Telemedicine as a socio-medical process. Experiences from remote monitoring of long-COVID patients in Poland

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Abstract

Aim. Long-COVID syndrome is still under broad investigation. It is known, however, that the consequences of COVID-19 disease can permanently affect the health and quality of life of patients in many respects. For this reason, monitoring parameters in patients who are still experiencing symptoms is an extremely serious task for medicine. It is possible with the use of telehealth paradigm, which helps to provide long-term care. The use of wearable medical devices that record certain vital parameters (e.g., Aidmed) can ensure that the patient is under constant surveillance after an infection. For this reason, the development and introduction of nationwide telemonitoring and telerehabilitation programs for the long-COVID patients seems to be a key solution.

Methods. The main goal of this analysis, which involved 373 patients, is to present practical experiences and discuss the strengths and weaknesses of the use of remote diagnostic tools in patients with long-COVID syndrome. The analysis based on a multicentre study in Poland focuses on the technological and social aspects of Aidmed telehealth system. The results were obtained on the basis of the deliberative reflection method, conducted by a multidisciplinary team: 2 medical sociologists, 1 epidemiologist, 2 biomedical students (secretary roles in the projects), 2 computer scientists and 2 medical doctors.

Results. The analysis showed that the use of telemedicine tools is quicker and allows to obtain more accurate diagnostic data (strengths). It is also inclusive and educational in relation to the excluded groups of patients (opportunities). However, it may lead to limitation of contacts between the doctor and the patient (threats) and limited access due to high costs and time investments (weaknesses).

Conclusions. Remote home monitoring and telerehabilitation of patients with long-COVID syndrome has the potential to reduce the burden of disease and prevent overloading of the healthcare system. Therefore, it should be widely used. However, we need to learn how to implement it correctly. Our recommendations are: 1) technology should be inclusive in both e-literacy and health literacy; 2) solu-

tions must be as simple as possible for an end user; 3) the entire process requires efficient logistics facilities.

Key words: telemedicine, m-health, e-health, COVID-19, long-COVID

INTRODUCTION

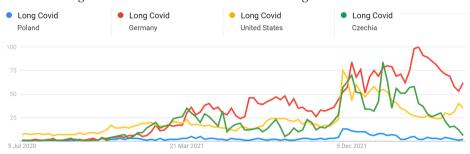
Long-Covid is a complex disease occurring at least 1 months after primary infection by SARS-CoV-2 and the onset of COVID-19 symptoms (Soriano et al., 2022). An extensive study conducted in Germany using wearable health monitoring devices showed that recovery time after COVID-19 infection in the first two waves of infections amounted to 3 months on average (Wiedermann et al., 2022). Continuation of telerehabilitation and telemonitoring for long-COVID patients can ensure the reduction of social and economic losses as the decision was made to cancel the outpatient and ambulatory rehabilitation in Poland starting September 2022 (Szczegielniak et al., 2021). Technologies used in telemedicine proved to be useful and cost-effective methods ensuring broad access to high quality health services and health care outcomes. Therefore, there are multiple reasons for monitoring long-COVID-19 patients (with the use of e-health solutions).

The first seemingly obvious premise is that we do not know what complications and long-term effects on the multiple physiological systems (Respiratory, Nervous, Autonomous, Cardiovascular, etc.) result from the infection with SARS-CoV-2. There is no single test for long-COVID conditions and even consensus on case definition was not established (Soriano et al., 2022). Classification systems for long-Covid based on sensory wearable data (HR-heart rate, counting steps, sleeping time) are slowly appearing (Wiedermann et al., 2022).

The second is a need for reacting to patients' voices. Some health-literate patients want to be better cared for and ask for rehabilitations also in a tele-rehabilitation form. Long-COVID is similar to myalgic encephalomyelitis/chronic fatigue syndrome and patients build organisations to act for their rights to be cured. Patient associations in Poland are not as strong as in Germany for instance (https://wir-fordern-forschung.org), but still we see increased interest in long-COVID syndrome in Poland (Fig. 1).

