

Review

PALLIATIVE CARE AND COVID-19 PANDEMIC BETWEEN HOSPITAL-CENTRIC BASED APPROACH AND DECENTRALISATION OF HEALTH SERVICES: A VALUABLE OPPORTUNITY TO TURN THE CORNER?

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ABSTRACT

Italy was the first Western EU country to have dealt with the severe effects of the widespread Covid-19 virus since the pandemic began. Many healthcare services were negatively affected, and the delivery of palliative care has been no exception. The Italian healthcare system has suffered more than others due to public spending cuts. The hospital-based approach has not allowed all patients to receive appropriate care. This situation was brought about not only by the pandemic emergency but mainly by pre-existing shortages due to the cut in financial resources before the Covid-19 pandemic. For countries similar to Italy, it is necessary to develop territorialised health care, decongestion hospitals, and strengthen the Third Sector, particularly the voluntary sector.

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1. Introduction

The epidemic of COVID-19 has globally struck the societies and healthcare organisations of our time hard, negatively affecting several healthcare services. The delivery of palliative care (PC) for patients has been no exception.

Many reasons contributed to making the side effects of the COVID-19 pandemic extremely severe globally. The absence of previous policies and investments in public health consistently contributed to the current situation.

At the international level, in September 2019, because a global pandemic was possible, the Global Preparedness Monitoring Board, formed by experts from the World Bank and World Health Organization (WHO), already called on the political world to strengthen health services; improving five areas in particular: leadership, building multisectoral country systems, research and development, financing, and robust international coordination (1).

European countries did not heed the call, and Sars-Cov2 found them unprepared (2).

The leading cause was the European economic-financial crisis in 2008-2013, which led to the rationalisation and reorganisation of resources in the health field and powerfully affected the delivery of essential health services (3, 4). Nurses and doctors were most affected by such measures (staff turnover rate, reducing overtime and changes in training), and various hospitals and territorial services were suppressed.

The consequence was that, with the pandemic, beds in emergency rooms and intensive care units were immediately occupied, and even patients who needed hospitalisation had to be left at home. Territorial medicine did not grow, so the hospital remained the only point of reference and became a vehicle for infection because of contagion between patients and healthcare providers (5).

Humanitarianism and equity - the main principles governing modern healthcare systems - require that all patients have the right to receive care and should never be abandoned for any reason, even if they are dying. In this vein, the closure of hospitals broke both these principles since it could no longer ensure adequate care for all citizens. The long length of time required to obtain a service has shifted demand to the private sector, creating a situation of serious inequity, especially for less affluent citizens. Technology has directed medicine toward super-specialisation that has privileged the hospital, moved away from epidemiology, and neglected the territory.

This situation strongly impacted the relationship between the hospital and the environment, affecting the dialogue between general practitioners in occupational medicine, hygiene, prevention clinics and hospital physicians, worsening difficulties and delays preventing effective management of the pandemic.

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2. Before the COVID-19 pandemic: a comparison with Europe

The delivery of beds has progressively decreased over the years since before the pandemic. It has been estimated that the bed ratio in Europe has fallen from 5.74 beds per 1,000 inhabitants to 5.319 beds. Italy ranks last among European countries, given that the total number of ordinary beds per 1,000 inhabitants is much lower than the European average (3.16 vs 5.32). Italy is only ahead of Spain (2.9), Turkey (2.8), Liechtenstein (1.4), Iceland (2.7), Sweden (2.0), Netherlands (3.0), Cyprus (3.11), Denmark (2.5) and Ireland (2.8). At the same time, Germany had 7.9 beds per 1,000 inhabitants, Austria 7.2, Bulgaria (7.7), Hungary (6.9), and Romania (7.0), thus more than twice as many as Italy (6).

From 2010 to 2019, the Italian National Healthcare Service suffered financial cuts of more than \notin 37 billion and with progressive privatisation of healthcare services. Public health expenditure as a proportion of gross domestic product was $6 \cdot 6\%$ for the years 2018–20 and is forecast to fall to $6 \cdot 4\%$ in 2022 (7, 8).

