporation of digital self-care into standard medical practice would necessitate significant changes in practices of medical regulation, supervision, and reimbursement. While the physicians we interviewed had varied experience with digital self-care, all differentiated between "good" and "bad" forms of digital self-care along the line of collaboration: Almost all of our respondents voiced serious concerns about digital self-care practices that were within the sole responsibility of patients, and that served to move decision making on diagnosis, treatment, or prevention out of the physician-patient relationship. They were much more positive about digital self-care practices that supported joint decision

making between patient and provider, or facilitated patient motivation and adherence to a treatment plan. In sum, they framed "positive" digital self-care as a relational practice where the value of the practice emerged in the interaction between digital tools, patients, and doctors. The ways in which we move to address the challenges of digital self-care will have profound consequences for how these practices occur and, in turn, how digital self-care will shape physician-patient relationships, ideas about health and illness, reimbursement, liability, and personal responsibility in the future.

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CRediT authorship contribution statement

Amelia Fiske: Conceptualization, Methodology, Investigation, Data curation, Writing - original draft, Writing - review & editing. **Alena Buyx:** Conceptualization, Validation, Resources, Writing - review & editing, Supervision, Project administration, Funding acquisition. **Barbara Prainsack:** Conceptualization, Methodology, Validation, Resources, Data curation, Writing - review & editing, Supervision, Project administration.

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