The third is the scale of the problem. Given the number of infections worldwide, this translates to a tremendous increase in the use of healthcare resources. Healthcare use after a confirmed COVID-19 is higher compared to matched testnegative individuals (McNaughton et al., 2022). Probably the biggest Polish post/ long-COVID registry (Chudzik et al., 2022) suggests that around half of registered cases developed long-COVID. The new, very large population of people who need to be placed under long-term surveillance due to health effects creates an additional burden on the health care system.

Figure 1



Interest in Long-COVID across various countries on Google Trends

Source: Own research based on https://trends.google.com/trends/?geo=PL

PATIENT EMPOWERMENT AND HUMAN-MACHINE INTERACTION

Even before the COVID-19 pandemic, one of the biggest challenges for the healthcare system was to provide adequate care for patients with chronic conditions. Such patients require regular contact with the healthcare providers, and one of the key activities is precisely the long-term monitoring of their condition. It is important for the patient to be independent or even empowered in the treatment process, and therefore able to observe their own complaints and carry out their own measurements with certified medical devices for home use (Bailo et al., 2019; Ćwiklicki et al., 2022). The results of these activities should be fed back to the healthcare professional taking care of the patient with long-COVID. Without such feedback in the circulation of information, the efforts of healthcare professionals and patients may simply be ineffective.

Telerehabilitation contributes to positive changes in the physical activity of the patients, which confirms the effectiveness of new technologies in patient care (Lavado, 2017). Authors of systematic reviews suggest that there is no statistical difference between the primary endpoint (physical functioning) as well as secondary endpoints (such as quality of life, satisfaction of procedure, etc.) gained through telerehabilitation compared to conventional outpatient or ambulatory rehabilitation (Lavado, 2017). This means that both forms are clinically equally effective. However, the use of e-health tools ensures continuity of care for the patient, ongoing motivation for disease management activities and avoidance of risks associated with unawareness of disease escalation or non-compliance with recommendations. Moreover, due to the issue of ageing society, it is necessary to provide adequate care for seniors who are most frequent long-COVID patients (Chudzik et al., 2022). This holds true especially in terms of improving their quality of life and increasing their physical activity by proactive tele-rehabilitation. Telemedicine solutions such as aimed monitoring of the health of the elderly by their caregivers and healthcare professionals could improve care.

CHANGES DUE TO COVID-19 AND PRIORITY GROUPS

We aim also at presenting our socio-psychological contribution to the research landscape of human-machine interaction in the medical field, largely important for the development of innovative solutions for healthcare. During COVID-19 we have observed:

- progress in the domain of e-health that resulted in the implementation of telemonitoring systems with a set of biosignals (soma) and traces of activity (psyche) to track the course of a disease (first acute and later long-COVID);
- optimisation of the activities of medical services: faster intervention in emergency situations (early warning alarms from telemonitoring system), reduced overcrowding in hospitals, and even providing care to a patient in need of help from a distance;
- the rise of mobile health technologies associated with access on smartphones, and other kinds of wearables equipped with a whole array of embedded sensors; this has led to more complex ways of monitoring people's health status and their activity regardless of where they may be during their daily routine (Ćwiklicki et al., 2022);
- better communication, as during the COVID-19 pandemic, telemedicine proved to be very useful in ensuring contact between patients and health care personnel (Vidal-Alaball et al., 2020). According to the report by the Centers for Diseases Control and Prevention issued in October 2020, the number of telehealth visits in the United States in the first quarter of 2020 was 50% higher than in the same period of time in 2019 (Koonin et al., 2020). The report found that 80% of visits to Polish primary care consultations in the first two waves of the COVID-19 pandemic were remote (Binder-Olibrowska et al., 2022; Okoniewska, 2021). As a result, as many as 87% of Poles positively evaluate the facilities offered by telemedicine (Okoniewska, 2021). This change in patient diagnosis and treatment has encouraged the expansion of the possibilities offered by telemedicine.

