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Telemonitoring: ethical lessons from the COVID-19 pandemic

Ineke Bolt^{1*†}, Jona Specker^{1†} and Maartje Schermer¹

Abstract

Background The COVID-19 pandemic accelerated the development and application of telemonitoring, enabling health care providers to continue to provide medical care. Telemonitoring oftentimes replaced face-to-face health care services instead of as being offered as a supplement to regular medical care. Given that pressure on hospitals is expected to remain, telemonitoring is seen as an important means of alleviating those pressures. In this paper, we consider the intensified deployment of telemonitoring during the pandemic as an excellent opportunity to learn how telemonitoring can be implemented in a morally responsible way.

Results In order to gain concrete, contextual and in-depth knowledge of the ethical issues raised by telemonitoring during the corona pandemic, we explore telemonitoring for two conditions: COVID-19 and Idiopathic pulmonary fibrosis. We conducted interviews with patients and professionals on five important ethical themes: 1. a shift in responsibilities, 2. empowerment and self-management, 3. the value of face-to-face consultations, 4. inclusivity and equal access, and 5. privacy and big data. Based on the findings of this empirical study and medical ethical principles, we formulate lessons for responsible implementation and upscaling: 1. ensure explicit and realistic allocation of responsibilities and avoid expectations that monitoring is more direct and continuous than it actually is; 2. create opportunities for an optimal form of self-management—in particular for patients with chronic conditions—and for meaningful conversations; 3. integrate telemonitoring within an established HCP – patient trust relation and stimulate research on the conditions for face-to-face consultations; 4. take vulnerability into account in inclusion & exclusion criteria and involve patients in design and implementation processes; 5. concerns of collection of data are beyond privacy and identify the risks of dependency on commercial companies.

Conclusions Our findings show that offering patients choices for telemonitoring will not necessarily result in increased and equal accessibility, good quality of care and patient autonomy. Whether or not these aims and promises will be fulfilled, and the ethical challenges adequately met, is highly dependent on choices regarding the design of specific monitoring systems, the development process and the embeddedness in a trusting physician–patient relationship.

Keywords Telemonitoring, COVID-19, Idiopathic pulmonary fibrosis, Ethics

[†]Ineke Bolt and Jona Specker contributed equally to this paper and share first authorship.

*Correspondence:

Ineke Bolt

L.Bolt@erasmusmc.nl

Full list of author information is available at the end of the article



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Background

Telemonitoring is a form of telemedicine defined as the “remote monitoring of client health or diagnostic data by [a healthcare] provider” [1]. Application of telemonitoring expanded considerably due to the COVID-19 pandemic [2–5] during which it was broadly applied in the care for patients with COVID-19 as well as for other conditions such as diabetes, lung cancer, kidney transplants and pregnancy [6, 7]. Remote monitoring of patients proved indispensable for the continuity of care in a situation where regular care facilities were closed or access was limited [8]. Telemonitoring, however, also raises ethical issues and challenges.

Ethical issues in telemonitoring

In literature on the ethics of eHealth, a number of potential ethical implications of telemonitoring have been identified. First, telemonitoring entails that tasks previously carried out by health care professionals (HCP)—such as tracking vital parameters or performing diagnostic or prognostic tests—are now to be carried out by the patient themselves. These shifts in tasks imply various shifts in responsibilities [9] which raises ethical concerns regarding “over-medicalization of previously more carefree spaces” [10] and over-responsibilisation [11] in case patient’s capabilities are overstretched and patients are unfairly held responsible for measurements, non-compliance, or failing to raise alarm if symptoms deteriorate [12]. Moreover, the shift from inpatient to outpatient treatment necessitates the involvement of more and new parties in organizing, facilitating and monitoring the telemonitoring itself, such as general practitioners, home health care workers, and informal caregivers. This implies new distributions of responsibilities need to be established.

A second ethical issue concerns the promotion of empowerment and self-management. The concept of empowerment can be defined as an enabling and educational process where an intervention and/or HCP promote the knowledge, self-awareness, attitude and skills of patients to co-manage their condition. Empowerment can contribute to the ability of patients to self-manage the disease and to autonomy understood as the ability to fulfil personal life goals and values [13–16].¹ However, telemonitoring does not automatically promote empowerment, self-management and autonomy, and might make patients even more passive,

e.g., waiting for the professional to alert them in case something is wrong [17]. Moreover, digital health applications may also promote empowerment in one respect (e.g., knowledge) but lead to disempowerment in another (e.g., be able to do something).² Further, it may enhance patient’s compliance to the medical regime but not support the patient’s own perspective on successful disease-management which is not automatically aligned with medical and health-related goals and values [14].

A third ethical issue concerns the value of face to face (f2f) consultations. Some commentators caution that telemonitoring may lead to poorer communication, damage the provider-patient relationship [9], and might even harm the patient, for instance by overlooking important medical, non-verbal or “tacit” information [19–21]. Under what conditions is it permissible to substitute in-person services with remote care altogether? Is the standard of what ‘good care’ entails being changed by telemonitoring?

