Italy and the COVID-19 long-term care situation

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1. Key findings

- The Italian government acted late on the Covid-19 outbreak management in nursing homes. The first operational guidelines were released after the country’s total lockdown on March 9th, only requiring care homes to suspend visitations. An update of the operational guidelines dedicated to nursing homes was released by the Ministry of Health only on March 25th. The first COVID-19 case was detected in Italy on January 30.

- Regions are responsible for the operational regulation of the LTC sector: after the outbreak, they enacted late and different responses without a clear guidance from the national legislator.

- Italy faced a massive shortage of Personal Protection Equipment (PPE): nursing homes were not prioritized for receiving new procurements. Workers and care users have not been sufficiently protected from the spread of COVID-19.

- The National Institute of Health (Istituto Superiore di Sanità) launched a survey to investigate the incredibly high numbers of deaths registered in residential centres for older people, after the national press raised the attention on the potentially large underestimation of COVID-19-related deaths in care homes. Preliminary results confirm that the actual number of COVID-19 related deaths might be much higher than the one reported in official documents.

- As of today, current procedures do not foresee testing older people in care homes, neither those who died after presenting symptoms.

- Coordination with health care actors (mainly acute care but also general practitioners) has been limited and poorly implemented, mainly relying on professional linkages of individual professionals and without a regional or national framework.

- The response to the COVID-19 emergency has been left to the initiative of each Nursing Home alone, relying on their capacity and willingness to cope with extraordinary conditions while having poor support from institutions.

2. Impact of the COVID19 outbreak so far and population level measures

2.1. Number of positive cases in the population and deaths

As of April, 29th the total number of positive cases in Italy is 104,657 and the number of deaths reached 27,682. A total of 71,252 people have currently recovered from the virus, and 1,795 are still hospitalized in intensive care¹. On the same day, 63,827 new tests have been

¹ Dipartimento della Protezione Civile: http://opendatadpc.maps.arcgis.com/apps/opsdashboard/index.html#/b0c68bce2cce478eaac82fe38d4138b1
performed: within this sample the ratio between newly positive cases over the total daily performed tests was 3.3% (1 case every 31 tests)\(^2\).

The most affected region is, by far, Lombardy: since the start of the epidemic 75,134 cases (deaths and recovered included) have been registered, followed by the regions of Emilia-Romagna and Piedmont, with 25,177 and 25,861 confirmed positive cases respectively. Among all deaths (with positive tests), the National Institute of Health (Istituto Superiore di Sanità, ISS hereafter) released some additional details updated until the 23\(^{rd}\) of April: 22,067 of the officially reported COVID-19 related deceased were over 60 years old (95% of the total)\(^3\). The average age of deceased is 79 years old although the median age is 81 years old (15 points higher compared to the average age of infected people that is equal to 62 years old). Deceased people are mostly men (63.2% of the total) and in 61% of cases were presenting three or more pre-existing chronic pathologies\(^4\). Lethality rate varies according to a specific age group and it appears to be particularly higher in older age segments: it is in fact equal to 10% for 60-69 years old; 24.9% for 70-79 years old, 30.8% for 80-89 years old and ultimately equal to 26.1% for the over90\(^5\).

### 2.2. Population-level measures to contain spread of COVID-19

After the first two COVID-related cases in Italy were registered and confirmed in Rome on the 21\(^{st}\) of January, the Italian government suspended flights to China and declared a six-months state of emergency throughout the national territory with immediate effect on 31\(^{st}\) of January.\(^6\) At the same time, the Italian Council of Ministers appointed the head of the Civil Protection as Special Commissioner for the COVID-19 emergency. In the following days and weeks, additional regulations\(^7\) opened the possibility for the central government as well as other administrative levels (regions, cities etc.), in case of absolute need and urgency, to adopt stricter containment measures in order to manage the emergency. At the end of February, the first cases and deaths were registered in small towns in Northern Italy (Codogno, Vo’) that were placed under stricter quarantine (schools closed, public events cancelled, commercial activities closed etc.); on February 22\(^{rd}\) the carnival celebrations and some soccer matches were cancelled.

