International Journal of **Health Science**

COVID-19 AND THE NEW MODES OF INTERACTION IN PALLIATIVE CARE

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Abstract: In the current world scenario, we are witnessing efforts of societies to face the Covid-19 pandemic. The forced social distancing has several impacts on social life, which intensifies the use of information and communication technologies (ICT). The objective of the study was to monitor the social dynamics in a pandemic scenario in order to project new trends in the assistance processes in palliative care. Bibliographic, documentary, and telematized research is used. In the Brazilian context, the incorporation of technologies aimed at quality of life tends to definitively mediate the relationship between palliative care and its assisted public. It is concluded that the intensive use of information and communication technologies (ICT) has two facets: they add and facilitate communication between people, groups and services and, at the same time, are unevenly distributed among the population, making them inaccessible. It is affirmed as necessary to reduce asymmetries through the establishment of public policies.

Keywords: information and communication technologies, telemedicine, palliative care, Covid-19.

INTRODUCTION

A look in the rearview mirror of history to shows the Spanish flu, which, between 1918 and 1919, infected 500 million people worldwide and led to death of at least 50 million. Pandemic is not something new. Masks on faces and social isolation were part of the daily life of many national realities, forcing a new mode of social interaction. The Spanish flu is an example of a pandemic that has been understood as a health problem of social scope, by its effects; economic, for its consequences; and, above all, political, as its management required the direct action of the corresponding states (BARRY, 2020).

At the end of 2019, Covid-19 was detected in China as a viral infection. Without known treatment and with high power of dissemination and lethality, it spread rapidly between continents, becoming a pandemic. In the current world scenario, the different governments, with the support of the World Health Organization, have been making efforts to overcome the crisis, increasing clinical research (vaccines and medications) to contain it, as well as minimizing the impacts on social life due to the forced social distancing in its different modalities. With this, the use of information and communication technologies (ICTs) has intensified, as can be verified, for example, in the media, with actions to clarify and raise awareness of the populations about the disease; in culture, with the domestic *lives* of several musicians; in the scope of work, with the home office *modality;* in education, through distance learning; and in health, with telemedicine.

The pandemic follows its path and its stories are constructed in daily life, in which the use of ICTs is evidenced as a mediation in contemporary social relations. All indications are that new directions, reschedules or readjustments will be materialized. Hence the importance of monitoring social dynamics with a focus on the field of palliative care.

The research is based on Ordinance No. 1,329 of the Ministry of Science, Technology, Innovation and Communications (MCTIC), which defines the priorities for the period between 2020 and 2023, aligned with the Multiannual Plan of the Union (PPA) (BRASIL, 2020a). Ordinance No. 1,122 establishes research projects as priorities, within the scope of MCTIC, development and innovations focused on five areas of technology: strategic, enabling, production, sustainable development and quality of life (BRASIL, 2020b). It is noteworthy that the study converges to the field of technologies directed to quality of life in the context of

palliative care in the Brazilian context. Thus, it aims to monitor the social dynamics in a pandemic scenario in order to project new trends in the processes of reception in palliative care.

THE METHODOLOGY

The research is qualitative in terms of approach, exploratory regarding objectives and telematized in relation to procedures. First, it was based on the bibliographic study through the integrative review method. An active search was carried out on the portals of the Coordination for the Improvement of Higher Education Personnel (Capes), publons and wellcome trust. The following descriptors were used to research the articles: *information and communication technologies, new normal, telemedicine, palliative care and Covid-19.*

The telematized investigation concerns the information extracted mostly by the Internet and was used to complement the bibliographic and documentary studies. The analysis of multimedia content as qualitative research documents provides records of time actions and real events. Therefore, it is possible to confluence between written texts, images and statements for content apprehension, aiming at the identification of relevant themes (Figure 1). Through the *descriptors telemedicine and new normal,* 296 references were found made available by traditional media hosted on the worldwide computer network, from April 23 to May 7, 2020, with the adoption of the following inclusion criteria: quality of the origin of and consonance with the theme in focus. Thus, 13 articles were selected, published in different media outlets.

The health scenario in the country, based on network references, suggests that telemedicine is an emerging demand due to the need for access to the basic health network and emergency services in a pandemic context.

Figure 1. Clouds of words.