The fourth ethical issue includes the effect of telemonitoring on equal access to care and inclusivity of healthcare services. Telemonitoring has the potential to reach patients who have limited access to health care such as patients in regions lacking specialist medical care [19]. In addition, telemonitoring may provide care for patients who face other barriers such as anxiety for medical settings [19, 22]. However, it is pointed out that eHealth may exacerbate existing health inequalities and disproportionately affect certain patients negatively, a problem labelled as digital inequity [12, 23–26]. Unequal access may arise between those who can afford necessary devices and resources, and those who cannot [9], and between those with lower and higher health and digital literacy skills [27].

Finally, telemonitoring raises concerns regarding privacy and the collection of big data from patients. Telemonitoring provides an excellent opportunity to capture data on a large scale and to integrate these data with other (health) data. However, this raises several ethical questions such as: do patients have a say in which data are collected and stored and for what purposes; is it allowed to use data for purposes beyond the interests of the patients who collected the data; will the increasing influence of commercial parties in research infrastructure and design of telemonitoring make HCP and hospitals too dependent regarding control over the telemonitoring system and its design [28, 29]?

¹ Currently, there is a lack of conceptual clarity of the concept of empowerment [15]. Lack of conceptual clarity inhibits assessment of interventions to promote empowerment [16].

² See for instance Schneider’s observation that patient-controlled electronic health records led to more knowledge about the condition but not to empowerment of all patients (depending on whether they had a proactive style; some patients felt overwhelmed by the data) [18].

Need for real world evaluation

So far, the assessment of ethical issues has been based on theoretical considerations and small-scale experiments with telemonitoring, and has mainly pointed out *potential* ethical implications. As such, these assessments are of a quite general and relatively hypothetical nature. Since there are high expectations of telemonitoring and we seem to be at the brink of large-scale implementation of telemonitoring technologies, it is urgently needed to investigate the ethical implications in real world settings and in specific contexts.

The increased deployment of telemonitoring during the COVID-19 pandemic—during which telemonitoring was offered on a larger scale and as a substitute rather than an add-on for standard clinical care—is an excellent opportunity to learn more about the ethical issues in concrete contexts. However, empirical studies about telemonitoring seldom focus on explicit ethical issues, and if they do mention them, they tend to restrict themselves to safety and utility issues, and, to a lesser degree, on equity [5, 7, 30, 31]. Other studies do focus on ethical and legal issues of telemonitoring, but are not based on empirical research [19, 32].³

For this reason, we studied two different cases of telemonitoring during the pandemic: telemonitoring for COVID-19 patients and for patients with Idiopathic Pulmonary Fibrosis (IPF) in the Netherlands.

Telemonitoring for COVID-19 patients was born from necessity and implemented quickly after the start of the pandemic. It either aimed at early detection of disease deterioration in patients diagnosed with COVID-19 residing at home, or at monitoring recovering patients after discharge from hospital [35–38]. COVID-19 telemonitoring systems implemented in different hospitals varied widely; some were more technology intensive (e.g., including a blood pressure monitor, thermometer, pulse oximeter, and measurements collected during video consultations entered into the patient's electronic medical record by means of an app [39]), whereas others were less technology intensive (e.g., monitoring by means of self-measurement by patients and phone and home visits by the general practitioner (GP), homecare staff and emergency-GP).

In contrast, telemonitoring for IPF was gradually developed before the pandemic. IPF is a rare, chronic progressive lung disease primarily affecting older males (50 years and over) with a mean survival of 3–5 years after diagnosis if left untreated. The disease course is rather unpredictable ranging from a slow disease progression

to a rapid decline with or without acute deteriorations. Although medication may inhibit the deterioration of lung function, lung transplantation is the only treatment option with significant survival benefit [40]. In the Netherlands, clinicians in cooperation with patients developed a telemonitoring tool, IPF Online; a personal platform containing information about the disease, real-time wireless daily home spirometry, online patient-reported outcome measures, medication use, symptoms score and side effects, and video consultations [41]. Due to lockdown measures the IPF Online tool was offered as a partly replacement of regular clinical consultations during the COVID-19 pandemic [42, 43].

In this paper we present the results of our study into the experiences and views of COVID-19 and IPF patients and HCP regarding the abovementioned ethical issues. Based on an ethical analysis of the results, we formulate ethical lessons for further upscaling and implementation of telemonitoring systems. These insights are important for good quality telemonitoring care during a possible upsurge of the coronavirus but especially after the pandemic to sustain health care in times of increasing shortage of health care professionals and an aging population.

Methods

A qualitative research approach was chosen as the most suitable method to investigate in-depth whether and how important ethical issues discussed in the academic debate – in times of relatively low scale implementation of telemonitoring and eHealth – are reflected in experiences of patients and HCP with telemonitoring during the COVID-19 pandemic. We chose COVID-19 and IPF because they are similar in a number of respects but also differ in relevant ways (see Table 1) and thus enable us to gain broad insight into experiences with telemonitoring. Both conditions are lung diseases and the diagnostic parameters the two telemonitoring tools intend to monitor, such as pulmonary function and disease progression, are comparable to some extent.⁴

We developed a semi-structured interview guide addressing the ethical issues derived from the literature on the ethics of telemonitoring (see Additional file 1). The preliminary interview guide was reviewed and discussed with other members of our research team (a bioethicist with experience in empirical bioethics, a philosopher, and a legal expert), and adapted accordingly. We developed one interview guide for both HCP and patients, with slightly altered phrasing of the questions posed to HCP and patients.