On 1\(^{st}\) of March, a Ministerial Decree\(^8\) established that the Italian national territory was divided in three areas: (i) Red zones (composed of municipalities in Northern Italy that registered a certain level of COVID cases and where the population was in lockdown); (ii) Yellow zones (composed of regions of Lombardy, Veneto and Emilia-Romagna, where certain activities were closed – schools, theatres – but people were still able to have limited

\(^{2}\) [https://lab.gedidigital.it/gedi-visual/2020/coronavirus-i-contagi-in-italia/?ref=RHPB-BS-I254751933-C4-P1-S1.4-F4\&refresh_ce](https://lab.gedidigital.it/gedi-visual/2020/coronavirus-i-contagi-in-italia/?ref=RHPB-BS-I254751933-C4-P1-S1.4-F4\&refresh_ce)


\(^{4}\) Last official data available on Epicentro ISS dashboard. Available at: [https://www.epicentro.iss.it/coronavirus/sars-cov-2-decessi-italia](https://www.epicentro.iss.it/coronavirus/sars-cov-2-decessi-italia)

\(^{5}\) See footnote 3


\(^{8}\) [https://www.gazzettaufficiale.it/eli/id/2020/03/01/20A01381/sg](https://www.gazzettaufficiale.it/eli/id/2020/03/01/20A01381/sg)

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movements); (iii) the rest of the nation where both safety and prevention measures were advertised but no further limitations were put in practice. On March 8th, the government approved a decree to lockdown the entire region of Lombardy (and 14 other neighbouring provinces) establishing “the impossibility to move into and out of these areas” – with only a few exceptions. Just a day later, on the evening of 9th of March, the government extended the Lombardy quarantine measures to the entire country. This national lockdown was extended several times until the 3rd May.

While the containment measures and lockdown were enforced by the central government, the same cannot be said for provisions detailing how the health and LTC sectors should respond and behave to the COVID-19 crisis. In Italy, in fact, the health sector management and legislation fall within the competence of the Regional level; hence, especially during March and April all Italian Regions have adopted, at different times, plans, norms and decrees for managing the crisis.

### 2.3. Numbers of residents in care homes infected and deceased

Major Italian newspapers published figures and accounts of incredibly high numbers of deaths in elderly residential centres, reporting total absence of guidelines, medical procedures and, more importantly, testing for COVID-19. Some nursing homes registered mortality peaks among their patients, doubling the rate of the same months in previous years. The ISS has started a dedicated survey to collect evidence on this, which was sent to 2,399 nursing homes out of the 4,629 operating on the national territory. As of April 14th, 577 nursing homes out of the 4,629 operating on the national territory responded and reported an overall mortality of 8.4% in the month of March, with a 13.7% peak in Lombardy Region (the region most badly hit by the virus). Among the 3,859 total deaths, only 133 were officially classified as COVID-19 after appropriate testing, though 1,310 more had flu and COVID-19-related symptoms. The ISS affirms that these two numbers should be analysed jointly, accounting for 37.4% of the deaths of the period as COVID-19 related. These first figures are close to those reported by nursing homes managing directors, which shocked the public opinion.

With regards care staff, there is no official data on the total number of positive workers in nursing homes, though local and national media report that the lack of testing and of PPE supply had major impacts on their exposure to COVID-19. Workers were dangerously exposed to the Coronavirus and many contracted COVID-19. These were forced to home quarantine, while others refused to work to protect themselves and their families. The above-mentioned ISS survey confirms such worries, reporting that 17.3% of the care workers who

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9 [https://www.gazzettaufficiale.it/eli/id/2020/03/08/20A01522/sg](https://www.gazzettaufficiale.it/eli/id/2020/03/08/20A01522/sg)