With the pandemic, beds in the emergency room and intensive care units were immediately occupied since the hospital remained the only point of reference. To face this situation, many countries made strong economic efforts and reallocated the resources for different healthcare services, increasing the number of beds in the intensive room. It was reported that in 2018 there were 8.42 per 100,000 inhabitants, while after the health emergency, they increased to 14 (9). Contrary to what one would have expected, these choices had not improved the condition of many patients; indeed, the conversion of entire clinical and surgical wards into Covid-19 wards, taking them away from patients with other diseases, was one of the most dramatic consequences of the pandemic (10). The conversion of ordinary hospital wards into Covid communities had reduced access to adequate care for patients who, in other circumstances, would have had to be hospitalised because the closure of many medical and surgical wards had increased waiting lists. Many patients could not benefit from the treatment, despite the incredible self-sacrifice shown by the entire staff (doctors and nurses) to the point of personal sacrifice of the many victims who had fallen while on duty (11,12). Because of the saturation of intensive care beds, some doctors, especially in northern Italy, had dramatically admitted that they had to choose which patients to treat and which not, based on age combined with previous severe illnesses.

Although the total number of doctors per inhabitant in Italy is still higher than the EU average (4.0 compared to 3.6 per 1,000 inhabitants in 2017), the number of hospital doctors and family doctors has fallen, and the government has recalled retired doctors into service. Italy also has fewer nurses than all Western European countries (except Spain), and their number is significantly lower than the EU average (5.8 nurses per 1,000 inhabitants compared to 8.5 in the EU) (13). The above data prompted the National Bioethics Committee to recommend a "comprehensive rethinking of our welfare system and its strengthening after years of cuts" (14).

3. Palliative care during the pandemic

Natural disasters or rising tide events such as epidemics and pandemics can affect the availability and quality of specific health services. PC is one of the most affected services during times of resource scarcity. The urge to save lives may often cause the suffering of many to be neglected and inadequately alleviated. However, in a pandemic, it is ethically essential not only "to maximise the number of lives saved, but also to minimise the suffering of those who may not survive" (15).

The fundamental purpose is not to heal the patient, but instead only to make the pain more bearable and to achieve the best possible quantity of life, creating an environment around the patient that allows them to live whatever time may be left with dignity, possibly in the house where they lived their lives (16).

PC have been impacted worldwide, both from a clinical and organisational standpoint, since the decrease in hospital receptivity has increased the care burden (17).

The lingering health emergency has heavily, albeit indirectly, affected the field of PC, determining, on the one hand, the increase in care costs determined by the decreased receptivity capacities of hospitals and, on the other hand, the emergence of new patients' needs. Until two years ago, the policies of access to PC had to meet the increasing average life expectancy of the population and the increase in the incidence of chronicdegenerative diseases. Nowadays, the current health emergency has forced societies to rethink the provision of services also based on priorities determined by the peculiarities of specific categories of patients. After all, the current pandemic has broadened the pool of patients in need of PC: in addition to patients already undergoing PC, some were highly dependent on intensive treatments (such as ventilation and dialysis) even before the pandemic, and those who were suffering from chronic diseases and whose health deteriorated due to restrictions and isolation measures (reduction of a hospital or outpatient access for visits and check-ups), and previously healthy patients who came to need life support after contracting COVID-19 for symptom control or, again, those who cannot access such treatments due to lack of resources or their refusal (18). The primary critical issues related to the Covid-19 pandemic have occurred in longterm care, that is, in-home services and nursing homes, RSAs in Italian, as shown in the OECD Report (Long-Term Care) (19). A research report by the International Long-Term Care Policy Network highlighted that this situation did not concern only Italy but the whole world, with particular reference to Belgium, Ireland, Spain, the United Kingdom and the United States. In Italy, as the pandemic erupted, PC became a separate medical speciality, launched in the academic year 2021/2022 (20,21). The second 2019 Report to Parliament on the state of implementation of the law on PC, relating to the years 2015-2017, has pointed out that the number of hospices and beds for residential care and the number of patients assisted at home has constantly been increasing. As reflected by the study by D. Clark, the highest level of PC offered in the world is available only to 14% of the world population. This availability is concentrated in European countries; Italy has provided the best care in the last ten years (22). The provision of PC has many obstacles and difficulties, while it should represent "an absolute priority for health policies" (23).

PC delivered at home has been the sector in which the most severe inefficiencies have been recorded, despite a growing number of patients in the terminal phase assisted at home (33.138, to reach 40.849 units in 2017), both in terms of "basic" home care and "specialist" care, i.e. relying on the intervention of multidisciplinary teams under the clinical responsibility of a PC specialist. It was reported that in 2015 to 2017, the number of hospices in the country reached a total of 240 facilities (231 in 2014) while the number of beds was 2.777 (226 more beds than in 2014). On average, in 2017, the national level of satisfaction with PC services was 10.02%.