³ Although there are little ethical empirical studies on telemonitoring specifically, such studies do exist for other eHealth technologies [33, 34].

⁴ The IPF tool has in fact been adjusted to allow for one year monitoring of recovery of COVID-19 patients after hospital stay [38, 44].

Table 1 Contrasts between telemonitoring of COVID-19 patients and IPF patients

Telemonitoring of COVID-19 patients	Telemonitoring of IPF patients
Novel, acute condition with unknown nature	A rare, chronic, progressive and relatively well-studied condition
Diverse population	Mainly male population (70%), mean age > 60 yr
Built from scratch in short period of time, adapted and refined during the pandemic	Incrementally developed telemonitoring tool, embedded in research
Sudden development in context of crisis, capacity constraints and pressure on healthcare system, multiple local experiments and set-ups	Patient participation in development of tool, active patient representation, continuous evaluation and customization
Self-monitoring and self-management of symptoms by patients using oxygen, thermometer, and pulse oximeter, communicated to own GP (or GP medical post after office hours) by telephone, supplemented if necessary with home visits of GP or homecare worker	A personal platform containing information about the disease, real-time wireless daily home spirometry, online patient-reported outcome measures, medication use, symptoms score and side effects, and video consultations
Responsibilities divided/ delegated over multiple different actors	Local close-knit team of developers and HCP

Between February 2021 and March 2022, we recruited a diverse group of HCP and patients in the Netherlands. We interviewed three patients with IPF (male, aged 66, 73 and 76) and two patients with COVID-19 (one male, aged 68, and one female, aged 56) that were monitored at home during the pandemic. We interviewed three pulmonologists who were involved in developing and maintaining a telemonitoring tool for IPF patients, used before as well as during the pandemic. We interviewed three healthcare providers involved in the telemonitoring of COVID-19 patients; one cardiologist involved in telemonitoring patients at home, one specialist nurse working at a homecare organization and one specialist nurse working at a GP medical post. The latter was interviewed three times over the course of 13 months (March 2021 – March 2022), in order to investigate possible shifts in policy and experiences. Interviewees were recruited through our network and key-informants in the hospital, and next through snowballing.

The interviews were carried out by one or two interviewers (IB and JS) and lasted approximately 45 to 60 min. They took place either at the patient's home, in a healthcare facility, or online due to COVID-19 restrictions enforced at that time. The interviews were conducted in Dutch, audio-recorded, and transcribed verbatim. The interviews were analyzed and coded independently by two researchers (IB and JS). We used a mixed method of deductive and inductive analysis [45, 46]. Predetermined codes were based on the ethical issues raised by telemonitoring as discussed in the academic literature. By using a mix method we could focus on parallels, refinement or rejection of (parts of) the existing theoretical debate on the ethics of telemonitoring.

The research proposal was submitted for review by the research ethics review committee of the Erasmus Medical Center. A waiver was granted as the

empirical-ethical study does not fall within the scope of the Dutch Medical Research Involving Human Subjects Act (MEC – 2021–0482).

Results: ethical issues in telemonitoring

In this section we present the findings of the interviews related to the ethical issues. We describe the experiences, concerns and views of patients and HCP with respect to: 1. the shifting responsibilities of patients, HCP and other parties; 2. the degree to which telemonitoring promotes empowerment and self-management of patients; 3. the value of 2f consultations; 4. the potential to increase health inequities and obstacles to access to medical care; and 5. the impact telemonitoring may have on privacy and the ownership of big data.

Shifting responsibilities

We asked patients and HCP about their experiences related to shifting expectations, tasks and responsibilities caused by telemonitoring. IPF patients indicated that telemonitoring makes them more inclined and even impelled to monitor themselves, intervene and raise alarm if things go wrong:

I think if you're involved via video consultation or involved via eHealth, in the development of your disease pattern and you see it like that, you're much more likely to get the urge to say hey, that's going in the wrong direction. I need to do something. (...) So you as a patient are forced to face the facts more, and then you accept that. You can also stick your head in the sand like an ostrich, but you can also say, it's still- I do have to do something. The incentive to do address that yourself or to contact [a doctor], that is, that is large. (IPF patient)

Although some IPF patients indicated that they hesitated about the right moment to raise alarm, they appreciate the opportunity to control and intervene if their

measurements show a negative trend. Their willingness to control and take responsibility, however, seems to be related with an active role of the HCP as well.

And the response of course from here [the hospital], because that's important. If you get that- Because that reassured me again, hey, there's control, if I have a problem, I have the people I trust who I call on. (IPF patient)

HCPs (IPF) also pointed at the shift in responsibility, in particular regarding the alarm system. They wondered whether the system should automatically generate an alarm in case patients report side-effects, or fail to perform spirometry, or use it incorrectly. If so, this may result in quite some false alarms. However, is it safe to design the system without an automatic alarm and leave all responsibility with the patients?