Telemonitoring and telerehabilitation of chronic pulmonary diseases, such as long-COVID, were never verified for cost-effectiveness in Poland, however some proof of concept simplified calculation was done for other conditions (Niewada et al., 2021). In the USA, the access to e-health for COVID-19 patients is better in highly urbanised areas than in rural areas (Lin et al., 2022). Variation in the use of telemedicine coverage among the US counties also depends on the socioeconomic status, household composition and participation of people with disabilities, population health, and education levels (Lin et al., 2022). This indicates that the most important predictors of high access to telemedicine is the health care access of primary care physicians (positive correlation), which means that telemedicine is not a remedy to inequality in healthcare access and can even increase inequality. Thus, tackling social inequalities in pulmonary health with the use of e-health and telemedicine solutions is a complicated challenge for Poland (Grabowski et al., 2022).

Research also shows that the support of priority groups (seniors, disables, living in remote areas) could overcome the discriminatory mechanism of geo-

graphic accessibility (Jarynowski et al., 2020). However, it is related to the adequate planning of the access to resources as e-health (Diesel et al., 2021). Patients with long-COVID and general chronic pulmonary disease are burdened with a high risk of developing health problems and social alienation (Romaszko-Wojtowicz & Konrad, 2021). The principles of patient tele-monitoring and tele-rehabilitation create a multidisciplinary process; there are also difficulties in rehabilitation of elderly patients.

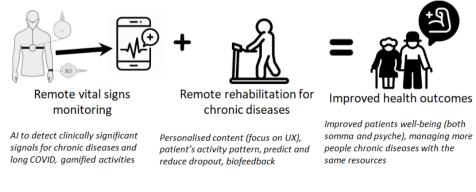
Through managing innovation in the context of COVID-19, healthcare services have an opportunity to overcome the challenges of the upcoming years. Persistent fatigue is a common symptom of long-COVID syndrome with multifactorial causes. Personalised remote diagnostics (sit-to-stand test) and automated supervision provides a tool to detect early indications of vital sign deterioration (low SpO2 - blood saturation, high HR or RR - respiratory rate). One should also bear in mind the psychological challenges faced by patients with long-COVID and the need for regular contact with the patient, for example by means of telemedicine. Thus, patients may follow interdisciplinary tele-rehabilitation to face long-COVID or other diseases such as Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome.

MATERIAL AND METHODS

In our study, telemonitoring with Medical Device (Aidmed, class IIa) was launched in multicentre study in Poland from May 2021 till April 2022 (Fig. 2). The trial has been issued a clearance by the Bioethics Commission at the University of Warmia and Mazury in Olsztyn (17/2021). The primary goal of the trial was to identify the most frequent changes in biosignals (in static and dynamical scenarios) and symptoms experienced by patients by monitoring: nasal airflow, 1-lead ECG, heart rate, respiration rate, body position and movement, snoring and coughing, temper-

Figure 2

Intended model of telemonitoring and telerehabilitation of long-COVID patients



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Source: Own research.

ature, oxygen saturation. 373 consents were received from patients to participate in the around 10 days of observation. Several patients were referred for further investigations (with, e.g., apnoea, arrhythmia, adverse events of vaccination). Twice a response was caused based on real-time signal monitoring. However, in this article we focus on social aspects of this trial. We wanted to show how the tools we used could be appreciated by both healthcare professionals and patients. At this stage, however, due to the insufficient sample size, we were unable to make a broad statistical description. Therefore, we decided to provide a reflective analysis of what we had observed in the study from a socio-medical perspective.

In this analysis we have followed a mixed approach (Cory et al., 2019) of reflective debriefing (our specialists were asked to reflect deeply on situations they personally were involved at the end of the trial to create change) with deliberate practice (our specialists were feedbacking ad hoc then the problem appeared). To have the widest spectrum we used feedback from multiple voices in providing e-health: two medical sociologists (from various environments) of whom one was involved in recruiting and second was an external observer; an epidemiologist, who was also coordinator of clinical trial and had contacts with most of the patients; a student of public health (intensive contact with patients with the goal of collecting socio-demographic data as well technical support); a student of microbiology (responsible for logistics and technical support); leading data science specialists who were modifying data structure; an engineer and programmer, who was supporting mobile app and recorder issues; MD specialising in pulmonology who processed over 100 patients; and MD (Prof.) who was the principal investigator of the whole trial. This is not a typical full report of the trial, but rather a selected part of our study, which has the qualitative value of sharing experience. Thus, we discuss pros and cons of the usability and inclusiveness (social aspects) of remote diagnostics of long-COVID patients.

