

# Invisible Patients?

## Patients' Agency within the Discourse on Telemedicine

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**Abstract** A wide spectrum of telematics applications has emerged within the last few years, ranging from video consultations to health apps and infrastructures of telematics in surgeries. These are due to new possibilities within commercial initiatives as well as the statutory health insurance system. The discourse on challenges, possibilities and the acceptance of these developments formed in health communication in Germany is mainly guided by politics, doctors' associations and health insurance providers. Based on a web crawling corpus compiling statements by these actors and parliamentary transcripts, I examine patients' agency within the discourse on telemedicine, focusing on discourse/practice-formations. In the arenas of politics and regulation, patients do not have a voice even though their interests are discussed. When patients' organizations make statements, they miss further involvement. Even more, within the discourse arena of infrastructures and data security, patients become invisible. Although there is a lot of information addressing patients, in regard to changing treatment or new possibilities such as apps, their interests are captured by experts only, the agency of patients themselves is missing.

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**Keywords** telemedicine – discourse analysis – discourse/practice-formations – power relations – infrastructures

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### Introduction

Digital healthcare in general is of growing relevance in health services, political discussions as well as in everyday life (LUPTON 2018; RUCKENSTEIN & SCHÜLL 2017). The ever-growing set of digital options within healthcare is connected to the terms of telemedicine, telehealth or e-health, not only focusing on remote services such as video consultations, but taking into account health apps and monitoring devices as well as the infrastructures of telematics in surgeries and hospitals:

Telemedicine describes remote clinical services in the form of patient and clinician contact. It includes diagnosis, monitoring, advice, reminders, education, intervention, and remote admissions. [...] In telehealth the scope expands beyond telemedicine to administrative meetings and other nonclinical services too (GOGIA 2019: 11).\*

As LUPTON puts it, the term telemedicine can be understood in a broader sense than Gogia does:

As I use the term here, telemedicine involves the use of digital technologies by healthcare providers to communicate with patients and other providers, effect clinical diagnoses and deliver healthcare in remote locations. It also includes patient self-care and self-monitoring systems using digital technologies (these are also sometimes referred to as 'telehealth' or 'telecare' technologies) and online medical education programs. (2018: 5)

In this paper, I stick to this broad definition of telemedicine. Since the implementation of telemedicine is in many ways determined by governmental practices, the following analysis focuses on the situation in Germany. Here, legal conditions have been laid out in order to establish different new forms of treatment that are mainly implemented by commercial initiatives. Developments in legislative processes are in a constant state of transition. When introducing telemedicine and similar developments in digital healthcare, the arguments mostly focus on the benefits that digital healthcare might bring: better care for the chronically ill and the monitoring of long-term treatments, solutions for those living in rural areas with a lack of medi-

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\* All source material presented here is in German, quotes were translated into English by the author.

cal infrastructures, and a rise in communication between different medical instances made possible via telematics infrastructure, as well as general potential for a better quality of medical supply and personal medicine. A core constraint for digital health in its various shapes, stated by stakeholders such as the political opposition, is data security and privacy protection which are assumed to be inadequate.

As of 2020, some telematics applications in Germany are mandatory by law (DVG 2019). Most other services are offered on a voluntary basis, in large parts funded by public healthcare. Most made statutory only in recent years or still are in development. The Covid-19 pandemic gave rise to a growing usage of digital services within the doctor-patient relationship, since visiting a doctor online became more attractive than visiting a surgery in person. There also is a sector of health and fitness apps as well as digital platforms aiming at supporting patients. Within the last ten to 15 years, an ongoing discourse has emerged on the role and acceptance of telemedicine, mainly guided by politics, doctors' associations, health insurance providers and private stakeholders, which is at times also picked up by the media. This discourse is at the center of the study presented here, focusing on the role patients' agency plays.

Based on a discourse analysis examining documents from the web as well as from political decision-making processes, I focus on patients' agency in the emerging infrastructures and its implementation in governmental technologies. After giving some methodological background, I outline the concept of telemedicine and refer to related work, before linking to governmentality and infrastructure as core concepts for the analysis, connecting them with the role of agency and practices within discourses. I then turn to the question of patients' agency within the discourse on telemedicine. The first part of the analysis outlines discourse positions on telemedicine, asking for the role patients play therein, before in the second part moving on to the arenas of telemedicine implementation for patients. The paper closes with findings on the invisibility of patients' agency within the discourse and connections to the power relations described here as well as remarks on future work.

