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 registered in Italy dates to January 30.
   
   - Regions own the responsibility for the LTC sector operational regulation: after the outbreak, they enacted late and different responses without a clear guidance from the national legislator.
   
   - Italy faced a massive shortage in PPE: nursing homes were not prioritized for receiving new procurements. Workers and users have not been sufficiently protected from the Covid-19 spread.
   
   - The National Institute of Health (Istituto Superiore di Sanità) launched a survey to investigate the incredibly high numbers of deaths registered in elderly residential centres, after national press raised the attention on the possible sharp 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 nursing homes, neither those passed after presenting symptoms.

2. **Impact of COVID19 on Long-term care users and staff so far**

   2.1. **Number of positive cases in population and deaths**

   As of April, 21st the total number of positive case in Italy is 107,709 and the number of deaths reached 24,648. A total of 51,600 people have currently recovered from the virus, and 2,471 are still hospitalized in intensive care. On the same day, 41,483 new tests have been performed: within this sample the ratio between positive cases over the total daily performed tests resulted to be equal to 5,2% (1 case every 19 tests).

   The most affected region is by far Lombardy: since the start of the epidemic 67,931 cases (deaths and recovered included) have been registered, followed by the regions of Emilia-Romagna and Piedmont, respectively with 23,092 and 21,955 confirmed positive cases. Among all deaths (with positive tests), the National Institute of Health (Istituto Superiore di Sanità, ISS hereafter) released some additional details updated until the 16th of April: 19,012 of the officially reported COVID-19 related deceased were over 60 years old (95% of the total of 19,996). The average age of decease is 79 years old although the median age is 80 years old. Deceased people are mostly men (64,2% of the total) and in 60,7% of cases were presenting three or more pre-existing chronic pathologies. 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 9.7% for 60-69 years old; 30,3% for 70-79 years old, 25,1% for 80-89 years old and ultimately equal to 25,1% for the over 90.

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1 Dipartimento della Protezione Civile: http://opendatadpc.maps.arcgis.com/apps/opsdashboard/index.html#/b0c68bce2cce478eac82fe38d4138b1
4 Last official data available on Epicentro ISS dashboard. Available at: https://www.epicentro.iss.it/coronavirus/sars-cov-2-decessi-italia
5 See footnote 3
2.2. 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 previous years, same months\(^6\). The ISS has started a dedicated survey to collect evidence on this\(^7\), which was sent to 2,399 nursing homes out of the 4,629 operating on the national territory. As of April 14, 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, counting for 37.4% of the deaths (1,443/3,859) 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\(^8\).

As 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\(^9\). 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 the 17.3% of the care workers of the respondents were tested positive, though assessing that due to the high variability in regional policies on testing this number could be much higher. Considering 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

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 LTC the sector was not conceived and developed as a comprehensive model, 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

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\(^6\) See for example:
- https://www.ansa.it/trentino/notizie/2020/04/03/coronavirus-altri-17-morti-in-trentino-204-nuovi-contagi_bd98b1e0-e10b-4830-92a9-b7ef4840aa25.html
- https://it.reuters.com/article/idITKBN2161IV

\(^7\) https://www.epicentro.iss.it/en/coronavirus/sars-cov-2-survey-rsa

\(^8\) See footnote Error! Bookmark not defined.

\(^9\) 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
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\(^{10}\) 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 people aged 75 (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 (Assistenza Domiciliare Integrata, ADI), 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. Moreover, considering that most part of the coverage need comes from public home care, which only provides 16 hours of care per year, it is fair to say that the public welfare system is far from meeting the needs of older people who need care and their families.

On top of this, the rate to which needs are covered 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 a reduction on the resources for this sector. The two-thirds of older people who do not make it to the public welfare system seek alternatives to meet their needs, mostly through one of these five ways, depending on the 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 fill 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, using their incomes and sometimes undermining their savings, trying to set up a 24/7 cycle of care (the number of care workers/family assistants, both regular and off the book, is estimated to be 1,005,303 (Berloto and Perobelli, 2019);
5. Older people 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.).

\(^{10}\) 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.

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4. Long-Term Care policy and practice measures

4.1 Care homes

4.1.1 Prevention of COVID19 infections

Multiple issues concurred to failures in controlling the disease, especially in nursing homes, exacerbating the difficulties of the Italian LTC system.

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 populations 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. This implies that fragile older people had been 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 toward 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. Lombardy Region was the only one that acted on March 8th, though 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.

The second issue was due to the lack of personal protective equipment (PPE) for Long Term Care services. 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 in finding 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. In the ISS survey, respondents stated that some of the major criticality encountered during the crisis were related to the weak guidelines given to limit the spread of the disease, the lack of medical supply, the absence of care workers, and the difficulty to promptly transfer positive patients into hospitals. All of these allowed the virus to spread in LTC services, determining an incredibly high number of infected elderly and care personnel, together with high mortality.

The third shortcoming was the inability to track down and control the spread of the COVID-19 in nursing homes, failing in testing suspected cases among older people and care personnel. Even today, current procedures do not foresee testing older people in nursing homes, neither those passed after presenting symptoms. 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.

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13 [https://it.reuters.com/article/idITKBN2161IV](https://it.reuters.com/article/idITKBN2161IV)
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