RESULTS AND DISCUSSION

During our research, a study team has been set to monitor the health of patients after COVID-19. After and during the trial, we carefully analysed the obtained material and experience and looked for potential avenues for improvement of the system after its implementation.

BARRIERS AND SOLUTIONS

We encountered many barriers that were resolved on an ongoing basis taking into account the changing epidemic situation and different social groups represented by patients.

Technical matters

As early as the qualification stage, we discovered that the type of a mobile telephone owned by a patient could be problematic with regards to the tested system. Many patients did not have a mobile phone with an operating system compatible with Aidmed, which would exclude them from the study. This problem was solved by lending these patients a compatible mobile telephone together with an Aidmed device.

Patient health/e-literacy and assistance

Then, we found out that some patients needed to be retrained in the use of the device. Hence, all patients at all stages of the study had access to a technical consultant who could support them in using the Aidmed One system correctly. We found it extremely time consuming to explain the technical issues to elderly people with low e-literacy (Ćwiklicki et al., 2022; Duplaga, 2020). We have overcome existing barriers by working with patients with deficits impaired contact comorbidities such as visual impairments (Binder-Olibrowska et al., 2022), hearing impairment or handicaps. Sometimes, contact with the patient's caregiver or family member solved problems (usually grandson/granddaughter were engaged in technical issues).

It is worth emphasising that, unlike popular lifestyle solutions available on the market, provision of telemedicine services should be egalitarian and inclusive to the highest possible degree. Hence, digitally excluded patients, especially elderly ones, should receive additional assistance. The mobile application was redesigned on the basis of patient feedback at the early stage of the trial. The former multipage design (with different information on separate pages) popular in lifestyle solutions was replaced with a single page only containing the most vital information. We observed that additional information confuses patients and increases the fear of using the application. Some less critical notifications were removed. In general, the application view was simplified with enlarged buttons, messages and explanations. More explanations and messages were added. We observe that taking decisions during interaction with application may be a problem for less e-literate patients. Therefore, the flow was changed to remove the user actions or user choice (e.g., patient has no possibility to choose examination type in the application; examination type is prescribed by the personnel during initial interview and patient only follows the plan). Pairing the mobile application pairs with the closest devices, and the patient does not have to initiate pairing.

A separate problem was the distrust, especially of the elderly patients. It turns out that a large number of Internet frauds, attempts to extort personal data, as well as financial resources, lead to increasing distrust of patients. We encountered this difficulty not only during telephone conversations with patients and remote registration but also during direct contact. Patients, fearing for their data as well as financial responsibility for the borrowed equipment (Aidmed), sometimes refused to take part in the study, although the recruitment was also carried out in the hospital by medical staff, which is generally viewed as the profession of public trust. Another problem was that patients and doctors would sometimes lack confi-

Another problem was that patients and doctors would sometimes lack confidence in the medical nature of telemedicine tools. We tried to be as inclusive as possible in long-COVID arm of trial, however in a control arm we had to exclude specific groups of patients (less e-literate, severely disabled, mentally impaired or demented without a communicable guardian/keeper) and we are aware that it is a common practice in tele-health.

Logistics and follow-up

In our study, patients were also provided with an easy way to return the device at the termination of their monitoring, which proved to be extremely convenient, particularly for persons living away from the medical station where the study was performed.