## Researching agency through discourse analysis

When looking at complex phenomena like the emergence of telemedicine, discourse analysis in combination with grounded theory (GLASER & STRAUSS 2010 [1967]) can guide the research in order to reduce complexity in a reflected way, following strategies of theoretical sampling, coding, contrasting and saturation (TIMMERMANS & TAVORY 2012; MORSE 2007). Discourses produce social orders and introduce specific ways of knowing, contest others and materialize them into regulation, institutions and practices (FOUCAULT 2002 [1969]; KELLER 2011b [2005]). Discourse analysis ties together a variety of methods and materials, in order to gain a deeper understanding of the processes of social ordering within discourses and the relations between power and knowledge (KELLER *et al.* 2018; KELLER 2011a). Being strongly connected to the assumptions of social constructivist sociology of knowledge (BERGER & LUCKMANN 1967), discourse analysis focuses on staying open and critically reflecting assumptions throughout the study. For the research grounding the conclusions here, possibilities of automation within this approach were scrutinized for the generation of a corpus of relevant discourse material. This was part of the collaborative research project "Automated modeling of hermeneutic processes" (GAIDYS *et al.* 2017), incorporating different methods and tools from digital humanities and computational linguistics while collecting, contrasting and filtering the discourse material.

In order to achieve a broad overview of relevant statements and narrative structures within the discourse, a thematically focused webcrawl was conducted. It compiles statements found online starting with a semantic word field gathered out of prior knowledge of the field and controlled vocabularies, containing terms such as telemedicine or telecardiology (ADELMANN *et al.* 2019). Groups were identified as having agency within this discourse, ranging from health insurance providers, doctors as well as patients' associations within the emerging field of telemedicine. Websites of these groups served as entry points for the automated crawling (searching) and scraping (saving) of relevant discourse material (for technical details, see ADELMANN & FRANKEN 2020). From a range of 8.788 documents captured in the crawl in March

2019, a shortlist of the most relevant documents was filtered with different digital methods, using keywords clustered by frequency along the semantic word field created (for keyword clustering see EVERT 2009) and topic modeling (BLEI 2012) with 100 topics using the tool Mallet (MCCALLUM 2002) as well as syntactically informed concept sketches (ANDRESEN *et al.* 2020). 87 documents of different types, ranging from press releases to scientific studies stretching from 2012 to 2020, were selected. The timespan was not confirmed for all documents collected, but no documents dated earlier were found within the selection process. To gain insight into political and normative discourse, all parliamentary minutes of the German Federal Parliament (Bundestag) were filtered with the same semantic word field used for the crawling in order to find relevant discussions, resulting in 118 sets of minutes with passages of relevance ranging from 1993 to 2018, where 1993 is the first time one of the words searched for was mentioned within the minutes. During the annotation process, more recent minutes up until August 2020 were included for the latest discussions, leading to 20 additional sets of minutes within the corpus.

Within the manual analysis, more than 200 documents were therefore analyzed, using Qualitative Data Analysis Software (MaxQDA) with all its limitations (MACMILIAN 2005) for the coding process. Annotations as a way of coding were used in the process of systematic data collection when putting together the corpus to be analyzed as well as in analyzing the filtered source material in detail. As a matter of structuring (KOCH & FRANKEN 2020), annotation was done using the approach of grounded theory. Following theoretical sampling and saturation, additional discourse statements were added manually when the knowledge about the field grew within the annotation of the two large corpora gathered automatically.

The combination of computational sampling and manual analysis provided a broad spectrum of discourse statements but limited the corpus in other ways. Especially, due to technical reasons text was given a priority, cutting the multimodal structure a corpus gains in manual sampling strategies. In addition, only the discursive formations connected with a term from the semantic word field were considered. Even with the limitation that the discourse analysis stays incomplete in its

horizontal dimension, it becomes more comprehensive through its enlargement of the manual qualitative approach. This brings more concepts, nuances and perspectives within the discourse to the attention of the analysis that would otherwise not have been found due to the mass and complexity of potential eligible data. Thus, the chosen methodological approach as a combination of a computational and manual qualitative analysis allows for a more saturated understanding of the discourse arenas in question.

