Where does patient autonomy live, in times of crisis in Portugal?

Abstract Coronavirus disease 2019 made us question daily practices, such as the simple handshake. It also raised some ethical and legal issues. Are the ethical principles, that should guide the provision of individualized care, being fulfilled? Will we, as health professionals, be able to provide patients with instruments so that they can fully exercise their autonomy? The guarantee of necessary security solutions, to reduce the risk of contagion in the provision of care, safeguards the principle of non-maleficence. However, the risk of contagion is impossible to completely eliminate, and there is a residual risk associated with the use of physical facilities in healthcare services. But, shouldn’t the decision to take that risk be the subject of the patient’s free and informed will? The incorporation of telemedicine platforms is ideal for managing several challenges posed by COVID-19, such as the decrease in face-to-face health care assistance. Can the patient really decide how he prefers to be consulted, or are we imposing the consultation model? There have been profound changes in healthcare systems. However, one must remember that there are ethical principles of biomedicine, that should always prevail?

Key words COVID-19, Telemedicine, Remote consultation, Bioethics, Personal autonomy
Opinion paper

In the late 1970s, Beauchamp and Childress described, for the first time, the four ethical principles that should guide the provision of individualized care. In 2019, the eighth edition of this document was published and focused on these principles, which prima facie are respect for autonomy, beneficence, non-maleficence and justice.

The respect for autonomy allowed the transition from a paternalistic model to a people-centered medicine, which, correctly clarified by the doctor, will be able to ponder and decide freely and responsibly, on whether to provide specific care or not, be it a diagnostic or therapeutic procedure.

The SARS-COV-2 pandemic made us question daily practices hitherto established, such as a simple handshake when receiving the patient, both because of the risk of infection and the need for social distancing, or even fear of the various actors. Many of the measures have been taken in the interest of public health, pushing individual interests into the background. We are witnessing a structural reorganization of Primary Health Care (PHC) and reinvention of the concept of accessibility to health care. The decreased face-to-face care activity led to the incorporation or intensification of other communication tools such as the telephone, e-mail, and, to a lesser extent, videoconferencing. Given the circumstances exposed, where does the patient’s decision autonomy lie? Can the patients decide how they prefer to be consulted, or are we, health professionals, imposing the consultation model?

The compartmentalization and sectorization of health care into COVID-19 exclusive areas (ADC) and “non-COVID-19” diseases’ areas reflect an investment in community health. However, efforts have also been made to ensure alternatives that seek to maintain a longitudinal follow-up of patients, based on the stratification by the need for care and working on effective health literacy forms.

The pandemic opens up new opportunities for developing a doctor-patient relationship. The need to streamline contacts with citizens and enhance their morbid problems’ self-management capacity exposes the fulcrum of patient autonomy. In this context, the doctor is a facilitator of a process through which the way the necessary care is provided is established simply and clearly, integrating the patients’ role and the support of their family. Therefore, this Individualized and Integrated Care Plan assumes itself as a convergent process between the objectives of connecting care and the best way to achieve it by identifying the stakeholders and goals. This process allows enhancing the management of resources, refining, and leveraging each citizen’s autonomy in each contact. As long as their concerns are duly clarified and they are properly informed, users will be able to choose the most appropriate service to their circumstances, face-to-face or not, without prejudice to meeting the needs of other users. Thus, another fundamental normative principle of biomedical action, namely justice, will, therefore, be consolidated. In this way, our health system’s equity will be safeguarded, globalizing the right of access to the care provided, while also considering individual interests. Therefore, there is an urgent need to provide patients with instruments to fully enjoy their right to autonomy, emphasizing individual and collective protection measures. On the other hand, the protection of health professionals also matters, because it would not be possible to provide any type of care without them. By minimizing the infective outbreaks in face-to-face care, we will be maximizing the practical possibility of non-maleficence in accessing PHC, that is, the assurance of safety solutions necessary to reduce the risk of infection associated with the provision of care safeguards the principle of non-maleficence. It could be said that it is impossible to eliminate the risk of infection and that there is a residual risk in using the health services’ physical facilities. However, as in any other procedure, the decision to assume this risk must be the subject of patients’ free and informed will, respecting their shared decision.

