



Patient empowerment:

A practical approach to guide ethical decision-making in telemedicine

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Abstract

This article aims to clarify the concept of patient empowerment and to assess its ethical implications in modern telemedicine. To achieve this goal, it provides a review of the ICT-based tools used by patients in telemedical settings, known as "Connected Medical Devices" (CMD), as well as an overview of some of the most advanced e-health systems enabling remote communications between patients and health practitioners today. Patient empowerment, it is then argued, is a capacity-building process whereby personal and inter-personal transformation may be achieved. Furthermore, it is a practical approach to ethical decisions, based on shared decision-making, with a focus on patient autonomy and self-determination. These views are consistent with telemedicine's main objectives, but also with the spirit of a new politics, and a new ethics, of vitality and "transformative" patient empowerment.

Keywords

Patient empowerment, telemedicine, autonomy, shared decision-making, vital ethics.

L'autonomisation du patient : une approche pratique de la prise de décision éthique en télémédecine

Résumé

Cet article vise à clarifier le concept d'autonomisation du patient et à évaluer ses implications éthiques dans le domaine de la télémédecine contemporaine. Pour atteindre cet objectif, on passe en revue les objets numériques connectés utilisés par les patients en contexte télémedical, plus connus sous le nom d'"Objets Médicaux Communicants" (OMC), puis on propose une vue d'ensemble de systèmes de santé numérique, parmi les plus avancés, qui

permettent des communications à distance entre les patients et les médecins aujourd'hui. Partant de ce double examen, on avance que l'autonomisation du patient est un processus de développement de compétences grâce auquel une transformation individuelle et inter-personnelle peut être réalisée. En outre, l'autonomisation du patient est une approche pratique de la décision éthique, qui repose sur un processus de prise de décision partagée, axé notamment sur l'autonomie et l'auto-détermination du patient. Ce point de vue est conforme aux principaux objectifs visés par la télémédecine contemporaine ainsi qu'à l'esprit d'une nouvelle politique et d'une nouvelle éthique de la vitalité et de l'autonomisation "transformative" du patient.

Mots-clés

Autonomisation du patient, télémédecine, autonomie, prise de décision partagée, éthique de la vitalité.

Empoderamiento de los pacientes: un abordaje práctico para guiar tomas de decisiones éticas en telemedicina

Resumen

Este artículo tiene como objetivo clarificar el concepto de empoderamiento de los pacientes y evaluar sus implicaciones éticas en la telemedicina moderna. Para lograr este objetivo, se ofrece una revisión de las herramientas basadas en las TIC utilizadas por los pacientes en los entornos de telemedicina, conocidos como "dispositivos conectados médicos" (DCM), así como una visión general de algunos de los sistemas de e-salud más avanzados que permiten hoy en día la comunicación a distancia entre los pacientes y los profesionales de la salud. Se sostiene que el empoderamiento de los pacientes es un proceso de creación de capacidades mediante el cual se puede lograr la transformación personal e interpersonal. Además, es un enfoque práctico para las decisiones éticas, basado en la toma de decisiones compartida, enfocado en la autonomía del paciente y su autodeterminación. Estos puntos de vista son coherentes con los objetivos principales de la telemedicina, pero también con el espíritu de una nueva política y una nueva ética de vitalidad y empoderamiento "transformador" de los pacientes.

Palabras clave

Empoderamiento de pacientes, telemedicina, autonomía, toma de decisiones compartida, ética vital.