10 See for example:
- [https://www.ansa.it/trentino/notizie/2020/04/03/coronavirus-altre-17-morti-in-trentino-204-nuovi-contagi_bdb98b1e0-e10b-4830-92a9-b7ef4840aa25.html](https://www.ansa.it/trentino/notizie/2020/04/03/coronavirus-altre-17-morti-in-trentino-204-nuovi-contagi_bdb98b1e0-e10b-4830-92a9-b7ef4840aa25.html)
- [https://it.reuters.com/article/idITKBN2161IV](https://it.reuters.com/article/idITKBN2161IV)


12 See footnote Error! Bookmark not defined.

13 For example in Brescia (in Lombardy Region) 25% of care workers both in nursing homes for dependent elderly and for disabled people were tested positive. [https://www.giornaledibrescia.it/brescia-e-hinterland/nelle-rsa-bresciane-545-positivi-in-una-settimana-di-tamponi-1.3473227](https://www.giornaledibrescia.it/brescia-e-hinterland/nelle-rsa-bresciane-545-positivi-in-una-settimana-di-tamponi-1.3473227)
responded had tested positive, though assessing that due to the high variability in regional policies on testing, this number could be much higher. Considering that we do not have complete data on the number of workers tested or monitored, it might be reasonable to think that the number of workers infected is much higher.

The combination of no social distancing measures and the lack of PPE for workers dramatically exposed everyone in nursing homes to the risk of contracting COVID-19.

3. Brief background to the long-term care system (only as relevant for context)

Even before the crisis, the Italian social and healthcare sector for LTC has been characterized by major weaknesses, due to a strong level of complexity and fragmentation both in terms of competencies and resources among institutional and non-institutional actors, and unheard struggles to enter the policy-makers agenda. This phenomena origin from the fact that the LTC sector was not conceived and developed as a comprehensive model, but rather from multiple legislative interventions that aimed intermittently at integrating what was already existing (Rotolo, 2014). One single Ministry responsible for LTC is yet to be created: the current LTC governance structure is, at the central level, somewhere in the middle between the Ministry for Labour and Social Policy and the Ministry of Health. Moreover, Regions implement the dual ministerial policies by defining regional policies and network of services; ultimately, local health authorities and municipalities manage services and interventions at the local and individual level. This fragmented situation is further compromised by the insufficient level of coordination that exists among all the actors involved in LTC supply chain: the absence of national awareness and lack of strategic vision inevitably inhibits dialogue, cooperation and joint actions even in non-crisis times.

As concerns the supply of public in-kind services in the country, data show that the total number of slots/beds available in public care homes and day care services in 2016 – latest data available – counted 285,686 units that hosted 297,158 older people. Looking specifically at the care homes segment, it is fundamental to notice how the distribution of nursing homes is diversified and heterogeneous throughout the national territory: in Trentino Alto-Adige Region, there are 25 beds per 100 not-self-sufficient over75 (who represent the share of the population that could most likely access nursing homes); in Basilicata there are 0.65, signalling the almost total absence of services in some areas of the country. As concerns the third pillar of the LTC sector, namely home care, in 2016 779,226 older people benefited from public home care and received 12,467,620 hours of care, meaning almost 16 hours per year per older person. Merging data on the potential target of services (i.e. 2,9 million not self-sufficient elderly) and on the number of users of public services one can find the estimate of the public services LTC coverage rate, which, in 2016, was equal to 37%. Again, in other words, this means that the LTC system is able to respond to one person in need out-of-three.

14 In Italy, publicly funded care home sector includes both nursing homes, which provide high intensity healthcare services, and residential homes, which provide housing and social care.
Moreover, considering that most part of the coverage need comes from home care providing on average 16 hours of care per years, it is fair to say that the public welfare system is far from covering and answering the needs of older people who need care and their families.