The right to individual privacy is closely related to the exercise of autonomy. While it is one of the most traditional moral principles of health care, confidentiality is still one of the least respected. According to the National Council of Ethics for the Life Sciences, four different privacy dimensions must be considered: physical, mental, decisional, and informational. While the obligation of confidentiality covers all health professionals, we can easily understand, through the right to the last two dimensions mentioned (decisional and informational privacy), that patients can choose whom they want to entrust information about their health status to. Concerning users’ rights, besides the right to confidentiality about their data in health services, the right to choose must also be highlighted. Choice of services, providers, wanting to convey the notion about their health status, illness signs, and
symptoms, only to their family doctor. The evolution of the COVID-19 pandemic led to a need to establish a screening on patients’ arrival. Will the previously mentioned conditions be ensured in the triage systems set up at the care units’ entrance (Family Health Unit, Personalized Health Care Unit, ADC)? At a time when many clinical secretaries and nurses participate in the screening of cardinal disease symptoms, will this aspect of respect for the users’ autonomy be assured in the context of the COVID-19 pandemic? Moreover, if they do not want to share this data with the screening professionals, can they be denied access to healthcare? Should this be a specialized/medical/clinical screening? Therefore, we must urgently reflect on these points and seek solutions that preserve the patients’ autonomy and confidentiality, considering the existing constraints, since some principles remain the foundation of good practice even in a calamity.

According to Article 29 of Chapter IV of the Medical Code of Ethics, medical secrecy is an essential condition for the doctor-patient relationship. It is essential in all circumstances, as it results from an alienable right of all patients. Boxes have been placed in the waiting room, or even at the entrance of buildings in several health units throughout the country in the last few weeks, where patients could leave their results of complementary means of diagnosis and therapy. This solution found to avoid contact with health professionals and other users, minimizing infection risk, seemed interesting. However, once again, the question arises: will confidentiality be assured (even if the decision to leave the results there belongs to patients)?

The risk of breach of confidentiality is also present in clinical meetings over the telephone. Who will be at the other end of the line? What if they are not the patients think they are? In teleconsulting, videoconferencing must be valued, for interactive visualization by users and professionals alike. The installation of the necessary software to carry out these consultations is already a reality in many care units. Telemedicine is considered by many to be the future of medicine. Now, in times of confinement, where patients’ freedom and ability to act are conditioned, telemedicine can be a valuable help in overcoming this limitation and providing access to healthcare. Thus, this new trend is already the focus of chapter VII of the Medical Code of Ethics. Article 46 of this chapter defines that telemedicine must respect the doctor-patient relationship, maintaining mutual trust, doctors’ independent opinion, and patients’ autonomy and confidentiality. Article 47 specifies that the physician must ensure that the training and competence of non-medical collaborators, participating in the transmission or reception of data, are adequate to ensure the appropriate use of telemedicine and the safeguarding of medical secrecy.

Article 48 also specifies that doctors should only use telemedicine after ensuring that the system used and their users assure medical secrecy, namely, through the encryption of names and other identifying data. Are the platforms made available to family doctors for teleconsultation and patient follow-up (for example, Trace COVID-19, recently created for surveillance of patients affected by the pandemic), suitable for these conditions?

The people-centered approach to care includes the values, preferences, desires, and needs of patients. In this dialogue, it will be crucial to understand how patients feel, given the different communication options available, in the current circumstances, in order to promote their satisfaction and well-being. It is also essential to try to understand how health professionals will be adapting to this new reality. Profound changes in the habits and ways of working of these professionals have been observed in recent months marked by the constant demand and need for adaptation. Many of these changes are here to stay. However, some principles, such as respect for patients’ autonomy and confidentiality, non-maleficence, beneficence, and justice, which, given their ethical-legal character in medical practice, should always prevail.
Collaborations

All authors contributed substantially to the realization of the paper. AF Fontes, RR Barbosa and D Brito made contributions to the conception and design of the paper, and participated in the drafting and critical review of this manuscript, concerning intellectually relevant content.

Acknowledgments

We are grateful to Professor John Yaphe MD MCISc, Universidade do Minho, for the scientific support provided.

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Article submitted 21/07/2020
Approved 31/07/2020
Final version submitted 02/08/2020