1. Introduction

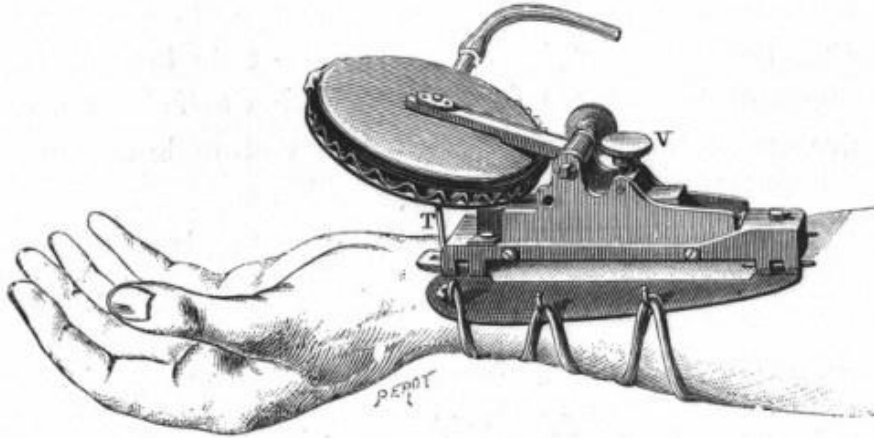


Figure 1. A sphygmograph, probably of Étienne-Jules Marey's design¹

Medicine has a long-standing tradition of assistive technologies for patients. Throughout history, numerous medical objects have been used to mediate the relationship between bodies, patients and healthcare professionals: stethoscopes, thermometers and other technical “tools” used, for instance, to measure vital signs. It is also important to note that today’s medical technologies have benefited from many past experimental patient-centric innovations, some of which have long been forgotten, such as the “sphygmograph” (see original picture above)².

In traditional telemedical research, the point about scrutinizing the relationship between human practices and technology has often been to measure the efficiency of medical devices and information systems, regardless of, if not patient concerns, at least patient experiences of these technologies. Fortunately, some major changes in telemedical assessment practices, in recent years, have raised concerns about the importance of acknowledging such experiences. As some early critics have observed, telemedicine has now shifted successfully from “device management” to “patient management”. Not only does this change attest to the progress made towards patient recognition, and acknowledgement of their technical know-how, but it also

¹ Source: Wikipedia (2014) Sphygmograph. Retrieved on September 9, 2014 from <https://en.wikipedia.org/wiki/Sphygmograph>.

² The sphygmograph was a mechanical device used to measure blood pressure in the mid-19th century. It was developed by German physiologist Karl von Vierordt (1818-1884). It is considered the first external, non-intrusive device used to estimate blood pressure. In 1863, Étienne-Jules Marey (1830-1904) improved the device by making it portable. Wikipedia (2014) Sphygmograph. Retrieved on September 9, 2014 from <https://en.wikipedia.org/wiki/Sphygmograph>.

shows that if it is to improve at all, for the sake of patients, telemedicine must address resolutely the value system³ underpinning its own technological development. In other words, telemedicine needs to redefine constantly its own “moral economy” (Daston, 1995)⁴, and acknowledge patients’ abilities and expectations, in order to design improved technological devices and systems. Beyond technicalities, such moral considerations are also at the core of modern ethics.

However useful an inquiry into the history of techno-medical innovations may be for a critical assessment of modern “technomedicine” (Pickstone, 2001)⁵, it is not the path chosen for this paper. Instead, this article aims to clarify the concept of patient empowerment, through medical technology and to assess its ethical implications in telemedical settings. To achieve this goal, however, it must first circumscribe clearly the various areas of the telemedical ecosystem as we know it today.

2. Medicine meets high tech

The American Telemedicine Association (ATA) has defined telemedicine as “the use of medical information exchanged from one site to another via electronic communications to improve a patient’s clinical health status. Telemedicine includes a growing variety of applications and services using two-way video, email, smartphones, wireless tools and other forms of telecommunications technology”⁶. What is important to underscore is that telemedicine is not a separate medical specialty. It is often part of an extended investment made by medical institutions in ICTs and medical care provision. Many services can be provided by telemedicine today: a health professional can provide an online consultation with a patient and render a

³ The term “value” is used here to refer to “[...] a standard that guides and determines action, attitudes toward objects and situations, ideology, presentation of self and others, evaluations, judgements, justifications, comparisons of self with others, and attempts to influence others” (Rokeach, 1973, ref. 7, p. 25).

⁴ This expression is adapted from Lorraine Daston’s concept of moral economy as “a web of affect-saturated values that stand and function in well-defined relationship to one another”. This concept highlights the relevance of individual viewpoints in medical settings whose transcendence “seemed a precondition for a coherent scientific community to many nineteenth-century scientists and philosophers” (Daston, 1995, p. 4, p. 9).

⁵ Broadly defined, technomedicine is the medical treatment that makes use of modern technology. For an in-depth discussion of the historical implications of technomedicine, see Pickstone (2001).

⁶ American Telemedicine Association (2012). *What is Telemedicine?*. ATA website. Retrieved September 9, 2014 from <http://www.americantelemed.org/about-telemedicine/what-is-telemedicine>.

diagnosis; connected devices may be used to remotely collect and send health data, such as patient heart ECG, to a diagnostic testing center; or patients and health professionals can use wireless devices to access medical information on the web.