### **Agency in the context of telemedicine as governmental practices in infrastructures**

Since the discourse is in many parts interconnected, it is reasonable to combine the developments of telemedicine and telehealth in their analysis. This involves a shift to the socio-technical entanglements patients are engaged within. Most of the many surveys on concrete usage of the possibilities of telemedicine (e. g. for intensive care units: KOENIG 2019, for Apps: ALBRECHT 2016) stay affirmative (LUPTON 2018: 2) and reflections on the changing role patients have within the digitization of healthcare are rare. If the patient is placed within the focus of interest, studies stay within clinical settings (e. g. BARDY 2019). In what follows, I examine the discursive developments that arise in the socio-technical implementation of telemedicine practices in German digital healthcare, including challenges, possibilities and acceptances.

Social practices cannot be understood without material configurations (SCHATZKI 2001: 3). Within the entanglements of more-than-human agency in socio-technical settings (BARAD 2003; 2007), agency is not limited to practices of (in my case) patients, health professionals and other human actors involved. It is reconfigured by materialities such as devices or infrastructures with their own agentic capacities. While discourse analysis focuses on semiotic systems, a turn to practices gives way to involve materialities and their agencies within what RECKWITZ calls practice/discourse-formations (2008: 193). These formations are heterogeneous and often compete with each other, giving way for an understanding of discourses as a specific group of practices that is embedded within communication (*ibid.*: 202–203). Therefore, health communication articulates discursive for-

mations that make agency graspable in different practices, providing options for new routines and social forms (RECKWITZ 2002). When looking at the ruptures and contradictions within practice/discourse-formations, “boundary-making practices, that is, discursive practices” (BARAD 2003: 822) can become visible. Agency in its relational practices in this regard is therefore strongly connected to power relations and governmentality, since it is articulated in discursive formations.

Power relations always contain imbalances and are connected to knowledge, at the same time being individualizing and totalizing (FOUCAULT 1982). Foucault understands governmentality as a form of power between institutionalized sovereignty, discipline and government as a practice (FOUCAULT 1991 [1979]; LEMKE 2011). It is connected to agencies and technologies of the governmental state: governing practices, disciplinary technologies and technologies of power, “mediating between power and subjectivity” (LEMKE 2011: 3). Therefore, governmentality forms the guiding principle to an entrepreneurial self, becoming responsible for the decisions taken and governing oneself with technologies of the self (BRÖCKLING 2016).

Governmentality has its core function in the technologies of governing the population (FOUCAULT 1973; CURTIS 2002). Power therefore is a construction which comes into practices within socio-technical relations in a rather indirect form of shaping the possible options that are available (LEMKE 2011: 18). Overarching processes are governed without giving out rules for concrete practices. Forms of power and governmentality therefore are directed at populations rather than individuals – even though they of course have concrete effects on the agency of individuals. People as individual human agents become meaningful only through their practices within the disciplinary technologies, determined by the governmental technologies. Therefore, not the individuals directly, but their practices are formed throughout and incorporated via governmentality. Connecting these fundamental considerations with health as culture, LUPTON (1994; 2018) claims that medical power can become productive as a need for interpretation of the body from specific discursive viewpoints with digital health technologies being socio-cultural artefacts that are determined by sociotechnical norms and assumptions.

If we attach these reflections to infrastructures and technologies, we get a rather detailed picture of what digital healthcare can be about when it comes to the implementation of telemedicine. Infrastructures have to be understood as relational parts of a socio-technical setting, taking into account individuals, their practices, and structures as well as institutions. In many regards, infrastructures work in the background, taken for granted (STAR & RUHLEDER 1996; STAR 1999). In order to study them and their evolution, this invisibility has to be questioned: “Understanding the nature of infrastructural work involves unfolding the political, ethical, and social choices that have been made throughout its development” (BOWKER *et al.* 2010: 99). For the development of new kinds of infrastructure, as is the case in digital healthcare systems, the data has to “render a realm into discourse as a knowable, calculable and administrable object” (GOFFEY 2017: 371). The implementation of telemedicine in Germany can therefore be understood as an infrastructural regime in the making, which can be well captured with a discourse analysis, focusing on the emergence of discursive constructions, that are to be understood as practices.