In contrast, at the regional level, significant differences have been reported in the quality and quantity of PC from region to region (24). For instance, the Italian region of Piedmont can boast the highest percentage, with 14.55% coverage, whereas Lombardy ranks very low with 1.88% (25). It should be kept in mind that the report refers to a normal situation, while the pandemic has considerably increased the criticalities.

4. The importance of social care integration in palliative care and the role of the Third Sector and Volunteer Work

Hospice and palliative home care services are the two models of providing care focused on the needs of patients in the last stages of life.

To optimise the provision of PC, social and socio-healthcare integration is crucial as it promotes social and socio-healthcare interventions aimed at helping individuals and families in need (26). Social and health integration is meant to combine "cure" with "care", thus combining health-related activities with social skills and interventions, since "care" and "taking care" is not aimed at curing the disease towards recovery, but rather at reducing the patient's physical and mental suffering. Therefore, social and healthcare integration expresses an all-encompassing concept of health extended to the social dimension that can already be seen in the definition provided by the WHO (27,28).

In the broader social and healthcare context, including the provision of PC, the Third Sector plays a valuable role. Apart from pain therapy, which needs to rely on medical and nursing expertise, the interventions that fall within the realm of PC are offered by a team made up of social-health workers, physiotherapists, social workers, psychologists, spiritual assistants to assist in the elaboration of loss and mourning, with a broader view towards a "global care" approach for patients and their families, but also by volunteers without specific professional skills and other non-specialist figures who have daily interaction with hospitalised patients, such as janitors (29).

In palliative medicine, the most involved Third Sector entities are voluntary associations. The first Italian PC services dated back to the 1980s and were established mainly thanks to the work of voluntary/non-profit associations. These associations, through the support of nurses and doctors, launched specific facilities with strong local rooting and aimed not so much at practising targeted therapies, but rather at controlling and alleviating pain and suffering. Volunteers in the team are essential because of their connecting role characterised by attention, listening, and sharing between the patient, their family and the healthcare staff. Furthermore, their relationship with the patient is independent of the disease, so in the eyes of the patient, the volunteer comes to represent an element of normality, which significantly helps patients continue to feel part of society.

Volunteer work can avoid hospitalisation whenever possible, allowing the patient to lead a life as "normal" as possible in their own family and emotional setting (30).

If broadly implemented systemically, creating multidisciplinary teams could guarantee tailored and targeted management according to the need for assistance. This would make it possible to improve access to care, limit the clogging of the health system and reduce the social and economic burden on patient care.

At the height of the COVID-19 emergency, the pandemic compelled hospitals and PC facilities to put strict protection and isolation measures in place by banning visits (31). The restrictions have limited the involvement of volunteers in patient care programs, both in hospitals and at home, as well as in terms of providing psychological and relational support for patients and caregivers (32,33). The pandemic has forced them to take shorter visits, wear masks, and keep a distance. Help towards the psychological support of seriously ill patients came from digital technologies, which made it possible to make phone calls or video calls (34). Unfortunately, not all health facilities had internet connections available to patients. Additionally, some patients could not use video calling due to medical conditions. This prompted health, social and spiritual assistants to organise and foster communication between patients and family members, who, in turn, were often in quarantine.

Despite the ongoing difficulties and limitations in these two years of pandemic emergency, volunteers represented an essential link between healthcare assistance and the territory. They have worked tirelessly, moving their activities onto territories to guarantee the best possible levels of home care for seriously ill people and to help patients with COVID- 19. The Italian State-Regions Conference which convened on 9th July 2020 acknowledged the value and importance of volunteering in PC. It recommended that organisations that manage voluntary activities in PC standardise their selection, training, and organisation processes (35).

5. The role of telemedicine in the pandemic

The pandemic has forced the entire health organisation to reevaluate traditional ways of providing care and treatment in favour of policies aimed at harnessing available technologies more effectively (36,37).

Some specific branches of telemedicine, such as telemental health (TMH), also known as telepsychiatry, telepsychology, or teletherapy, are particularly well-suited for providing remote assistance thanks to their reliance on audiovisual communication and less on physical examination. Furthermore, the development and widespread use of telemedicine tools to modulate access to health services, for example, can help reduce the contagion risk among healthcare personnel and patients (38).

However, the pandemic has shown that the health system still needs to be more forward in its use of information technology systems (IT system), which still need to be fully harnessed to guarantee effective communication, either within or between the territories and hospitals.