In addition, several delivery mechanisms can be used in telemedicine such as programs connecting health professionals with clinics or hospitals in rural or suburban areas; initiatives from public and private hospitals and clinics to provide delivery services or outsource specialty services to independent medical service providers; or monitoring systems for chronic patients care in hospital or in the home. There are also many popular websites, under telemedicine, providing direct patient care or information (PatientsLikeMe, CureTogether, Webicina, etc.). According to ATA, telemedicine offers four fundamental benefits: improved access for patient in distant locations, cost efficiencies through better management of chronic diseases, reduced travel times for patients and fewer or shorter hospital stays, improved quality of healthcare services and patient satisfaction⁷. Many countries around the world have implemented telemedicine with a view to provide similar benefits.

Telemedical services and mechanisms have only become possible, however, through the development of wearable wireless sensor technology and other innovative mobile health (mHealth) technologies. Thanks to these advanced high-tech devices and systems, telemedicine allows now for the much greater individualization of the prevention and management of multiple chronic and acute conditions. For instance, if a patient knows that they have a genomic risk for diabetes, they can use a digital meter, pump or continuous glucose monitoring (CGM) sensor to prevent the condition from ever occurring. Telemedicine's principal aim, as ICT-based medicine, is therefore to understand the unique intricacies of a specific individual's physiology and to measure physiologic metrics at home, which used to be measured in a doctor's office or hospital setting: blood pressure, heart rhythm and rate, oxygen saturation in the blood, stress levels, etc. As a result, high-tech medicine increases considerably the abilities of care teams to make sense of the daily variability in these various metrics and also provides them with technical means to better inform patients about their conditions, even though there may be occasional risks for technical language to prevail over empathy.

It should be noted, indeed, that in high-tech medical lingo, which is very different from medical parlance, telepatients are often referred to as "end users", thus implicitly stressing patient technical "operativeness" as a core value in the telecare relationship. For the sake of argument, however, this article must reiterate the importance of "humanness" in the (tele)care

⁷ American Telemedicine Association [ATA] (2012). *What is Telemedicine?*. ATA website. Retrieved September 9, 2014 from <http://www.americantelemed.org/about-telemedicine/what-is-telemedicine>.

relationship and express the view that, if carefully acknowledged, humanness may be the cornerstone of a better approach of patient needs, aside from technological considerations. Yet if technical values – and efficiency - often seem to prevail over human values in the telecare relationship, it may be argued that technical values are, in fact, as equally important as human values to assess the benefits of the existing reality of the telecare relationship in its complexity. To address the ethical implications of technologies, this article therefore proposes a prior examination of how patients use, or are required to use, “Connected Medical Devices” (CMDs) in telemedical settings. Or, to put it differently: it aims to question how, and to what extent, patients are technologically empowered today.

3. The benefits of CMDs and e-health platforms

Any assessment of patient empowerment in telemedicine may indeed begin with a review of the ICT-based tools used by patients, known as CMDs, but it may also benefit from an overview of the most advanced e-health systems that enable remote communications between patients and health practitioners. A flurry of CMDs and e-health platforms are currently under development in many countries around the world. Table 1 below shows a selection of CMDs that can be used in telemedicine to address the needs of (chronic) patients today.

Device categories	CMD types	Solution providers	Pathologies
Implantables/Embeddables	Smart pacemakers RIFD chips Body sensors	SORIN ORANGE HEALTHCARE EQUIVITAL	Heart failure Kidney failure Other pathologies
Ingestibles	Digital pill	PROTEUS	All pathologies
Connectables	Health & wellness electronics (wireless blood pressure monitors, activity e-trackers, etc.)	WITHINGS iHEALTH BODYTRACE	All pathologies
Wearables	Fitness bands Sensors	iHEALTH APPLE	Arythmia Vital signs

	Smartwatches	WITHINGS	All pathologies
Next Gen Wearables	Smart clothing	BIOSERENITY CITIZEN SCIENCE	Epilepsy All pathologies
Patchables	Electronic tattoo* [*In development]	UNIVERSITY OF AUSTIN	All pathologies
Actuables	Insulin & chemotherapy pumps	MEDTRONIC VOLUNTIS	Diabetes Cancer
Interfaceables	Tablets Smartphones PCs	MICROSOFT SAMSUNG APPLE	All pathologies

Table 1: Selection of CMDs, grouped by device categories, and CMD providers.