I now have over two hundred patients and if they blow wrong, technically, I can receive an alarm but I can't keep on looking. So now I have turned the alarms off and I tell them, if you don't trust it, just call me. So that's-There you do give responsibility to a patient. (HCP IPF)

Whereas telemonitoring of IPF patients primarily involved a shift of responsibilities from HCP to patients themselves, telemonitoring for COVID-19 patients involved more stakeholders: the lung specialist in the hospital, the general practitioner, the regional center for general practitioner emergency care during weekends, home care, informal caregivers, and the patient. With telemonitoring of COVID-19 patients, this shift was also more sudden in nature, due to the crisis context of the pandemic itself, and there was less experience and knowledge regarding the condition itself:

Patients can suddenly turn ill, from one moment to the next. If people are chronically ill and informal caregivers are involved, they grow more along with it (...) But in this case: from one day to the next you are a caregiver. While no one has asked you if you wanted that at all. (...) And that there wasn't always enough space to say to a caregiver who was in doubt: okay, then we're not going to do it. Yes, to what extent was there a choice? Of course there really wasn't. (HCP COVID-19)

HCPs also emphasized the vulnerability of some of the COVID-19 patients and their informal caregivers. Not every patient is able to handle the instruments, to understand and interpret data, or to contact HCP in time. Not everyone has a sufficient social or familial 'safety-net'.

There is, of course, a great deal of responsibility on the part of the patient. Either they are responsible for this or the informal caregiver. But of course we all know that this is also becoming increasingly vulnerable and that patients are sometimes completely unable to do this and that we simply chronically overestimate it. (HCP COVID-19)

Because of all the different parties involved, one respondent pointed out that constant evaluation and adjustment of protocols and aligning arrangements was needed in order to improve the telemonitoring system and distribute responsibility fairly.

I have made a lot of changes to the registration form. That has become much more extensive. So that we kind of forced the GPs to just fill in everything. And we have communicated that, also simply explained under the heading of quality of care, because otherwise we simply cannot guarantee it. That was a very big change. And that we have placed that responsibility much more on the GP in the sense of, well, we really want to facilitate this, but we also need you for that. And that was actually picked up. (HCP COVID-19)

Empowerment and self-management

Depending on the context, telemonitoring has the potential to promote empowerment and self-management to different degrees [14]. For instance, telemonitoring enables the patient to take over some practical tasks of HCPs, in particular measurements. Patients may also take over interpretative and decisional tasks of the HCP. The patient can understand and interpret the measurement data, and take action if needed, for instance by adapting medication dosage.

Look, now I can monitor, now I can say myself, I see it going down too much. And then I can intervene. And they can see that too. So, in that respect, I'm really glad it's here. (IPF patient).

Telemonitoring may also empower patients to an optimal degree of self-management and autonomy when telemonitoring enables the patient to realise his or her preferences, priorities and values as the following quote shows:

Well, that's [a hobby] one of the things that I actually let that slip a little bit, because I've been a graduate, in that for twenty years. And afterwards I picked it up again. And I attribute that to this. [...] You feel more confident. Oh, I can pick that up again. And so I did. (IPF patient).

Both COVID-19 and IPF patients express a need for further explanation from HCP with regard to how to distinguish between normal fluctuations and worrisome changes and how to interpret fluctuations in measurements over time. Being required to regularly measure key parameters was experienced as insecurity inducing if no feedback or interpretation is provided:

I don't need feedback every week, but I would like it after a month or two months. Feedback like: yes, you are doing well and the condition of your lungs is fine. You see? But you didn't receive that. You participate, you blow every week, you possibly report on your complaints, whether you are short of breath or cough. You pass that on, but after that you don't get any feedback, like 'there is progress' or 'you remained stable.' (COVID-19 patient monitored at home during rehabilitation).

In case of the monitoring of COVID-19 patients, HCP suspected that patients felt somewhat pressured to agree to being monitored at home:

I think there was just some sort of social pressure to participate. The news featured predominantly those patients who were very happy that they were discharged [from hospital]; Guys, look how well I'm doing with my oxygen tank in the garden. (HCP)

Value of f2f consultations

IPF respondents were clear and explicit on whether telemonitoring could function as a replacement of f2f consultations. According to them telemonitoring is a wonderful fall back solution and a useful addition, but not a replacement for quarterly consultations with their doctor. Respondents indicate that the value of f2f encounters lies in the personal touch, the body language, and the trusting relationship with the HCP.

You're going to trust those people. And if that becomes more distant, as it becomes with an e-consultation and a video consultation []. And you need those contacts, because it's part of the guidance. But well just that pure, that ..., that human, I personally need that. I find it very important that that's there, that it is possible. (IPF patient)

Further, IPF patients prefer to discuss the development of the disease and to interpret the generated data in a face-to-face encounter with HCP.

The last time I met [the doctor], then she turns that screen. We get into a conversation, she turns that screen. She says, 'look, because that line- And then the graphs come, so that's not just the spirometer,

but so, so everything. And that little line runs this way and that little line runs that way and if you look now, that's there for this and that reason and probably that ... And you are actually back to the level of that period.' Try to do that with a video consult, that's quite difficult. (IPF patient)

They also consider the equipment in the hospital of better quality and more reliable, and feel they receive more extensive examinations there.