NEW NORMAL, TECHNOLOGIES AND PALLIATIVE CARE

"I'm happy for a whisker / for a whisker I'm happy / barely escape hunger / barely escape the shots / barely escape the men / barely escape the virus / near pass/ taking off even my varnish" (*Feliz por triz*, Gilberto Gil).

In Brazil the coronavirus generated a humanitarian crisis that may have unimaginable proportions without effective measures from prevention (FIOCRUZ, 2020). According to the World Health Organization (2018), the humanitarian crisis is seen as large events that affect the population causing terrible consequences, such as the massive loss of life, disruption of subsistence, the collapse of health system and forced displacement of people, serious political and economic impacts, in addition to social, psychological, and spiritual effects. The first case of Covid-19 recorded was in February 25, 2020. On May 13, 2020, the country officially recorded 188,974 confirmed cases and 13.149 Deaths (the Authorities Admit an existence from underreporting). In mortality statistics, the number of deaths had doubled in just five days. A recent study by Imperial College London looked at the rate of active transmission of the new coronavirus in 48 countries and found that Brazil is the country with the highest transmission ratio (RO of 2.81) (THE LANCET, 2020).

The word *utopia* means *nowhere*, that is, a place that does not exist in reality. It

may refer to the conception of a fair society, without social or economic imbalances, in which all people enjoy good living conditions. Despite the social inequalities presented in the Brazilian reality and in other states of this nation, it is possible to affirm that the field of palliative care is not seen as utopian, but as an existing reality developed for patients from any social class (FROSSARD; AGUIAR; FONSECA, 2020). With the realization that death is a natural event and after the certainty that the patient has no real chance of cure, intensive treatment is halted and it is made use of palliative care.

In this sense, palliative care, by definition, consists of a multidisciplinary approach that prevents and relieves suffering through early identification, correct evaluation and treatment of pain and other problems, which can be physical, psychological, social or spiritual. They are intended for all patients who have a health condition that threatens or limits their lives and plays a crucial role in the process of care and humanization in health actions (WHO, 2018). Many patients are not indicated for admission to an intensive care unit, as a result of the disease phase that affects them. Faced with an irreversible situation, this entry can lead to greater suffering and isolation. On the other hand, patients who choose noninvasive treatments can recover and be discharged. In addition, there are cases in which the palliative activists recommend a temporary strategy, to test the feasibility or not of hospitalization in an intensive care unit. Thus, the patient's responses are observed and, together with the family, it is decided how to continue the treatment (ANCP, 2020).

It is known that all historical facts, such as tragedies by pandemics, affect reality and end up introducing a new normal (KARNAL, 2020). In the contemporary pandemic context by the Sars-CoV-2 virus, death is presenting itself as a material and affectively helpless thing, causing fear in citizens due to the lack of care – which can effectively lead patients to death. A survey conducted with 2,732 people in brazil about the perception of death identified the dependence on care compared to death as the largest generator of fear among Brazilians (COLLUCCI; PINTO, 2018).

In general, patients, when facing a disease that threatens the continuity of life, have time to think about their lives and to share, in person or virtually, their fears, pains, plans and love. In a pandemic context, this time is compressed, generating intense suffering and pain. It is understood that relief from the suffering of seriously ill and dying people should be allowed and guaranteed during a humanitarian response. There's always something to offer, even at the end of life. Thus, pain and symptom control, support for complex decisions and management of clinical uncertainties are key attributes of palliative care and essential components of responses to epidemics and pandemics (POWELL *et al.*, 2017; ETKIND *et al.*, 2020).

Before the pandemic, especially in the last 15 years, social relations have been modified by technologies. Social media, in a dialectical continuum, bring together those who are already far away or drive away those who are close. At the moment, you get the feeling that the world has stopped and time is suspended. All citizens are more susceptible to death and mourning. With the near ly, the feeling of smallness in the face of nature is influenced by the predominance of the disease, which leads to new forms of interaction. It is in this interval between the recent past, the intensity of the present and the unknown of the future that people are being forced to incorporate a new reality, while baring the various facets of social inequality.

In this direction, the elements causing vulnerability gain greater intensity in the in a pandemic. Social pain, whose concept

concerns vulnerability and implies a vision of the whole by bringing together the different aspects of the life of the patient and his family, expresses the social question and contributes to the emergence and worsening of the situation of disease that affects countless families in a state of poverty and extreme poverty. The intense use of telemedicine can supply partly the needs of populations, especially in access to health services, considering the so-called digital inequality.