Fundamentally, CMDs are used by, or installed for, patients to collect and transmit health data, via wireless communications, to health professionals. Also, CMDs are typically used in conjunction with e-health platforms, which provide health professionals with a secure system for practicing medicine remotely, tracking patient health data and sharing medical records with consulting practitioners. Most telemedicine platforms are software systems that are either installed on a medical practice's computers and live on their servers, or are cloud-based solutions that live entirely online. Others might simply involve a mobile application that allows health professionals to practice telemedicine via smartphone. Usually, telehealth platforms have a variety of features. For example, a platform might allow a health professional to connect with a patient via secure, high-resolution video for a remote visit, share medical images, send text messages or online chats in real-time.

To fully understand the benefits of e-health platforms for patients and, to a lesser extent, for health professionals, it may be worth examining a key telemedical feature known as "remote home monitoring"⁸, which has indeed become a top priority in public healthcare in recent years. Remote monitoring devices and e-health platforms enable people with cardiac disease, diabetes and other chronic illnesses to stay at home and out of the hospital while their diseases are managed remotely by healthcare providers. The monitors keep track of patients' heart rhythms (or other physiological parameters), send the information to doctors remotely, then alert them if intervention is needed.

⁸ Remote monitoring is a technology that enables healthcare providers to monitor patients outside of conventional clinical settings, which may increase patient's access to care and decrease healthcare delivery costs.

Table 2 below shows how the SMARTVIEW remote monitoring solution from Orange Business Systems and Sorin Group allows healthcare providers to get access to valuable cardiac data and alert messages from Sorin's implantable pacemaker, while the patient is at home. Sorin's CMD, called PARADYM RF, is a smart pacemaker equipped with an accelerometer to allow adaptation of pacing to suit the patient's activity. It is also equipped with the RF wireless technology which enables to remotely monitor the patients who have the Sorin SMARTVIEW Monitor installed at home⁹.



Table 2: SMARTVIEW: a remote monitoring solution for patients with implanted cardiac rhythm management (CRM) devices¹⁰.

A key benefit of SMARTVIEW remote monitoring solution is that it allows for the early detection of cardiac disease progression without having the patients regularly see their doctors for regular checkups, saving time and money. "With remote monitoring, I can efficiently review clinical and device data – usually collected during in-office follow-up – while patients stay at home," said Philippe Mabo, MD, PhD, University Hospital of Rennes, France. "Also, the SMARTVIEW solution provides information based on Sorin's advanced device technology that

⁹ "PARADYM RF SonR is an implantable cardioverter defibrillator for the recognition and treatment of ventricular tachycardia and fibrillation, with ventricular resynchronization, in patients with spontaneous or inducible tachyarrhythmias." Source: Implant manual, SORIN PARADYM RF SonR, p. 6. Retrieved October 1, 2014 from www.pacemaker.ch/.../sorin_crt_d_paradym_rf_crt_d_sonr_9770.pdf.

¹⁰ Sorin Group (n.d.). SMARTVIEW. Retrieved November 16, 2013 from <http://www.sorin.com/product/smartview-remote-monitoring-system>.

may enable early detection of clinical events and better patient care,” he added¹¹. It should be noted that the SMARTVIEW remote monitoring solution is a *Machine-to-Machine* (M2M) platform which does not therefore require any patient’s direct handling of CMDs in the remote monitoring process¹².

Unlike SMARTVIEW, PROTEUS Discover remote monitoring solution does require patients’ direct participation in the remote monitoring process: a practice called “patient direct-use”. In essence, such practice requires patients to use digital tools (CMDs) to collect and send their own health data to health professionals via a medical app and a dedicated online platform. PROTEUS Discover remote monitoring solution is the brainchild of Proteus Digital Health, a California-based company that has successfully developed and marketed the “smart pill” system¹³. Once ingested, PROTEUS digital pill, which contains a sensor the size of a grain of sand, has the ability to send a signal to the Patch worn by the patient after it reaches the stomach, and therefore to track and transmit patient data about everything from sleep and body temperature to hydration and respiratory function. Hence, PROTEUS digital pill can be used to monitor vital signs for virtually all conditions.