That equipment is better, you get walking tests, an ECG, a blood draw, so it's much better communicated. (IPF patient)

HCP respondents emphasize that some aspects of care require personal contact, and some conversations can't be done remotely, such as conversations about the end of life -these have to be discussed during a f2f consultation. Moreover, they point out that monitoring may not capture all relevant facts.

Because yes, in the end I do believe that the patient is more than his or her illness. So you can organize that monitoring is very much based on all kinds of hard facts, but then you do not yet know how things are going, partly. So it's yes, a bit of a double, I guess. I think it can be done very well, but really as a support and not as a replacement. (nurse involved in telemonitoring of COVID-19 patients)

Equal access to care and inclusivity

IPF patients in our study are clear about the ease of use of the IPF telemonitoring system ("a child can do the laundry"). According to them, everyone should be able to use it. The IPF patients all received instructions how to handle the tool and a free, pre-installed tablet. They are all very engaged and at least one of the three patients has been involved in the development and continuous adjustment of the tool from the very first start and is quite Internet-savvy:

And if you don't have internet, well, then, you buy a mobile router and the country you travel to, you buy a card at the airport. You put that in your mobile router and you have internet. Right? (IPF patient)

According to the HCP a small group of IPF patients, however, does not want telemonitoring; either because they do not want to be confronted with the disease, have concerns about privacy or think they are unable to use it.

Some of the patients you can't serve. The patients now are all white natives. Those 20% are often patients with different cultural backgrounds or

Table 2 Ethical lessons**Shifting responsibilities**

Ensure explicit and realistic allocation of responsibilities

Embed telemonitoring in a trusting care relation

Beware of (unwarranted) big sister conceptions. Avoid expectations that monitoring is more direct and continuous than it actually is

Empowerment and self-management

Create opportunities for optimal form of self-management—in particular for patients with chronic conditions—and as an explicit aim of telemonitoring

Create possibilities for meaningful conversations (i.e. about the interpretation & implication of the data, shared decision making, end of life)

Value of f2f consultations

Integrate telemonitoring in good clinical care practices, and preferably within an established HCP – patient trust relation

Stimulate further research on the importance of and conditions for F2F consultations

Appraise and determine the golden standard of quality of telemonitoring care

Equal access and inclusivity

Take into account vulnerability in inclusion/exclusion criteria, beware of noncompliance

Involve patients in design and implementation processes, and consider implementation as an iterative process requiring continuous adjustment

Stimulate careful upscaling: What works for one patient population does not automatically work for another

Privacy and big data

Identify the risks of the dependency on commercial companies; concerns of collection of data are beyond privacy; power of commercial parties over data collection tools and the infrastructure of clinical studies and clinical care may negatively impact the quality of care

lower levels of education. Age is not an issue, older people can do just fine. However, access to internet is an obstacle for some (HCP-IPF).

as too vulnerable, because this and this and this is going on. So we can't do that home monitoring. (HCP COVID-19)

HCPs involved in telemonitoring of COVID-19 patients stressed the particular vulnerabilities associated with the sudden onset and unknown course of the disease, as well as the unequal distribution of capabilities and resources of patients to participate in telemonitoring adequately: do patients have sufficient disease insight and skills to handle the tool, interpret the data and act upon changes in data if needed; do patients have an informal network capable to take over care?

There are really quite a few inclusion criteria also set, for example, they must have a certain saturation value, over a longer period of time. Well and quite a few other things: the situation must not be too fragile. And what we notice in practice is that the situation is often quite vulnerable, but also that, for example, there is informal care available but with an enormous language barrier. (HCP COVID-19)

HCP of COVID-19 patients stated that gradually, lessons have been learned and inclusion/exclusion criteria adjusted. If patients are too vulnerable, or if informal care is not available, telemonitoring should not be started.

In the last weeks we direct on increasing safety by making sure that simply... that the registration form is correct and also because we can already say at the front door: this patient really just comes across

Privacy and data use

Views on potential breaches of privacy and concern about the collection and storage of data differ. Some IPF patients were concerned about potential breaches of privacy, others not. HCPs however, did mention privacy as a concern. According to one HCP responsibility for warranting privacy also lies with the technicians who should manage it properly. Further, HCPs considered the issue of data ownership; some felt that since the patients 'do the job' they are therefore owners of their data. Further, some of them were concerned about the increasing influence of commercial companies and the lack of research into efficacy:

So, I do see a lot of opportunities there, but I also see some threats, and that's particularly on the technical front as well. For example, that it is still not properly integrated into the electronic patient file and that [company's name] has an enormous monopoly on what can and cannot be integrated and what is allowed there. And then another very fast company comes along and does it slicker and faster. And do you then have to switch, do you have to force your patients into something that maybe you think is nicer and slicker, but are we getting anywhere with it? I find that very difficult, to get the technology right and also the funding, the

structural and sound research. And that is I think needed, there are three hundred thousand health apps, but there is hardly any research. (HCP IPF)

Discussion

In this section we discuss the results of the interview study in relation to the existing literature and draw some ethical lessons for telemonitoring in a non-pandemic situation and for a responsible upscaling of telemonitoring (see Table 2) [47].