### **Patients’ agency within the discourse on telemedicine**

One could argue that the political and practical implementation of technical infrastructures is usually accompanied by different discursive threads. Some concern the technical feasibility, others modes of participation. While both are often integrated into one sooner or later, they are – just like in other examples from media history (BRIGGS & BURKE 2010) – only partially interconnected in the implementation of telemedicine. The discourse on challenges and possibilities of telemedicine as well as the acceptance of these developments is mainly guided by the agency of politics, doctors’ associations and health insurance providers. This does not mean that individual projects are not developed in cooperation with patients, patients’ associations or advocacy groups, but on a discursive level, discussions remain about the general potential of telemedicine – or any other matter of digital medicine – and concern feasibility and financial matters first. As I will show, patients and their advocacy groups are mainly talked about, but not talked

with. Where do they have their own voice, how do they materialize within the discourse? Where do they stay passive or invisible and why, and is there agency within this?

#### Supporting the needs of patients? Discourse positions on telemedicine

Most documents retrieved within the webcrawl come from medical associations and health insurance providers, since both are directly confronted with legal changes and try to have an impact on the decisions taken on a political scale within the last years. They are responsible for the implementation in medical practice. In addition, their mode of communication is open and easy to find. Both try to ponder the pros and cons of telemedicine, but stick to the advantages most of the time. A lot of information for doctors is given, especially on existing projects in the context of telemedicine, on legal conditions and technical possibilities available. If patients are addressed as well, information is specialized and in an expert language unsuited for interested laypersons. Medical associations state that telemedicine is a support for patients, but stay with general assumptions of telemedicine being faster and more detailed since supported by technology. There are two main arguments for the support of telemedicine: additional service for patients and the availability of new forms of data for better health research. In both master narratives concerning the infrastructure (STAR 1999: 385), patients are mentioned very vaguely.

Health insurance providers mostly offer telemedical treatment today and advertise this as an additional service (e. g. AOK HESSEN 2019). They therefore encourage patients to use these services. It can be assumed that costs will as a result be reduced due to people contacting “only” the app or the hotline instead of visiting a doctor. A better surveillance of patients’ health behavior would be possible as well. This governmental technology is implemented by most insurances, giving concrete advice on how to choose for example an app, stating that those apps helped other patients to get a better impression on their health and help to democratize medicine since information is available to everyone (AOK HESSEN 2018: 10–13). They also offer own teledoctor apps for video consultations instead of visiting a doctor. Medical prevention,

well-implemented within the German healthcare system, is now to be assisted via apps and online assessment for illnesses such as depression, obesity or tinnitus (e. g. BARMER 2018: 18; BIG DIREKT 2017; DOCDIREKT 2019; MHPLUS 2019; SBK 2019). The association of health insurance providers points out the possibilities for change that reside in telemedicine, but also references the developments as “resulting from legal mandate” (GKV 2018: 82). The partnerships and often non-transparent cooperations between health insurance providers, doctors and private companies, caused by an ongoing privatization of the health sector, can blur the boundaries of different institutions and interests in the implementation of telemedicine (LUPTON 2018: 3).

An economic as well as a scientific perspective points out that the potential big data made available through the digitization of health is of great relevance. Medical associations do want the data to be made available, in medical settings as well as in self-tracking, to be made accessible for research purposes (e. g. DEUTSCHE DIABETESHILFE 2019: 266). Foundations active in the health sector have initiated large studies in recent years, pointing out that more needs to be done to achieve better healthcare via the use of this data (e. g. BERTELSMANN STIFTUNG 2018: 64). The same can be said about some politicians, aiming at a wide use of telemedicine in order to get enough data to do reasonable health research based on this (as in DEUTSCHER BUNDESTAG 15/170). Within this argumentation, it is assumed that the quality of medical treatment will improve because of the availability of data. For politicians, the latter issue is seen in close conjunction with security of this data, but patients do not play an active role in these considerations (DEUTSCHER BUNDESTAG 16/112). Data collected goes to the companies developing the apps and platforms instead of research initiatives. Even though there are patients’ organizations actively engaged within the field of healthcare data, these do not become visible within the political or the public discourse examined via the corpora studied here. GOFFEY (2017) sees an interest in this data from the economic angle much stronger than the connected scientific work that could enable a better healthcare. The opposition parties in parliament in this context raise security issues and the need for data security and argue for informational self-determination, but not pointing to patients in

this regard (no results were found within the protocols from legislative period 16 and 17, 2005–2009 and 2009–2013). Only single voices within politics demand a right for patients to be involved in legal developments, and the issue of data security as a main concern that might keep patients from using the functionalities.