Based on ICTs, medical devices to provide remote assistance can rely on telemedicine, which was regulated provisionally at the height of proximity Covid-19 pandemic in the country. The Federal Council of Medicine (Conselho federal de medicina - CFM) sent a letter to the Minister of Health releasing virtual care for screening and monitoring of patients in isolation, opening the possibility for distance care to be done not only in cases of suspected disease, but for other clinical conditions in which the remote care was shown as an alternative to reduce the displacement of people and, consequently, the spread of the virus (CFM, 2020).

According to Wen (2008, p. 7), telemedicine is one:

> effective application of technological solutions for the purpose of education optimization, logistics planning, regulation of assistance and implementation of methods to provide multicentric research, based on strategies of sustainability management and the development of new models.

According to the author, telemedicine can be grouped into three sets of activities: interactive tele-education and collaborative learning network; telemedicine and telehealth, under the focus of logistics and strategy; and technology-mediated tele-education.

Interactive tele-education and collaborative learning network refer to the use of interactive technologies focused on expanding knowledge through the democratization of access to educational materials, using, for example, distance education or technologies to support face-to-face education. They are based on teleassistance and epidemiological surveillance, emphasizing assistance in projects such as the second specialized opinion and telescience, stimulating multicentric research and the integration of centers of excellence.

Telemedicine or telehealth, in turn, is associated with logistics processes and distribution of health services. The first term concerns the optimization of the process of recovery of a patient's health status from a humanized perspective. The second has an eminently preventive character directed to the valorization of health (e-care, e-health). Finally, interactive tele-education is characterized by mediation between education and technology. It facilitates learning through collaborative and interactive posture, aiming at professional qualification. It employs the model of semi-face-to-face education or totally at a distance.

The CFM recognizes the possibility of remote medical care during the fight against Covid-19, since it is important to allow the doctor to perform a screening and can recommend going or not to a hospital in order to reduce the burden in emergencies and hospitals due to the increase in the number of cases of the disease. Thus, the following remote care formats can be offered: teleorientation, for medical professionals to perform, the distance, guidance and referral of patients in isolation; telemonitoring, understood as an act performed with medical guidance and supervision for monitoring or validity at a distance of health parameters and/or disease; and teleconsultation, exclusively for the exchange of information and opinions among physicians, for diagnostic or therapeutic assistance (CFM, 2020).

That being said, as isolations, distances, quarantines, lockdowns are eliminated, it is

unknown whether there will be significant changes in conventional forms of interaction, in other words, the establishment of a new normal, which leads to questions such as: when the pandemic ends, what will be the relationship of people with the digital connection? Will the massive use of these resources be intense in post-pandemic routine or will the lack to be personally and/or in groups be such that it could change the meaning of relationships? Still, regardless of what may occur in a pandemic scenario, will the relationships *be resignified?*

It is believed that the incorporation of technologies directed to quality of life tends to definitively mediate the relations between palliative and its assisted public, despite what happens in a pandemic scenario (CLARK, 2020).

The establishment of the relationship between the palliative and/or team and their patients, including families, has its root in the teachings of Saunders, founder of contemporary palliative care, whose contents are timeless and the reason for being palliative practice: treating the patient with respect, understanding their individuality and subjectivity, observes as a whole, from its history, the intensity and characteristic of its pain and symptoms, to its nonverbal language and respecting, in a special way, its wills and limitations (FROSSARD; AGUIAR; FONSECA, 2020). In a post-pandemic scenario, the proximity of relationships must find the exact measure – neither too close nor too far - to assist patients, ensuring adequate reception.

Welcoming is an action of approximation. Thus, welcoming is *being with* and being *close to*, that is, an attitude of inclusion, of being in relation to something or someone. Considering and prioritizing the suffering experienced by family members and/or companions of patients with a view to their relief through reception technique requires encompassing the term welcoming in the spatial dimensions (formal reception with comfortable, administrative environment (referral to specialized services) and telematized (remote assistance) (FROSSARD; AGUIAR; RODRIGUES, 2020).