Responsibility

Shifts in tasks and responsibilities are experienced by all respondents. The IPF patients value this shift since it gives them the opportunity to intervene in time – in this sense, increased responsibility is also a form of empowerment. Their positive attitude, however, seems to be related with their experience that the HCP is also close on it and intervenes if necessary. They trust that HCP will provide appropriate feedback if necessary. This phenomenon has been discussed in literature as the ‘big sister’ conception: the impression of being surveyed by HCP they know and trust [48]. It is of course essential that such a conception is in fact warranted. If not, this may jeopardize patient safety and cause serious harm which contravenes with the ethical principle of non-maleficence [49].

At the same time, HCP struggle with whether or not setting an automatic alarm, or leaving responsibility for reporting abnormal measurements with the patient. Here as well it is crucial that mutual expectations are warranted, which in turn requires clear communication and agreement about tasks and responsibilities between patient and HCP. Moreover, alarm fatigue and habituation, well-known pitfalls in intensive care units, may become challenges in non-intensive care facilities as well and this requires ethical reflection on responsible design of alarm management in telemonitoring [50]. HCP simply should not turn on alarms if they cannot follow up on them. On the other hand, shifting this task to patients may not always be warranted either (e.g., when patients or informal caregivers are too vulnerable due to lack of disease insight or low digital and health literacy skills). Development of smart alarms in joint collaboration with developers, HCP, and patients is needed: e.g., which alarms are clinically significant, in which cases should an alarm be sent to a HCP and/or to the patient, and should alarms for technological malfunctions be included? Design of telemonitoring systems thus mediates the distribution of responsibilities of the involved parties and should be developed in close collaboration with these stakeholders.

Telemonitoring raises concern for over-responsibilization: an unrealistic expectation of patient’s capabilities and unfairly ascription of accountability [12]. Respondents underlined the need for an explicit and a realistic division of responsibilities and in/exclusion criteria for telemonitoring of COVID-19 patients. The multiplicity of (new) parties involved, the vulnerability of some of these patients and their informal caregivers, and the unexpected and sudden transition to telemonitoring increased the risk of harm due to an unclear or unrealistic division of responsibilities. It is not only an issue of clear communication about how and to whom which responsibilities are ascribed; it also includes a realistic assessment of what can be asked and expected from people in terms of being able to carry responsibilities [51].

What we are talking about here is prospective, forward-looking responsibility⁵: who is supposed to do what in the (near) future, who is capable to do what, and which moral requirement should be imposed and justified to prevent harm [52, 53]. Factors that may hinder the capability of patients to use telemonitoring are low health and digital literacy, but also social and economic factors such as a fragile social network and lack of internet facilities. In order to avoid unrealistic and unfair ascription of responsibilities to patients involved, explicit conditions have to be developed [11]. For instance, guidelines about the capabilities needed to use tools adequately, instructions to assess whether patients possess and are able to exercise these capabilities, and how patients lacking these capabilities can be supported and by whom.

Empowerment and self-management

Promoting empowerment and self-management involves both a practical and a moral ideal [14, 54]. Practically, empowerment and self-management are seen as means to increase efficacy of care and efficiency, which can be important during a time of crisis and scarcity in the course of and, even more so, outside the pandemic. As a moral ideal, empowerment and self-management are desirable because they contribute to the realization of independence and autonomy. If we take the value of autonomy seriously, the optimal form of self-management is that in which patients are empowered to live according to their own values and goals, and to enhance their overall quality of life as they see it [14].

⁵ This is to be distinguished from retrospective responsibility. Retrospective responsibility is focused on the question of accountability. Who is to blame if something went wrong? Answering this question requires determining whether the conditions of knowledge, causality and voluntariness are fulfilled (e.g., did the patient know the spirometer didn’t function, is there a causal relation between harm done by the malfunctioning spirometer and the fact the patient did not contact the HCP, were there any controlling influences preventing the patient from raising alarm?).

As the two cases, in particular IPF Online, illustrate telemonitoring has the potential to promote empowerment and self-management. Telemonitoring may support patients to arrange their life in line with their hobbies, lifestyle, preferences and personal values and as such contribute to personal autonomy. However, this may not be feasible or desirable for each patient (population) or in each context. Especially for acute disease, like COVID-19, this goal is less easy to reach – and perhaps less urgent. Which degree of self-management is feasible and desirable should be determined as much as possible per patient population and even per patient. For patients with a chronic condition, such as IPF, attaining the optimal degree of self-management and autonomy is especially important given their long-term dependence on telemonitoring and its potentially pervasive impact on their lifestyle. To be able to achieve the optimal degree, at least two conditions should be fulfilled. Firstly, it is paramount to design a system that incorporates opportunities for meaningful f2f conversation (feedback, interpretation and implications of the generated data), since this empowers patients to learn and to engage in optimal self-management ('empowerment by design'). Patients appreciate feedback on how to interpret the collected data and expressed a need to discuss its meaning and implications for them personally. One way to ensure that telemonitoring is designed in view of optimal self-management is to develop, evaluate and adjust the system in close collaboration with patients. Secondly, telemonitoring provides patients with information but as Kapeller et al. argue in order "to turn information into knowledge" – to be able to understand the meaning of information for themselves and act on it—patients need the help of doctors to contextualize the information [55].