The economic sector focuses on the opportunities but does not take risks into account at all (DELOITTE 2014). Within these discussions, the role of the patient is limited to a data generator, not even mentioned within the conditions of an implementation of digital healthcare (STRATEGY & PWC 2016: 19). Most references to patients state rather generally that developments will help them. Patients are talked about as those who need help that can be granted better with technology. The medical association of surgeons lists potential benefits of telemedicine – but no risks – sorted by groups (BDC 2015). The main potential for patients is seen here in a faster treatment with fewer risks of mistreatments and better access to information. It remains unclear on what these potential benefits are based and whether patients were involved in these findings. As BARDY notes,

the patient is situated upstream of expert knowledge (interpretation, diagnosis) constituted from life data transmitted by care devices, which are installed and self-managed in the person's home and/or mobile devices (smartphone and health application, insulin pump, cyler, pacemaker). In this process of constructing the person as an 'autonomous agent' of care, producer of data and receiver of 'objective' medical knowledge, the patient experience, nevertheless, covers another practical reality: that of the experience of the illness, of the relationship to oneself – constitutive of an intimate knowledge of the illness – and that of the person who is experiencing it, whose psycho-emotional dimension must be taken into account (2019: 60).

But patients' agency is limited by the perspective of experts. The association of medical specialists even claim that doctors should have the decision on when and where telemedicine is appropriate, taking all agency from the patients to the doctors: "The doctor is the one to decide if and for which patient a digital treatment is suitable" (SPIFA 2017: 3). The role of an informed and active patient is diminished here, even in the form that technical needs are addressed for the medical side only, but

not for patients. While labeling the position as patient empowerment, this association focuses on the right of doctors to not divulge every piece of information as "unnecessary burden" in the diagnosis (*ibid.*: 26).

Even where the patients' organizations form their voice, they mainly miss further involvement and talk about patients rather than talking for or with them. Those organizations are not included within the consultations for the respective laws (DEUTSCHER BUNDESTAG 19/171: 21431). Asked about the reasons, the government answers that in a circle of experts, these organizations are not to be invited (DEUTSCHER BUNDESTAG 19/041: 4092). There are no participative processes in order to involve patients' agency within the implementation of telemedicine. The main outcomes of the web-crawl in this regard are scientific studies, focusing on areas such as diabetes or cardiac insufficiency. The patients' role is limited to perspectives on their security and their acceptance of the applications developed, strongly focusing on the positive aspects arising from technological developments, such as reduced morbidity (e.g. DSCK 2012; KBV 2017). The telemedical infrastructure set up in relation between technology, organizations and social practices (BOWKER *et al.* 2010: 106) seems to be installed without engaged participation of patients, focusing mainly on the practices of doctors and the broader healthcare system, and producing biases that do not take diversity into account. Nevertheless, it is unlikely that this will lead to a failure of these infrastructures, but rather to power relations that give little room to patients' agency in order to keep the infrastructure intact.

When addressed as users of the electronic health card, it is pointed out to patients that "the highest priority is on data security and the right to informational self-determination" (GEMATIK 2012: 2). Patients are described and addressed as powerful here, but the focus always stays on the perspectives of the technology making everything easier and less time-consuming. At the same time, patients are asked to give all of the data and responsibility to the health authorities. The core agency of the patient and its enlargement throughout the new features remains uncertain. Patients' advocacy does not seem to criticize this. Only one position was found with a – in comparison – rather harsh critique by patients' associations:

Whether digital care for the patients is better or worse, nobody can seriously tell at the moment. There is no scientific work on the use and harm. But this is not the focal point here. It is on more efficient methods to reduce time and costs on the part of the patients and the doctor in charge (DPB 2017b).

(Tino Sorge, CDU politician: DEUTSCHER BUNDESTAG 19/116: 765). Again, the needs of patients are assumed without further clarification of where these statements come from.

What does this mean for the practices for patients?