COVID-19 could be a valuable opportunity to expedite the development of forms of remote assistance aimed at the elderly, geared to assist them as the emergency lingers, and could also allow for devising remote assistance models capable of improving access to cure. New technologies capable of offering quality care even remotely are essential in that regard, with the dual purpose of countering the spread of COVID-19 and guaranteeing continuity in taking care of vulnerable subjects, as a constitutional right to be upheld at all times. Telemedicine can make it possible to monitor many diseases from home and bring home a set of skills that are now centralised and only accessible in hospitals (39). The teleconsultation of local and hospital specialists can be integrated with other professionals as well as health and professional social profiles tasked not only with continuing to monitor COVID-19 patients in this fourth wave, but shortly with following the patients at home, particularly those more in need (40, 41).

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6. Discussion and conclusions

The SARS-Cov-2 pandemic has highlighted how even the Italian Health System is now inadequate to face the public health challenges of the third millennium and has shown how the strengthening of primary care, territorial services, and general medicine is of utmost importance to act as a filter and prevent hospital overload.

A reconfiguration of the healthcare administration by integrating the "hospital-centric" model, which is prevalent today, with a system of territorial services that invests more in socio-health integration, should be more adequate and effective in managing how any new healthcare emergencies are performed. Because in nursing homes for the elderly, for example, where many illnesses and many deaths among the patients have occurred, the use of small territorial facilities may prevent widespread infection and diseases. In these facilities, the functions currently carried out in hospitals should be performed, for example, screening, follow-up and rehabilitation of patients, home care and PC, etc. These activities should cooperate with general practitioners and non-profit organisations in the sector. Even advanced and structured telemedicine programmes should be introduced throughout the country. These programmes may be developed both in the hospital setting and at the level of community medicine but should provide for periodic in-patient observation by general practitioners and specialists. The European Union has financially supported some countries, including Italy, to counter the economic crisis induced by the pandemic. Italy's legislative and regulatory tool to transform these loans into development has taken the name of the "National Recovery and Resilience Plan". According to such a blueprint, €20 billion have been allocated to healthcare and can help to build a social and health system closer to the public health needs of our communities. The Plan will provide for 1,288 community homes and 381 community hospitals by mid-2026 - either renovating existing ones or building new facilities - where general practitioners, paediatricians, specialists, community nurses, other health professionals and social workers will work. The plan also provides for the development and launch of new remote assistance and telemedicine projects to serve the needs of people suffering from chronic diseases, with the activation of 602 Operations Centers.

The prevention, care and assistance to patients must be uniformly distributed throughout the territory and rely not only on doctors, nurses and other health professionals but also on Third Sector organisations to improve assistance by taking into account the current actual needs of patients; also those of "extra-clinical" nature (psychological, social, family, stemming from economic or cultural disadvantage, logistical), which can strongly influence clinical management. Italy has recently undertaken a policy in this direction: the decree d.l. 19 May 2020, n. 34, so-called Decree "Relaunch", for example, provides for the establishment of the SACU special assistance continuity units, which are also tasked with strengthening territorial home care and streamlining and optimising the management of socio-health integration by supporting non-selfsufficient people, like the elderly in situations of fragility and at risk of hospitalisation, with the involvement of local institutions, local volunteers and non-profit organisations of the Third Sector "(Article 1, paragraph 4 bis, Legislative Decree 34/2020, introduced by Law 77 / 2020)(21). With the 2022 budget law, the Italian government allocated 67 million in 2022, followed by 101 million a year until 2026, to create at least one for every 100,000 inhabitants and 600 throughout Italy.

The current lingering emergency circumstances have laid bare and highlighted the weaknesses of the Italian National Health Service, which has proven unable to keep its promises of equality and universal access to care since it has been compelled to choose which patients will be treated. Instead, even in such an emergency scenario, access to PC and pain therapy must always be guaranteed at all levels of hospitalisation and in all contexts of care. Therefore, since physical and psychological suffering conditions the possibility of making free and informed decisions (42), palliation is useful for allowing the patient to express his will in advance before losing his ability to understand (43, 44). Over the past months, as the COVID-19 pandemic unfolded, the balance has been upset, and countless human tragedies have occurred. The circumstances have also highlighted the need and urgency to overcome traditional care models and offer new ones. To this end, the loans granted by the European Union provide great opportunities to enhance personnel resources, training, and technological resources to foster the use of digital medicine as well. Yet, the contribution that individuals and associations can make now is also essential. This is all the more critical PC since pain perception is substantially influenced by the quality of the assistance received. Moreover, this different approach would prove very useful even after the pandemic has ended.

Hopefully, the pandemic will serve as an opportunity to increase the territorial scope and dimension of healthcare as well as the social side of medicine through the harmonisation of professional skills of healthcare operators and by enhancing the role of the Third Sector solidly grounded in compassion, selflessness and solidarity.

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