On top of this, the need coverage rate through public services is not expected to grow anytime soon: the older population in Italy is expected to grow sharply in the near future (+ 5 million by 2037, Istat) and budget constraints are continuously pushing for resources reduction in this sector. The two-thirds of older people who do not make it to the public welfare system seek alternatives to answer their need, there are mainly five possible different answers, which refer to families’ ability to self-organize (Notarnicola and Perobelli, 2018):

1. Families self-organize to answer their relatives’ LTC needs, assuming both the informal caregiver role and that of care and case manager;
2. Families access professional private services to filling the gap left by public services;
3. Families seek responses in other public services through the NHS channel, hoping to find a quick, universal and free response to their needs, especially in case of urgency or of financial constraint; although this answer can only work for a limited span of time (few weeks maximum) and cannot represent a solution;
4. Families turn to the regular or irregular market of care workers/family assistants, gleaning their incomes or undermining their savings, trying to set up a 24/7 cycle of care (the presence of care workers in Italy is estimated to be equal to 1,005,303 (Berloto and Perobelli, 2019);
5. Elderly and their families remain alone in facing their need, without activating any alternative response to the public one (for economic reasons, lack of competences etc.).

4. Long-Term Care policy and practice measures

4.1 Whole sector measures

4.1.1 National and regional policies for LTC

On March 17th the Ministry of Heath published the operational guidelines for a “rational” (quote) use of PPE in healthcare and LTC settings15. The guidelines list the basic principle to ensure personal protection and recommends that regional authorities guarantee adequate provision of PPE and engage in training activities for care workers.

On March 25th the Ministry of Health published the first guidelines for COVID-19 management in nursing homes, requiring providers to ensure the training of care workers and suggesting extensive testing.

Regions enacted a number of fragmented and uncoordinated norms. From a first mapping of the norms and guidelines (last update: April 28th) enacted by 10 among the worst hit regions in Italy (Emilia – Romagna, Lazio, Liguria, Lombardy, Piedmont, Pulia, Tuscany, Sardinia, Valle d’Aosta, Veneto) we found that:

- Only a part of the selected Regions enacted norms and promoted guidelines for the LTC sector;
- Norms mainly focus on COVID-19 positive cases, whereas there is a lack of guidance on care homes management (in terms of isolation, social distancing, ...)
- Norms have on average a two weeks timeframe, consistently with national dispositions on lockdown. Dispositions mainly refer to the contingency and do not adopt a longer-term vision.
- In some regions, local health authorities promoted additional guidelines to care providers.
- In some Regions (e.g. Liguria and Lombardy) institutional care settings are now allowed to deviate from certain rules and operational frameworks around staffing levels.

The main aspects that have been tackled by the regions are:

- The closing of day care services;
- Norms and guidelines to manage positive cases in care homes and ensure care workers’ safety.

Moreover, they started dealing with COVID-19 only at the end of March, signalling once again the poor political attention to LTC in the Country.

### 4.1.2 Funding packages

As of April 30th, no funding package to support care institution has been announced.

### 4.2 Care coordination issues

One of the major defeats in the management of the COVID-19 crisis in Italy, was the absence of care coordination between care settings. The efforts have been focused on acute hospitals, trying to preserve their safety and resilience. This implied that in many Regions, transfers from Long Term Care services (nursing or care homes) to Hospitals were blocked, providing guidelines to treat even the most severe case without access to the National Health Service (NHS). The same applied for emergency care. No specific national measures have been promoted on this. In some territories (such as Lombardy and Sardinia) nursing homes were formally asked to accept patients transferred from hospitals, becoming COVID-19 centres. Nursing homes representatives refused to accept this proposal, considering that they had neither the appropriate staff nor equipment.

Concerning staff, transfers from settings happened on voluntary basis and following local necessity. We have records of situations were trained staff were moved from acute care
setting to nursing homes so to provide training and expertise. This happened following specific agreement between providers. At the same time, many providers reported that they had been losing nurses and care personnel following the massive campaign of recruitment from the NHS. In March an extraordinary enrolment of health staff was implemented in Lombardy, Piedmont, Veneto, Apulia and other regions, so that many professional workers applied attracted by public sector contractual conditions (generally better than the contracts in private nursing homes).

4.3 Care homes

4.3.1 Prevention of COVID19 infections

Prevention of COVID19 infections in Italian Care Homes was poor, especially in the first phases of the spread of the virus.