From a technical point of view, a remote, objective assessment of patients' health, which can be conducted independently at home with Machine Learning algorithms producing alarms and helping with diagnostics, may save limited healthcare resources. Possibility to include chronically ill patients with other barriers to access to services, e.g. territorial (at least we try to also attempt patients from remote areas by sending recorders), epidemic (study was run in the middle of COVID-19 restrictions), etc. Thus, we were able to limit physical contact with infectious patients (respiratory infection), which is especially important in pulmonology as it minimises the risk to patients and staff. Some patients were preparing for hospitalisation for various reasons not always related to their primary disease (long-COVID) and we had a possibility of quick intervention and initial triage before hospitalisation.

Patients were educated by trying to understand the signals they were seeing on the phone. We tried to have a patient-centred perspective, and healthcare professionals could discuss the results of monitoring and answer questions. The followup of these patients was easier as quite an extensive database was collected and made available on a cloud service for other healthcare professionals. We could provide better diagnosis and improved treatment outcomes (which is to be addressed in forthcoming papers). Here, we have examined adults in their natural conditions (minimalizing white coat effect), but we see significant potential of using Aidmed in children (upon approval, as bioethical commission allowed to use Aidmed for adults only) where home conditions are even more important. Our study could also include a larger multidisciplinary team in the work: after our screening by internal and lung medicine specialists, we could immediately share signals and reports remotely with other specialists (i.e. cardiologists) for consultation.

The last stage of patient observation, around 10th day after inclusion into trial, aimed to discuss the results with physicians in the form of teleconsultation. Answering the phone and scheduling appointments was the only problem encountered at this point. Patients listened eagerly to the results and recommendations for further treatment. Many patients followed these recommendations and reported to a pulmonology or cardiology clinic for follow-up. Moreover, some of the patients reported additional problems, such as issues with the application, by the virtue of which further improvements could be achieved. At this stage, the patients did not show the previously described distrust phenomenon anymore. From the doctor's point of view, this type of "pre-hospital" diagnostics is an excellent method for an objective assessment of the patient's vital functions without the need for hospitalisation.

Costs and awareness of staff and decision makers

Settlement and service costs are quite high, especially at the beginning of the process. NFZ (national insurance agency in Poland) does not reimburse long-COVID monitoring or tele-rehabilitation. Respiratory rehabilitation or breathing/ physical exercises are indicated in most of long-COVID patients (Szczegielniak et al., 2021). However, full courses for stationary rehabilitation could not be applied to all patients in need due to high costs and limited resources.

Lack of awareness of staff and decision makers is a barrier, but in this project, we have trained over 30 HCW (healthcare workers) to use an e-health system - for many of them it was first contact with modern telemedicine. We wanted to convince decision makers that tele-monitoring and telerehabilitation can be applied for long-COVID patients. Thus, all costs must be paid by patients or cover from another source (as the Polish Medical Agency in this case). The Aidmed recorder price at the time and the purpose of the trial was around 500 EUR (with access to an app and analytical platform). Additional costs for each patient consisted of: 15 EUR for suppliers, 15 EUR for logistics and 30 EUR for medical consultation. We have lost 1 recorder per circa 100 patients (damage to the devices is excluded because the company delivering equipment serviced it).

Stationary rehabilitation (similar to this dedicated to long-COVID) costs for a single day amounted to around 20 EUR for outpatients, meaning the cost of 420 EUR monthly (Niewada et al., 2021). Thus, using a telerehabilitation set (with an interactive app) for a month could cost around 100 EUR for renting a recorder with software (app and analytical platform) and 50 EUR for the medical component (feedback from physician or physiotherapist) and 30 EUR overheads (logistics and disposable supplies), which gives 180 EUR monthly total.

Even assuming less insensitive load of exercises online (for instance only 1-2 h daily) and less effective diagnostics, over twice as many patients could be severed with telerehabilitation solution than in the case of outpatients.

Integration with HIS

Another barrier is that Aidmed was not integrated with existing hospital information systems (HIS), so it was necessary to look into patients' medical records via other sources (if patients were in the same unit, then local HIS was employed, as well EWP, the Polish Sanitary Inspection surveillance system was used to verify laboratory confirmation of previous COVID-19 infections; finally, printed documentation also had to be examined). We also encountered challenges when collecting disease history from patients, as we used mostly surveys and telephone interviews (for instance patients could not provide information on the medication they were taking). Thus, sometimes data was insufficient to ensure continuity of care remotely and patients were advised to physically visit a doctor. Patients often picked up privacy concerns. Some patients did not want to fill psychological surveys (they expect classical somatic diagnosis only), and some asked to delete data that had already been collected.