The benefits of PROTEUS Discover for the patient and their healthcare team are two-fold. First, the Discover App, which receives physiological data from the Patch, “helps patients keep track of their medications, steps, activity, rest, heart rate, blood pressure and weight. Patients can also set multiple medication-taking schedules and receive medication reminders”. Second, “the Discover Portal allows healthcare professionals to drill down into an individual patient’s data and allocate resources to those who need it most. The information in the Portal provides

¹¹ Hirsch, D. (2012, June 13). Sorin Group and Orange Business Services Offer Implanted Cardiac Device Remote Monitoring. *HealthTech Zone*. Retrieved October 2, 2014 from <http://www.healthtechzone.com/topics/healthcare/articles/2012/06/13/294657-sor-group-orange-business-services-offer-implanted-cardiac.htm>.

¹² Machine to Machine (M2M) refers to technologies that allow both wireless and wired systems to communicate with other devices of the same type. Usually, a M2M platform comprises a *device* (such as a sensor or meter) to capture an *event* (such as temperature, heart rate, etc.) that is relayed through a *network* (wireless, wired or hybrid) and to an *application* (software program) that translates the captured event into *actionable information*. Source: Wikipedia (2014). *Machine to Machine*. Retrieved September 28, 2014 from https://en.wikipedia.org/wiki/Machine_to_machine.

¹³ In the USA only, at time of publication. Proteus Digital Health, however, has recently announced plans to open a digital medicine manufacturing plant in the UK along with partnerships with the National Health Service (NHS) to help develop its “smart pill” system.

insights that helps healthcare professionals select or determine the best treatment for the individual patient¹⁴.

Like PROTEUS, GLOOKO is a powerful remote monitoring solution that requires patient participation in the remote monitoring process. Unlike PROTEUS, however, GLOOKO offers a mobile phone and application service that enables diabetic patients to make Diabetes Management service easier. GLOOKO's powerful application allows patients to download their glucose readings to their iOS or Android device, integrate food and lifestyle data, and share reports with their care team.

Essentially, diabetic patients can use GLOOKO to synchronize their glucose meter, pump and continuous glucose monitoring (CGM) and to track their blood glucose and insulin data next to exercise, diet and more. GLOOKO can easily integrate popular health and fitness apps including Fitbit, Moves, iHealth and Strava. Automatically, GLOOKO adds activity/exercise, blood pressure and weight data while people are on the go. The California-based company's remote monitoring system allows for the inclusion of all integrated data in standardized reports which provide a holistic view of people's diabetes management and overall health. Hence, GLOOKO's remote diabetes management service improves people's ability to make decisions. Its mobile application allows patients to email, print, or fax standardized reports to their healthcare team. Reports include blood glucose averages, statistics and graphs, and a glucose logbook that includes food and insulin data. And with the patient's permission, their care team can also sign-up for online access to their GLOOKO information.

GLOOKO's powerful mobile application and integrative technology, but also SMARTVIEW's smart pacemaker and health platform and PROTEUS's digital pill and remote monitoring system, which have been selected here as case studies, serve a common purpose: to provide technical, cognitive and medical assistance to both patients and health professionals. It should be noted that the benefits of these CMDs and health platforms extend to the patient's personal sphere as they can gain more decision-making power through these technologies. With SMARTVIEW, PROTEUS or GLOOKO, patients are indeed called upon to play a key role in their health management. With SMARTVIEW, patients remain very active, despite the M2M configuration, because they have immediate access to their own health data and can therefore make informed decisions, with their practitioner's advice, in the event of health complications. With PROTEUS and GLOOKO (direct-use configurations), not only does the patient control their own health data 24/7, but they are also in charge of many technical aspects of their health management,

¹⁴ Proteus Digital Health (2015). *How does Proteus Discover Work?* Proteus Digital Health website. Retrieved on June 2, 2015 from <http://www.proteus.com/how-it-works>.

including “self-monitoring”: a medical practice implemented through the use of advanced CMDs (such as smart pills, patches, tablets, etc.). With both M2M and direct-use remote monitoring systems, patients are able to share responsibilities with health professionals. In addition, with a remote monitoring solution, as it is often argued, patients may no longer feel isolated in their homes as “objects of care”, but rather they can keep in touch with their relatives or health practitioners or become technically co-responsible for their health as “subjects of care”. Although not “on par” with doctors, who possess medical expertise, patients can nevertheless engage in a socializing and empowering care experience in such telemedical settings.