Finally, the principle of respect for autonomy also implies that HCP should abstain from coercion or undue pressure to make patients use telemonitoring. Participation of patients and informal caregivers should be voluntary. Especially since, as Barbara Prainsack notes, "it may be much harder for patients to deviate from *digital* monitoring and surveillance technologies compared to *non-digital* home monitoring or medical devices"⁶

⁶ See for instance Prainsack: "Another concern is that for patients, the "script" provided by digital surveillance technologies in the health domain is much more detailed and much harder to deviate from than it has been the case before the digital era. As Nelly Oudshoorn (2011: 10– 11) argues, there is an important difference between telecare technologies and devices such as the inhaler for asthma or the familiar thermometer. Whereas using a thermometer or asthma inhaler can be considered as isolated individual acts that patients can perform wherever and whenever they prefer, the use of telecare devices is materially and morally integrated into a network of care that guides and restricts the actions of patients" [29].

Value of F2F consultations

All IPF patients strongly prefer telemonitoring to be complimentary to onsite consultations in order to warrant quality of care. Telemonitoring is qualified as a wonderful emergency solution in lockdown but only as a *supplement* to regular physical consultations. The reasons for their strong view are diverse: they perceive the quality of the research facilities at the hospital as better, and feel f2f consultations are necessary to build trust as well as to enable good communication (be able to ask more focused questions and to discuss intimate personal issues, especially in life-threatening conditions). Their willingness to participate in telemonitoring also seems to be related with having trust in their HCP to respond in time. In order to be successful, telemonitoring should be integrated in good clinical care and an established HCP – patient trust relation.

The preference of patients for onsite consultations is on itself not a sufficient moral reason to abstain from further upscaling of telemonitoring. We need to establish the reasons for onsite consultations and evaluate whether these reasons are morally decisive or not and whether they are indeed backed up by evidence. Creating and maintaining a trusting relationship may be one of the reasons to prefer onsite consultations. As suggested by some respondents, discussing sensitive and emotionally charged topics such as end-of-life care may also require f2f consultations. Further research is needed to establish when and for which patients f2f interaction is needed in order to provide good quality care.

Some HCP are concerned that telemonitoring may result in a lowering of the standard of good quality care. Similar concerns are described in the ethics literature; even harm might be done as a result of overlooking important medical, non-verbal or "tacit" information [19, 21]. This raises the question of what should be the golden standard of quality of care? Which determinants and outcomes should be considered? Under what conditions is it permissible to substitute in-person services with remote care altogether? Parsons cautions against too rapid implementation of telemonitoring systems and argues that if and when telemonitoring is intended to partly or entirely replace standard in-person care, conditions of safety, efficacy, acceptability, etc. should be met [19]. Others also argue that the condition of effectiveness should be clearly fulfilled, and that its use should be based on a careful consideration of data supporting expected benefit [33]. The question of what constitutes good care, what parameters are important in this regard, and when care is 'good enough' is clearly an ethical question and one that really needs to be put on the agenda.

Equal access and inclusivity

Patients may have different levels of skills as well as different intentions for using telemonitoring. As Kapeller et al. point out: “patients are not equally ‘non-empowered’ to begin with and that care must be taken to not further enhance the power differences between patients who are well-educated and socio-economically privileged, i.e. are more likely to have ‘knowledge and skills,’ and those patients who are less so” [55].

From a moral point of view telemonitoring should be as inclusive as possible, meaning it should ideally be equally accessible for all patients [19]. As is evident from the IPF case, active involvement of patients promotes accessibility and thus inclusivity of telemonitoring. Telemonitoring for IPF patients was developed over the years in an iterative process allowing for continuous adjustment and an essential contribution of patients, embedded in a trustworthy patient-physician relationship. However, even then the tool may be less accessible for patients with lower health or digital literacy. Moreover, as the COVID-19 case shows, patients and informal caregivers may not have sufficient disease insight and skills to handle the tool and to interpret the data. Even in a prosperous country as the Netherlands, the number of citizens with low literacy is relatively high; 2,5 million Dutch citizens are low literate [56]. More attention is needed for making telemonitoring tools and support accessible to people who lack those skills and onsite regular care should remain available if that support fails [19].

Further, a comparison of the two cases shows the need for careful upscaling: what works for one patient group—‘experienced’ chronic patients—may not automatically for another – patients newly diagnosed with acute disease. Future research should look into the question of which elements are important for equal accessibility: which characteristics of patients and patient groups, the disease, the context and the tools and technologies co-determine how ‘equally accessible’ a telemonitoring system is? Operationalization of the concept ‘equal access’ is needed. Is the condition of equal access fulfilled if the telemonitoring tool is used by an equal number of different patient populations, if the outcomes are equal for different patient populations, if the tool is included in the reimbursement system, or when patients have the real opportunity to choose whether or not to participate in telemonitoring?