Arenas of telemedicine implementation for patients

When it comes to the datification of health care and self-care, proponents in medicine, government, and technology typically emphasize its potential to prevent and mitigate the physical and financial burdens of 'lifestyle diseases' [...] by shifting their management away from hospitals and doctors and into the hands of empowered patients (RUCKENSTEIN & SCHÜLL 2017: 262).

When looking at the discourse, there are three main phenomena discussed that are connected to direct change for patients: the doctor-patient relationship in general, digital information and monitoring via apps and platforms and the enhanced possibilities of treatment for chronic diseases.

The discourse in many regards promises a stronger agency for patients to be realized with telemedicine and its accompanying infrastructures, such as the empowering of patients through the management of their own health conditions. But this empowerment comes along with a huge amount of responsibility for the patients in forms of invisible work (STAR & STRAUSS 1999). They are seldom addressed directly neither forming their voice, but rather addressed as consumers and in advertising language. This account of patients being passive holds true for a long tradition of medical-historical settings, where patients are not given agency with regards to their treatment and health.

Regarding the doctor-patient relationship, doctors strongly argue that telemedicine does not replace personal consultation as a "gold standard" (KBV 2018: 5), but rather augments it as a bridge between appointments for continuous monitoring. The option of using video telephony already exists. When in 2019 remote treatment was legally implemented, it came as a small part of a large legislative package and was mentioned as a side argument only (for the missing discussion see DEUTSCHER BUNDESTAG 19/071; 19/086). But until 2020, video consultations were possible only if patients visited their doctor beforehand, so especially long-term contacts and follow-up consultations were moved to digital communication. The argumentation on the enabling of video consultation focuses on the advantages of saving time and travel distances with this method. The aspects at the patients' side – who have to have not only an internet connection, but the technical skills to start a video consultation – as well as the social setting of a meeting in person (HELMAN 2007: 345) are not taken into account much by politicians and medical associations. The "power [that] enables doctors to act in the competent role demanded of them by most patients, and which is legally and professionally prescribed" (LUPTON 1994: 118) stays unchanged here, being remediated (BOLTER & GRUSIN 2000) in regards of the communication channel only.

There are voices within the discourse that assume that digital treatments are accepted since a number of patients uses them (DEUTSCHE DIABETESHILFE 2019: 177). Others state that e.g., apps can lead to misinformation, and risks of false security are expressed via the use of apps (ALBRECHT 2016). Also, a need for more guidance is formulated, since "users of health apps have the challenge to identify a fitting and trustworthy app out of very broad range of offers" (*ibid.*: 32). Patients are treated as a homogeneous group. The agency of patients is not visible within this knowledge configuration. The same goes for the arenas of politics and regulation, even though patients' interests are discussed here. There is discussion *about* patients, but not *with* patients. Politicians assume that patients do want new developments, when discussing the respective laws: "Many patients are waiting for this. Many patients do want to use digital options"

After accomplishing pilot projects, it is possible today to see a doctor via (video)telephone even if doctor and patient haven't known each other beforehand (KVBAWÜ 2019). Medical associations aimed for an update in this regard in their arguments but were divided in their valuation of personal contact. After a general decision for enabling

remote treatment in special cases (DEUTSCHER ÄRZTETAG 2018), due to the Covid-19 pandemic, video consultation was made possible without any personal contact or specific reasons in 2020 (KBV 2020). The infrastructure here became visible upon breakdown (STAR 1999: 382) and was adjusted accordingly. When forming a voice on this, associations of chronically ill patients see a clear pro in telemedicine when it comes to regular consultations to be held online or to information that is made available in formats such as videos or apps, since “information can be adjusted to the needs of the patient within his medical care (‘patient journey’)” (DPB 2017a: 17). As LUPTON states:

Rather than power being experienced by its subjects as repressive (although this may happen in some contexts), the diffuse and heterogeneous ways in which it is exercised renders it productive, generative of knowledges, practices and forms of sociality (2018: 15).