In this regard, it should be noted that remote patient monitoring typically requires a small team of professionals to gather onto a single technical platform, thus forming a quality-driven micro-community around the (chronic) patient. Telemedicine has thus become patient-centric, but also, it should be added, increasingly distributive. Indeed, high quality healthcare, which is provided by state-of-the-art remote monitoring technologies, such as CMDs and e-platforms, contributes to the reinforcement of a growing trend in telemedicine: that of the delegation of monitoring power to patients. Consequently, patients acquire digital skills that allow them to become actors in their own health (sometimes to the point of being able to disengage temporarily from the telemedical control exerted on them through CMDs, as Nelly Oudshoorn and Ivo Maathuis have shown in their article for this special issue)¹⁵. It ensues from this two-fold approach to CMD use and e-health systems, combining both “patient competency” and “practitioner control”, that any resolute attempt at defining “patient empowerment” requires a prior understanding of the distribution of powers among the stakeholders involved in the telecare relationship.

4. Autonomy and authority in telemedical settings

With the advent of telemedicine, the balance of power in healthcare has been significantly altered. As CMDs and e-health platforms bring patients and health professionals together, a new world of participatory medicine is evolving in which patients become potent agents in creating and managing their own health in partnership with their care teams. Patients’ increasing involvement in the telecare relationship is therefore not just a matter of taking advantage of CMDs and e-health information systems as a pre-requisite to the cure, but also a

¹⁵ See Oudshoorn and Maathuis (2014).

question of mastering their acquired knowledge to be able to reach the next level: self-discipline, self-education and technological self-care. In parallel, the omniscient, paternalistic approach of traditional medicine is challenged with emerging medical technologies. As a result, the case of technologically assisted healthcare, and distribution of powers in telemedical settings, cannot be understood within the narrow scope of a sterile alternative between patients' quest for autonomy and health professionals' eagerness to consolidate their authority. The issue of autonomy and authority in telemedical settings has indeed become a matter of sharing responsibilities and co-constructing health knowledge. What lies behind this new technologically-based contractual form of healthcare is the possibility for patients to define their own health standard, but without necessarily depriving practitioners of their medical authority. As French philosopher Philippe Barrier points out: "the patient has a potential for *self-normativeness*; they can figure out their health on their own, but with the help of a healthcare professional" (Barrier, 2014)¹⁶. So how, in this context, does the concept of "patient empowerment" make sense to the telemedical communities today?

In Europe, patient empowerment is supported by the EU through the European Patients Forum which aims to "[...] promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition" (Bravo et al., 2015, p. 2). As recent studies have shown, however, "patient empowerment is neither well-defined nor consistently operationalised and there is no consensus on the best way to measure it" (Bravo et al., 2015, p. 2). A recent influential survey from the Cochrane Healthcare Quality Research Group (CHQRG) from Cardiff University¹⁷ identified five of the most frequently cited definitions of patient empowerment in the literature (Bravo et al., 2015, p. 6). Among these definitions, that of American research scientists Martha Funnell and Robert Anderson, given below, provides a useful semantic disambiguation of the concept of patient empowerment.

We have defined the process of empowerment as the discovery and development of one's inherent capacity to be responsible for one's own life. People are empowered when they have sufficient knowledge to make rationale decisions, sufficient control and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of their decisions. Empowerment is more than an intervention or strategy to help people make

¹⁶ This quote has been translated from French by the author of this article.

¹⁷ The Cochrane Healthcare Quality Research Group (CHQRG), Cardiff University, is a group of health researchers specialising in healthcare quality, patient care and shared decision making (see Bravo et al., 2015, p. 3).

behaviour changes to adhere to a treatment plan. Fundamentally, patient empowerment is an outcome. Patients are empowered when they have knowledge, skills, attitudes, and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives (Funnell & Anderson, 2004).

With this definition, Funnell and Anderson extend Barrier's concept of self-normativeness by hinting at patients' strong potential for impacting other people's behaviour (for instance, social or family caregivers), beyond their own behaviour, as they become more autonomous by acquiring valuable technical skills and medical knowledge. Patient empowerment is therefore a process of personal and inter-personal transformation. It is also "the capacity-building process whereby individuals increase their belief that they play an active role in their care (i.e., taking action to solve their problems)" (Bravo et al., 2015, p. 7). These views are consistent with telemedicine's main objectives, which have been outlined in this article, but also, as it is argued below, with the spirit of a new politics, and ethics, of vitality.