Privacy, big data and dependency on tech companies

Whereas some patients were concerned whether their privacy was sufficiently warranted, others trusted the HCP in an adequate regulation of privacy. Specific privacy requirements can be qualified as an enabler for upscaling of telemonitoring [47]. HCP pointed at another

concern, that is the topic of data ownership and dependency on and power of commercial companies. With respect to the latter, HCP mentioned the lack of a good integration of the telemonitoring system with the electronic patient file, and the asymmetric power relations between patients, HCP, and commercial enterprises owning the (creation of) digital infrastructure and other health care innovations. As Sharon shows tech commercial enterprises in general are aware that privacy is seen as an important issue and the increasing collection and analysis of data can be tackled by developing tools (privacy by design) [57]. Protection of health related data is important for respecting autonomy and to warrant trust. In the European Union privacy of personal data is protected by the General Data Protection Regulation (GDPR). European as well as (under some circumstances) non-European companies have to comply with the GDPR requirements [58].⁷ Moreover, patients need to give informed consent and should have the option to opt out at any time. A less easy to tackle concern, according to Sharon, is the increasing role and influence of companies in data collection, data analytics and infrastructure development in health care and research settings [57]. This is all the more the case if several digital systems and data sources are combined. Who has access to the datasets, who determines the research questions and agenda? It already appears that HCP and patients are increasingly dependent on the companies for infrastructure in order to provide digital care. This concern is not easily addressed since, as Sharon argues, the tech companies step into the gap that is left by governments in the public sector due to privatization, deregulation and reorganization of the public sector [57]. Prainsack also points at the power asymmetries between the patients the data come from and the companies who produce and own the instruments, tools, and software. Principles of informed consent and privacy by design will be of less use here, she claims [29]. The lesson to be learned is that telemonitoring systems should be developed with due diligence and care corresponding to current privacy laws and guidelines. The role of power asymmetry and the dependence on tech companies, however, is not specific for telemonitoring and needs to be addressed at a collective governmental and institutional level.

Study limitations

Before drawing a conclusion, we need to address two important limitations of our study. Due to a small study population, restrictions caused by the lockdown

⁷ See Gerke et al. 2020 for a comparison between privacy laws in the USA and EU [58].

measures during the COVID-19 pandemic and time constraints of the project, it was difficult to recruit and interview a larger sample of respondents. Given the small number of respondents, the extent to which the results are representative is hard to ascertain. However, generalizability of the results is not the aim of our study; the aim is to understand how important ethical issues discussed in the academic debate are reflected in experiences of patients and HCP with telemonitoring during the COVID-19 pandemic and to draw lessons from it. Further, the study was executed in times of a crisis and may therefore not be generalised to regular medical practice after the pandemic. Even though COVID-19 is no longer a global health emergency, healthcare faces other crises such as higher cost, shortage of medical professionals, increase of chronic conditions. The question is therefore whether 'business as usual' is realistic and whether we should not increasingly reason and design from a scarcity situation.

Conclusion

Telemonitoring is on the verge of a large upscale for an increasing number of chronic as well as acute diseases and for a diversity of patient populations. Further upscaling of telemonitoring may contribute to the realization of important goals and values including equal access to good quality care, efficiency, and empowerment of patients. However, in order to realize these promises, certain conditions need to be fulfilled, and ethical issues addressed. Our analysis shows that offering patients choices for telemonitoring will not necessarily result in increased and equal accessibility, good quality of care and patient autonomy. Telemonitoring is not a box of tools, nor a formula one can roll out for multiple disease states. Whether or not the aims and promises will be fulfilled, and the ethical challenges adequately met, is highly dependent on choices regarding the design of specific monitoring systems, their development processes and their embeddedness in trusting physician–patient relationships. Telemonitoring is beyond the acute phase and must be integrated into and relate to existing practices and ethical and legal norms of good care. It is a living practice that should be responsive to emerging experiences and evidence in different populations and conditions in health care.

Supplementary Information

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Additional file 1. Semi-structured interview guide

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Authors' contributions

The authors confirm contribution to the paper as follows: study conception and design: IB, JS, MS. Draft manuscript preparation: IB, JS, MS. The data collection and analysis of the empirical studies was conducted by IB and JS, and the results of studies interpreted by IB, JS and MS. All authors read and approved the final manuscript

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Availability of data and materials

The qualitative empirical data that support the findings of this study are not publicly available due to privacy conditions. Restrictions apply to the availability of these data, since the consent of the interview subjects is only applicable to this interview study. Data are however available from the authors upon reasonable request and with permission of the interview subject.

Declarations

Ethics approval and consent to participate

The qualitative empirical research project on which this publication is based received a waiver of approval from the ethics review board of Erasmus MC as it did not fall under the Dutch Medical Research with Human Subjects Law. All methods were performed in accordance with the relevant guidelines and regulations. Informed consent was obtained from the respondents.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

¹Department of Medical Ethics, Philosophy & History of Medicine, Erasmus MC, Dr. Molewaterplein 40, Rotterdam 3015 GD, The Netherlands.

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