Another growing sector is the above-mentioned digital training of patients, e. g., when a new diagnosis makes a lot of communication necessary. In these cases, training can be conducted via a digital platform or app where patients are asked to inform themselves in order to acquire the knowledge and practical skills needed to cope with the diagnosis. Apps and online tutorials, sometimes connected to personal contact with medical specialists via telephone or chat, serve as an addition to physical contact when prescribed by doctors. While information and interaction are seen at the center of the range available, medical devices with treatments are rare (ALBRECHT 2016: 17). Up to now the concrete use of these apps as well as the usability and data security has not been studied much, often because apps are not developed in cooperation with doctors or patients, but with commercial interest (*ibid.*: 20–21). Within this governing technology, repetitive tasks of information giving and explaining are outsourced from the medical responsibility and handed over to the individual patients that have to catch up with this information, but also with the insecurities and fears that might arise in the context of the new knowledge about one’s own body. This is a form of entrepreneurial self-technology (BRÖCKLING 2016). Apps also are available as a form of reference or personal health or fitness diaries, often connected to forms of tracking, in-

cluding measurements and monitoring (WIEDEMANN 2019; ROTTHAUS 2020), but forming a much broader scope of digital health than telemedicine since the healthcare system is not involved here. The same can be said about information on health being sought online and the forms of power (im)balance this might have, not connected to the healthcare system but addressed as telemedicine in some cases (HELMAN 2007: 334–354).

At the same time, clinical treatments are advertised to be accompanied or even replaced by an online treatment by clinics, such as a therapy to reduce stuttering (KASSELER STOTTERTHERAPIE 2019) as well as best practice examples from health insurance providers (AOK HESSEN 2019). For specialists and chronically ill patients, there are new ways of support, for instance digital tracking of symptoms such as blood sugar. When medical organizations discuss digital possibilities, they engage with those as possible next steps and see them as a chance for future treatment opinions, as within the field of diabetes: “smart pumps will make calculations for the amount of insulin to be applied and deliver them via cloud” (DEUTSCHE DIABETESHILFE 2019: 172). They demand a higher level of research engagement in order to use and strengthen the existing therapies supported by digital technology (*ibid.*: 174). It is assumed that diabetes is a data-intensive illness and therefore has to be treated by making data capture as easy as possible, kept in “a standardized readable and usable data-pool which patients, doctors and researcher can access (with different access and usage rights)” (*ibid.*: 260). A critical introspection on the implications of such a database is missing. The emergence of infrastructure is embedded (STAR 1999: 381) into other structures of monitoring and extends rather than altering them. Furthermore, this is a call for new infrastructures to be implemented, making patients use this technology without taking their expertise and needs into consideration.

When looking at another realm of medical treatment, an early study on telemonitoring for pacemakers puts it very clearly: The technology enables faster interventions and “can help to raise life expectations of patients” (DSCK 2012: 49). Patients’ associations as well as doctors strongly encourage telemedical support for this diagnosis (KARDIONETZWERK 2019). Doctors also mention that in order to achieve positive aspects, a participa-



tion of the patients is needed: they are the ones that have to maintain the devices on a daily basis, make sure that an internet connection is stable and the like. Even though they are included in the consultations here, responsibility is given to the patients without them having much agency in the setup of the infrastructure or in the way their data is used and stored. At the same time, the “range of choices offered to users, however, is delimited by [...] how the technologies work, what they can or cannot do” (LUPTON 2018: 2). The technology is assumed to make everyday life for the (chronically ill) patient easier and less focused onto their own health, therefore descriptions such as “easy to understand”, “comfortable” or “simple” are used, reducing patients to end-users. Only for dermatosis and its treatment on the basis of telemedicine, could a concept paper of pro and contra be found (BVDD 2019). The doctors’ association that formulated this paper argues that with telemedicine, there is not only a need for accuracy and data security, but also a sense for the need of personal contact and affection. Their conclusion is, that not everything that is technically possible should be seen as reasonable.

In all of these cases, the doctor-patient relationship becomes enhanced via technology with its own agency, in one way or the other mediated by digital infrastructure. Whether the patient is the one sending data – as is the case with the monitoring of chronic illness – or the doctor is storing information within an app or changing the communication platform to a video, the infrastructure is linked to conventions of practice and built on an installed base, to name the most important properties STAR (1999: 381–382) sets for infrastructures. This has impact on the power relations: they are remediated within a different infrastructural setting.