5. From pastoralism to shared decision-making

Improving communications and giving patients more control over their care are critical goals of telemedical initiatives. Telepatients are not just data producers nor passive recipients of treatments, but rather they are potent actors increasingly concerned with maximizing their own vitality through telemedical means. To fully understand the ethical implications of this process, it is important to replace it within its historical and political background. It may be argued, indeed, that the figure of the "empowered patient" today is at the core of a revisited "vital politics". Once defined as a "politics of health" delimited by "the poles of illness and health" and concentrated on "eliminating pathology to protect the destiny of the nation"¹⁸, modern vital politics "is concerned with our growing capacities to control, manage, engineer, reshape, and modulate the very vital capacities of human beings as living creatures" through the employment of various "rationalities and technologies of government" (Rose, 2007, p. 3). Telemedicine is one such technology as it helps patients reshape their vital capacities by applying step-by-step

¹⁸ Here, Nikolas Rose refers to the vital politics of the eighteenth and nineteenth centuries which was "a politics of health – of rates of birth and death, of diseases and epidemics, of the policing of water, sewage, foodstuffs, graveyards, and of the vitality of those agglomerated in towns and cities" (Rose, 2007, p. 3).

procedures for calculations of bodily variations. In addition, telemedical processes entail “an increasing emphasis on the responsibility of individuals to manage their own affairs, to secure their own security with a prudential eye on the future” and, as sociologist Nikolas Rose goes on to suggest, “nowhere have these been more telling than in the field of health, where patients are increasingly urged to become active and responsible consumers of medical services and products” (Rose, 2007, p. 4). As biological creatures, or selves, patients have thus become the target of novel and digitally-based forms of authority and expertise which re-define the meaning and the scope of patient autonomy and self-determination: two organizing principles of patient empowerment in telemedical settings today.

Current telemedical forms of authority and expertise do not indeed reduce vital politics to a “politics of self” imposed on the patient by medical institutions. Telemedical authorities have instead allowed for the possibility of enlarging the scope of patient intervention in the telecare relationship, thereby creating opportunities for greater autonomy and self-determination as well as inter-personal communication. As a result, vital politics has become a dynamic politics, and a politics of human dynamics, based on the reciprocal causal relationships between three sets of ethos¹⁹ focusing on responsibilities and/or opportunities at the patient, healthcare provider and healthcare system levels.

As the discussion of e-health platform models in this article has shown, patients have rights (to be informed), responsibilities (for compliance and self-efficacy) and opportunities (to engage with other stakeholders) relating to autonomy and self-determination. Patients also have power within the telecare relationship as they can optimise the healthcare service by providing valuable feedback. Furthermore, this ethos of patient empowerment is interrelated with, and dependent upon, the ethos of healthcare professionals, who have responsibilities to respect patient’s autonomy and to adopt a partnership style within the healthcare relationship, thereby creating further opportunities for self-determination. The ethos of patient empowerment is also aligned with the ethos of the healthcare system that has responsibilities to optimise healthcare service use and maximise patient health status and well-being: two objectives that patients themselves aim to attain.

Aside from these sets of ethos, there are several key indicators for autonomy and self-determination underpinning a practical ethics of patient empowerment. For instance, autonomy can be measured in the patient’s capacities, states and resources such as self-efficacy, knowledge, skills, attitudes and self-awareness, acquired through telemedical means, that may

¹⁹ Ethos is used here in its etymological sense: a greek word meaning “character” that is used to describe the guiding beliefs or ideals that characterize a person, community, nation, or ideology.

influence their own health behaviour, but also their perceived personal control over health and healthcare. The level of patient autonomy may be assessed in the way that patients “work on” their condition, or their health literacy, and on their determination to feel respected. Patient autonomy is also visible in patients’ behaviours: the role they take in healthcare consultations; their preparedness to make informed decisions about their health and/or care; choose personally meaningful, realistic health-related goals, or take steps to achieve those goals. Patient autonomy is also about participating in patient support/advocacy groups; using the internet to collect/share health information and support. Last but not least, patient autonomy and self-determination may be perceived in, and ethically evaluated on the basis of, patients’ adaptation to (chronic) illness, patients’ quality of life, well-being and sense of independence. Essentially qualitative, such patient outcomes, it should be noted, are acquired through telemedical apparatuses (i.e., CMDs and health information systems) concentrating mostly on quantitative knowledge.