The “original sin” was an incautious neglect of the LTC system. The moment national institutions recognized the COVID-19 pandemic as a serious threat for citizens’ health, the public attention was directed primarily towards acute care hospitals. Little attention was given to nursing homes, despite the potential risk they hold for hosting one of the most vulnerable target population for COVID-19. The first operational guidelines for nursing homes were released after the country’s total lockdown on March 9th, only requiring residential services to suspend visitations (some nursing homes autonomously suspended external visits before this date). This resulted in frail older people being exposed for at least three weeks to visitors, possibly positive and asymptomatic, with no restriction nor disposition for social distancing. At national level, an update of the operational guidelines dedicated to nursing homes was released by the Ministry of Health only on March 25th, whereas the first measures towards the general population were enacted on February 22nd. Following the national level, most of the regions (responsible for LTC sector operational regulation) promoted the first guidelines for COVID-19 management over a month after the outbreak. The Lombardy Region was the only one that acted on March 8th, through asking local health authorities (ATS) to identify nursing homes that met “adequate” structural (meaning, having independent pavilions) and organizational requirements to host low intensity COVID-19 positive cases. Such disposition was highly contrasted by both care providers and their representatives due to high risks that such exposition could represent for both workers and patients. For this reason, this measure was implemented in a very few cases.

On April 26th, the Italian Government issued a new decree with one clause addressed to care homes. External visitors can now be accepted upon decision by the Clinical Director of each organization.

4.3.2 Controlling spread once infection has entered a facility

There was no possibility of tracking down and controlling the spread of COVID-19 in nursing homes and a failure to test suspected cases among residents and care personnel. Even today, current procedures do not foresee testing residents in nursing homes, neither those who passed after presenting symptoms\(^{18}\). This compromises data gathering on the actual number of COVID-19 related deaths, as shown above. The ISS report shows that most compromised COVID-19 positive cases were treated in nursing homes, without hospitalization. As of 28th of April, there is not a plan for a full-on testing activity for care homes residents.

**4.3.3 Ensuring access to health care (including palliative care) for residents who have COVID19**

During the spread of Coronavirus COVID-19 in Italy, care homes were in fact isolated from the rest of the healthcare system. Hospitals in many Regions (such as Lombardy, Veneto, Emilia-Romagna, Marche and Piemonte) who were under pressure for the peak of COVID-19 patients, started to reject and deny admission to care homes residents who might have problems related with COVID-19 (since testing was not available for all, the evaluation was based on symptoms). As a result, many of them were taken care of in facilities not equipped for high-severity conditions and lacking the specialized health care workers that you can find in other settings such as hospitals. Moreover, access to palliative care has been critical, not only for care homes patients. The associations representing palliative care and intensive care unit doctors (SICP, SIAARTI and FCP) issued a press statement on the 3rd of April urging for specific protocols for COVID-19 patients\(^{19}\).

**4.3.4 Managing staff availability and wellbeing**

Another relevant issue was the lack of personal protective equipment (PPE) for Long Term Care services, including Care Home workers. Italy faced an enormous shortage in masks, tests, gowns, which deeply affected the social and healthcare personnel. New PPE supplies were primarily directed to hospitals and nursing homes have been struggling to find the adequate equipment to protect their workers and guests. In the Lombardy Region, the first supply of masks for nursing homes arrived on the 12th of March but proved to be insufficient to cover their actual needs\(^{20}\). In the ISS survey, respondents stated that the main problems encountered during the crisis were related to the weak guidelines given to limit the spread of the disease, lack of medical supplies, absences of care workers, and the difficulty to promptly transfer positive patients into hospitals. All of these allowed the virus to spread in LTC services, resulting in an incredibly high number of infected residents and care personnel, together with high mortality.