Summarising Our Preliminary Observations

Summarising our observations, the most important elements that contributed to the success of the study should be emphasised and should be taken into account when implementing similar systems:

- 1. Technical matters. Mobile phones owned by a patient could be problematic as regards the tested system. A small fraction of patients did not have a telephone with an operating system compatible with Aidmed, which would exclude them from the study. This problem was solved by lending these patients a compatible mobile telephone together with an Aidmed device.
- 2. Patient health/e-literacy and assistance. Tutorials and a helpline with technical support was enough for a great majority of patients. However, some patients needed to be retrained a few times in the use of the device. Some patients were wearing recorders incorrectly; the most common mistake was that the finger saturation sensor was moved from the operating position. We ensured feedback from the healthcare professional to the patient with a possible suggestion of where an error could occur. Hence, all patients at all stages of the study had access not only to system documentation, FAQ and educational videos, but also to a technical consultant who could support them in using the Aidmed system correctly. Hence, digitally excluded patients, especially elderly ones, should have received additional assistance.
- Logistics. We ensured an easy way to provide and return the device at the termination of their monitoring, which proved to be extremely convenient, particularly for persons living away from the medical station where the study was performed.

Conclusions

The lungs are the most often affected by a SARS-CoV-2 infection (Romaszko-Wojtowicz & Doboszyńska, 2021), thus further pulmonological and interdisciplinary observation of patients after COVID-19 is needed. Telemonitoring with neurological, pulmonological and cardiological tests allows for early diagnosis and treatment of complications that may arise over time. For assessment of individual long-term complications, it is important to conduct a long-term follow-up with personalised diagnostics and rehabilitation plans. Technologies used in telemedicine constitute useful and possibly cost-effective (to be verified in future pilot studies) methods that can be employed to ensure access to high quality health services and health care outcomes. We stress the importance of practical boundaries in interdisciplinary attempts on healthcare AI (Kornowska et al., 2022), and telemedicine specifically, on long-COVID patients. However, reducing inequalities in healthcare access were not adequately investigated in the Polish setting (Jarynowski & Belik, 2021; Witeska-Młynarczyk, 2015). Such challenges can only be adequately tackled by an interdisciplinary team, where technology is designed in compliance with the use of digital technologies for e-health services, thus improving population health and promoting health equity.

We stress out our findings in a priority list: 1) having resources for patient assistance (in both e-literacy and health literacy); 2) providing easy to follow technical solutions not only for technical geeks (not another life-style app); 3) reaching out to people from remote areas (logistics).

Collecting data is an excellent tool for medicine, however the real challenge is to use these data to treat patients more efficiently. The use of artificial intelligence methods combined with remote observation can help in the personalised assessment of a patient's condition, screening for diseases, etc. With detectors, the physician/healthcare professional receives pre-described reports and alerts to make clinical decisions. We have been building multiple machine learning detectors for cough, ECG/HRV events, breathing patterns, monitoring physical activity by measuring acceleration, desaturation events, socio-psychological portraits based on surveys and some preliminary results are available (Romaszko-Wojtowicz et al., 2022).

Thus, allowing the management of patients with chronic diseases remotely is likely to be a more and more common practice. The use of a variety of diagnostics, treatments, rehabilitation forms of support including apps and wearable and reminder systems is an expedient and appropriate action in the care of long-COVID or Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

Improving prevention and reducing health inequalities through a personalised care system for long-COVID patients including remote monitoring and telerehabilitation based on Artificial Intelligence methods should be a next step. We suggest being more inclusive in selecting participants of telemedical trials to also include less privileged people from remote areas and with lower e-literacy, which usually are underrepresented in tele-health projects.

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