## Conclusion

When looking at patients’ agency within the discourse on telemedicine, it is either low or missing completely within the discourse production on technical feasibility considered here. It can be understood as a discursive practice that patients remain silent. Agency is instead distributed to the speaker positions of political, medical and clinical professionals as well as health insurance provid-

ers. Their main discourse positions in supporting telemedicine focus on additional service, making healthcare better and faster – and selling it to doctors and health institutions in the first place while not yet considering patients. Little rejection of these developments was found. Most fundamental discussion emerged around the data generated with the governmental technologies implemented and its use. Nevertheless, it is promised that telemedicine and the infrastructural regime connected to it will lead to a rise in patients’ agency, once implemented. In regard to arenas of telemedicine, three main phenomena have been found that connect to patients and involve changes for them. The doctor-patient relationship is enhanced with technology in telemedical settings. Via apps and platforms, information and training are delivered in a digital format. For chronic diseases, telemedicine plays an important role in improving continuous monitoring. Overall, a remediation of healthcare is manifest in this discourse arena. The different aspects of the intense discourse/practice-formations around it focus on politics, health professionals and insurances.

Although there is a lot of information addressing patients, with regard to changing treatment or new technologies such as apps, their interests are captured by experts only, the agency of patients themselves is missing. Digital healthcare could have the opportunity to enhance patients’ agency and autonomy, but this is by now seldom an argument. This might also be grounded within the methodological approach chosen here: a discourse analysis, especially when conducted computationally, gives rise to the most important actors. If one would take into account for example ethnographic approaches to the voices patients actually raise in different constellations, the outcomes presented here might be questioned.

In accordance with GOFFEY (2017: 375) there is a fundamental difference between the objectives claimed as desirable and the part being implemented within practice so far. Power relations guide the discourse as well as the implementation.

In the recent upswell of scholarship around the datafication of health care and self-care, social scientists have brought a great many concepts and analytical frameworks to bear on a great many cases and concerns; they have spent less time identify-

ing the possible points of tension or internal contradiction among them, or reflecting on how they might be combined in complementary and generative ways. (RUCKENSTEIN & SCHÜLL 2017: 270)

The concepts of governmentality and infrastructure served well as analytical frameworks here in order to carve out the materializations of patients' agency within the discourse on telemedicine. When population is to be seen as an object of political knowledge and at the same time individualized to take care of one's own needs, as Foucault describes it, digital infrastructures are capable of moving this knowledge further on to new concrete measurements. The discourse/practice-formation is in many regards making patients' agency invisible, but at the same time promising a stronger agency for patients to be realized with telemedicine and its accompanying infrastructures in the future. How these relations and contradictions will be further transformed is yet to be established within the evolving discourse itself.

### Future Work

The work presented here did not aim to look at the usage of digital media within patients' attempt to actively engage with their illness and well-being. It attempts to focus on the discursive level of digital healthcare and the role of patients therein. Even if one can assume that the "users of digital health technologies are not simply passive recipients of health and medical information delivered to them by others" (LUPTON 2018: 5), this has been and is to be studied by research focusing on the use and appropriation of digital technologies and the digital information available to learn more about patients' agency.

By now, the thematization of telemedicine coming from patients seems to be rather low. Looking at social media, especially at groups and forums, the role telemedicine plays here is limited. A first glimpse into the existing Reddit Communities Telemedicine and Telehealth (REDDIT 2020), using the semantic word field generated for the webcrawl, shows that there is not much discussion going on. Rather, there are professionals advertising different possibilities and raising concrete professional questions. Most of the posts are re-postings of media coverage, but no comments or remarks by pa-

tients. Looking at Twitter with the same semantic word field, the tweets are in large parts filled with professional communication and advertising for new features possible, such as apps and tele-consultations with doctors. Telemedicine and telehealth therefore seem to remain a mostly technical discussion resembling discussions concerning medical equipment. Future work would have to take a closer and more systematic look into these and other communication platforms in order to find out more about what patients do talk about and where telemedicine plays a role within that. This could be more efficiently retrieved by using a different set of search words, focusing for example on the patients with chronic illness and the growing need and possibility to monitor in a digital way, or on specific apps and treatments. Furthermore, the media coverage of the discourse was not the focus of our initial webcrawl and therefore remains to be analyzed.

In what ways are the infrastructures implemented within telemedicine being questioned, appropriated, or reinterpreted? To answer these questions, research will have to dig deeper into the practices of patients not being represented within the public discourse and more closely connected to specific diseases or treatments, with in-depth interviews and other ethnographic methods. Within the political, economic and scientific discourse that was captured with the corpus processed for the study presented here, patients' agency is low and often stays invisible.

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