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\(^{18}\) [https://it.reuters.com/article/idITKBN21611V](https://it.reuters.com/article/idITKBN21611V)

\(^{19}\) [https://www.fedcp.org/images/file/1113/comunicato-stampa-congiunto020420r.pdf](https://www.fedcp.org/images/file/1113/comunicato-stampa-congiunto020420r.pdf)

4.4. Community-based care

4.4.1 Impact on unpaid carers and measures to support them

Informal caregiving has a great relevance in the Italian Long Term Care system. Prior to Covid-19 emergency, researchers (Berloto and Perobelli, 2019) estimated that more than 8 million informal caregivers provided assistance of family members, plus more than 1 million paid care workers among which nearly 60% without professional contract or formal appointments. In Italy, these carers are called “badanti” and represent a parallel and unorganized Long Term Care system. Typically, these irregular (without job contracts) care workers are women, older than 40, non-Italian with a prevalence from East Europe or Central America countries, often without legal permission of stay in the EU, without any form of professional training and providing 24/7 cycle of care by living together with the people they provide care to. No forms of compensation or support are foreseen at the national level for informal caregivers, with some regional exceptions.

The emergence of COVID-19 had a tremendous impact on informal caregiving systems. Social distancing and lockdown based on municipalities and regional territories initially suspended any form of connections between people in need of care and their non-resident carers. After a first period, assistance to dependent family members has been added to the exceptions allowing some people to travel from one place to the other. Media reported that major issues have been faced by carers in accessing stores to buy food and medication for the people they provide care to since no preferential access was organized. As of the 30th of April, no specific measures at National or Regional level have been taken regarding unpaid carers.

Similarly, no specific measures have been adopted concerning regular and irregular care workers. Media reported that the majority of them simply lost their jobs (i.e. being replaced by family members forced at home by the lockdown, media reported that this happened in 30% of the cases) or continued moving from one place to the other to provide assistance without having any form of training or PPE, probably contributing to the spreading of COVID-19. Since many of them are irregular they have been excluded by any form of income support. As of the 30th of April, the issue has entered the political public debate, and possible measures to spread regularization.

4.4.2 Dispositions on people with disabilities

On March 17th the National Government established the closure of all day care homes for people with disabilities. Local health authorities can, in collaboration with LTC day care providers, provide care interventions considered “not deferrable” for people with disabilities that require highly intensive care. The pre-condition is that the care provider can guarantee adequate safety measures. The norm does not specify what a “not deferrable” intervention is and the final decision lays on the local health authority.

With regards home care, the same law established that local authorities shall try and guarantee interventions to those that were benefitting from the service, only if they can

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21 http://www.handylex.org/stato/d170320.shtml#a47
guarantee adequate protection for both care workers and users. Caregivers might break the lockdown rules to visit people with disability only in case of necessity.

The National Office for People with Disabilities created a section on its website providing answers to frequently asked questions in relation to COVID-19\textsuperscript{22}. As concerns people with intellectual disabilities, the ANFASS (the National Association of People with intellectual and relational disabilities) drafted guidance for caregivers and family members on how to deal with the emergency and with stress.

As of April, 30\textsuperscript{th} the national measures to support caregivers are mainly related to flexible work arrangements. The National Association for People with disabilities (FISH) is calling for stronger action to guide people with disabilities and their families in tackling the emergency, both in terms of services’ provision and of economic intervention.

4.4.3 Impact on people living with dementia and measures to support them

In Italy, people living with dementia are mainly treated and supported in day care centres or specific wards within nursing homes when independent living is not possible. Generally speaking, even before COVID-19, specific measures to support them at their home were scarce and only promoted at the local level. National Associations of patients reported that the COVID-19 crisis impacted on the support of people with dementia. The majority of day centres (both public and private) have been closed since 8\textsuperscript{th} of March, and no alternative has been provided. Equally, the home care activities that existed have been cancelled. As of the 30\textsuperscript{th} of April, no specific measures have been taken at the National or Regional Level. Some initiatives have been promoted by other stakeholders, such as the National Organization of Alzheimer Patients (AIMA) promoting the spread of technologies to promote social interaction and monitoring of people who need care at home. Other associations promoted call centres dedicated to supporting caregivers.

\textsuperscript{22} http://disabilita.governo.it/it/notizie/nuovo-coronavirus-domande-frequenti-sulle-misure-per-le-persone-con-disabilita/