A fact that the health care in the pandemic, which imposes social distancing in its different versions, became the protagonist by reducing the distance between health services and patients' homes in obtaining care, benefiting even the most vulnerable populations that live in remote areas. Furthermore, video visits can keep patients and providers safe, allowing hospitals to have more protective equipment and respirators when people infected with Covid-19 need care (SARSAK, 2020; CONTRERAS et al., 2020).

However, access to an adequate connection and technological tools can be a barrier for people in vulnerable situations. It is not enough to connect those without connection; you also need to reduce asymmetries without creating scanning stratification. Poor patients in Brazil should have access to distance health care in a similar way to patients with adequate access conditions.

Technology can aggravate vectors of inequality and contribute to further increase the difficulties of access to health services and therapeutic resources, although 96% of Brazilian households have TV sets, 93% have mobile phones *(smartphones)* and 79% access to the Internet (IBGE, 2018). The largest share of those who never access the network is in the rural area, and 41% of this population (10.3 million individuals) has never used the Internet. Of the five million rural establishments in the country, 72% do not have access to the network (IBGE, 2018).

Another highlight is access to technological devices that improve people's quality of life: *wearable* technology, as, electronic

equipment that contains processors and which can be used as clothing or accessories. It is a technology capable of connecting to the *smartphone* to monitor the health of the wearer, among other functions. Most of these devices rely on *smartphones* for connection or data processing. In addition to the watches, there are smart accessories such as bracelets, rings, clothing, helmets and glasses (GUPTA; RODRIGUES; MATHEW, 2018).

The National Telecommunications Agency (Anatel) has as its north the so-called Structural Plan of Telecommunications Networks (Pert). The document, which provides a diagnosis of broadband infrastructure and was updated in April 2020, draws attention to the deficiencies in the system in different regions of the country – almost 53% of municipalities without fiber optics are in the North and Northeast regions. These data show the need to prioritize investments in the most deprived locations. According to Anatel (2020), the fixed broadband market has 14,716 companies, but five groups account for almost 70% of subscribers. Despite not using the system, Brazil has sufficient satellite capacity to adopt public policies to encourage demand in remote areas.

Law No. 9,998, published in *the Official Gazette* of August 17, 2000, section 1, p. 1 (BRASIL, 2000), establishes the Telecommunications Services Universalization Fund (Fust), with the purpose of providing resources to cover the portion of costs exclusively attributable to the fulfillment of the obligations of universalization of telecommunications services that cannot be recovered through the efficient operation of the service, in accordance with the provisions of item II of Article 81 of Law No. 9,472 of July 16, 1997. Article V, referring to the application of resources, is highlighted in paragraphs IV and V. Says the first: implementation of individual accesses to provide telephone services in favored conditions, to educational establishments, libraries and health institutions. The second has: implementation of access to the use of digital networks of information for public access, including the internet, under favored conditions, to health institutions.

Brazil has 5,570 municipalities, and more than 1,500 do not have a fiber optic network, which would allow greater stability at times like the current one, with records of radical change in internet consumption. Therefore, the Internet Steering Committee should propose projects for digital inclusion in health, particularly in the field of palliative care on cancer, with the use of funds such as Fust. There is a consensus between Anatel, civil organizations and companies in the field: the use of sectoral funds, such as Fust, to support the universalization of broadband, since this fund was created for the universalization of broadband services telecommunications, with contribution from Brazilians, collects about R$ 1 billion per year and its resources are not applied to improvements in the sector (ANATEL, 2020).

CONCLUSION

The lines previously woven indicate that palliative care professionals are facing the greatest challenge in the history of their field of activity, considering the pandemic scenario, digital inequality in the country and the perspective of regulation of telemedicine in the Unified Health System after the pandemic. The intensive use of IT Has two facets: it aggregates and facilitates communication between people, groups and services and, at the same time, is inaccessible because these technologies are distributed unevenly among the population. The incorporation of technologies directed to quality of life tends to definitively mediate the relations between palliative and its assisted public.

This incorporation needs to be democratized through appropriate public policies through the use of Fust resources, enabling the creation and development of a National Palliative Care Plan.

AUTHORS' CONTRIBUTION

The authors participated in all phases of the preparation of the article.

CONFLICT OF INTEREST

None to declare

FUNDING SOURCE

INCA

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