Whilst modern vital politics focuses on telemedical authority and expertise, modern “vital ethics” is concerned about patients’ autonomy and self-determination in their quest for a better life, which are both requirements for, and outcomes of, patient empowerment. Modern vital politics, which is mostly about distributing powers and responsibilities among the stakeholders in the telecare relationship, is therefore the other side of an empowerment approach which is essentially “practical” and ethically “vital”. Patient autonomy and self-determination, along with other core values, such as self-efficacy, self-awareness, warmth, empathy, collaboration and (mutual) respect, which would require further examination, are indeed aligned with the goals of an empowerment approach that values life, not just the living mechanisms of the human body. As Funnell and Anderson have suggested, “the empowerment approach does NOT involve convincing, persuading, ‘empowering’, or changing patients (or getting them to change). Instead, the empowerment approach involves facilitating and supporting patients to reflect on their experience of living” with their (chronic) disease (Funnell et al., 2010, p. 8). Patient empowerment is therefore about providing patients with tools, but also human resources, to achieve autonomy and self-direction with a view to improve their quality of life. To realize this, autonomy and self-determination, as guiding principles of patient empowerment, may be implemented through a key feature of telemedical practices: shared decision-making.

The acknowledgement, or lack thereof, of shared decision-making, is central to the ethics of patient empowerment in telemedical settings. Shared decision-making is indeed often described as an intervention at the healthcare provider level that may promote patient empowerment. As Bravo et al. observed:

this is consistent with published models of shared decision-making e.g., Elwyn et al.'s 2012 three-step model proposing that shared decision-making can be implemented by healthcare professionals by i) introducing a choice to the patient, then (ii) describing the options (sometimes supported by decision support tools), and (iii) helping patients to explore their preferences and then make a decision. Patient self-management is described to be an activity that is undertaken by empowered patients (Bravo et al., 2015, p. 12).

Elwyn et al.'s model may be realized in a near future as it entails a dynamic set of relations between counselors and counseled individuals, marking a sharp break with traditional "pastoralism", "where a shepherd knows and directs the souls of confused or indecisive sheep" (Rose, 2007, p. 29). Most importantly, it seems that the new pastors of the telemedical age feel increasingly inclined to "espouse the ethical principles of informed consent, autonomy, voluntary action, and choice and non directiveness" (Rose, 2007, p. 29).

It is therefore important to note that shared decision-making and pastoral expertise are at odds in telemedical settings. Shared decision-making helps patients make meaningful decisions while paving the way for actionable treatment plans based on patients' own assessment of health related goals. Pastoral expertise, on the other hand, as the kind of knowledge deployed by medical counselors on paternalistic grounds, affects the patient's decision-making capacity by putting too much emphasis on the practitioner's personal values. As Hermann et al. observed:

Though guided by existing standards, capacity judgments are in the end discretionary, as the evaluator alone determines whether or not it is legitimate to intervene on paternalistic grounds. Such judgements necessarily involve values which render them less objective and more susceptible to external and potentially inappropriate influences. It has been shown that such influences are not always deliberate but evolve tacitly from physicians' personal inclinations and values, affecting the stringency of standards required for DMC [Decision-making capacity] (Hermann, et al., 2015, p. 744).

Another key benefit of shared-decision making, from an ethical viewpoint, is therefore that it allows for the potential reassessment of practitioners' judgments. Shared decision-making enables patients to express concerns about, and cope with, arbitrariness or even undue and disguised paternalism. With the rise of technological culture in medicine, shared decision-making is at the cornerstone of a relational ethics of patient empowerment. Not only does shared decision-making contribute to the betterment of the patient-doctor relationship, it also

entails a major shift of perspectives in modern telemedical ethics: from traditional pastoralism to collaborative and mutually beneficial counseling.

6. Conclusion

The complex issues surrounding the moral economy of telemedicine can be apprehended from the review of CMDs and e-health platforms used in telemedicine today and from the ethical assessment of patient autonomy and self-determination, which are major outcomes of patient empowerment in telemedical settings. Unsurprisingly, the perspective of achieving autonomy and self-determination through shared decision-making, on ethical grounds, is not new. Back in 2009, bioethicist Maartje Schermer had already reached a similar conclusion: "Instead of reproducing an outdated paradigm of patient-professional interaction in which compliance is the aim, the new technological possibilities should be seized to develop and implement a new paradigm based on collaboration and concordance" (Schermer, 2009, p. 691). What is new, however, is that the rise of patient empowerment in telemedicine has allowed for a shift from outdated pastoralism to modern informed guidance. By successfully implementing shared decision-making, it is hoped that telemedicine will help redefine the scope of patient knowledge, reinvigorate the patient-doctor telecare relationship, and open new perspectives for an ethics of vitality and transformative patient empowerment.

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